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INEVITABLE MORTALITY AND THE INCESSANT MOMENTUM OF MEDICALIZED
DEATH

A Thesis
presented in partial fulfillment of requirements
for the degree of Master of Arts
in the Department of Philosophy and Religion
The University of Mississippi

by

Clifford McKay

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ABSTRACT

Atul Gawande, MD, affirms the inevitability of human mortality and the end of life in natural death. He decries current medical delivery's incessant momentum toward medicalized death and recommends a meaningful conversation between doctor and patient to chart a course of care that supports what is important to the patient. But the tradition of a doctor's dominance and a patient's submissiveness disrupts the conversation. New definitions of both doctor and patient, and the intent to respect a patient's autonomy, will facilitate decision-making and support patients' values at the end of life, diminishing the momentum of medicalized death.

TABLE OF CONTENTS

ABSTRACT.....	ii
I. MORTALITY AND MEDICAL DEATH.....	1
II. DEFINITIONS: DOCTOR AND PATIENT.....	7
III. AUTONOMY AS RESPECT.....	17
IV. THE CONVERSATION.....	27
V. CONVERSATIONS—THE BEST PATH TO NATURAL DEATH.....	40
VI. AVOIDING MEDICALIZED DEATH.....	48
BIBLIOGRAPHY.....	61
VITA.....	66

I. MORTALITY AND MEDICAL DEATH

The Problem

Despite the trajectory, despite the length, despite the fixes and repairs along the way, the end of every life is mortality. Every living thing will at some time die: insects, animals, plants, trees, human beings. The length of life varies, but at some point, every individual member of every species dies. Mortality is the inevitable and inescapable end of every person. There is no reliable record of any human being surviving past the age of 123.¹

Before the use of the experimental method to better understand and control illness and disease, the trajectory of mortality was level . . . until it suddenly turned sharply downward. At that time when cancer, heart disease, emphysema, liver disease, or infectious diseases were present, health deteriorated rapidly, and the end soon followed. When medical science developed treatments for some of these conditions, the sudden downward spiral leveled out, and persons with these issues survived longer, sometimes for years. The illness was not cured, but its ravages and death were delayed and postponed. The path to inevitable mortality was extended but not negated. Despite longer periods of living with disease, sometimes multiple diseases, people were allowed to live out the full measure of their body's natural existence, wear out, decline, and die with a worn-out body – the unavoidable mortality.

¹ Aronson, Louise, *Elderhood: Redefining Aging, Transforming Medicine, Reimagining Life*. (New York: Bloomsbury Publishing, 2019).

Felix Silverman, author of numerous studies on aging and Senior Geriatrician at the Parker Jewish Institute, said in a conversation with Dr. Atul Gawande that there is “no single, common cellular mechanism to the aging process.” We accumulate lipofuscin, oxygen free-radical damage, random DNA mutations, and other problems at the microcellular level, a gradual but persistent accumulation with no particular pathway. “We just fall apart.”²

The human body comes with a built-in decline. The story of aging is the story of our parts and essential systems weakening and losing function. When any one of several essential functions is lost, the entire system shuts down, and life is over. Calcium collects, some tissue hardens and loses function, other tissue softens and loses function. The twenty-nine joints of the hand deteriorate with bone loss, stiffening and swelling. When younger, the three-pound brain fits tight in the skull, but in the seventies, the loss of gray matter leaves an inch of spare room. The newly expanded tools of medicine can solve some problems but not all, and they can only delay the decay of aging, not stop it. “In truth no single disease leads to the end: the culprit is just the accumulated crumbling of one’s bodily systems while medicine carries out its maintenance measures and patch jobs.”³

The milestones along the path to a natural mortality are not clearly marked. With their extensive hands-on experience, nearing the end of life, nurses can read the subtle signs of organ failure and predict with reasonable accuracy the time left. Doctors, with a desire to encourage their patients and maintain their hope, are often overly optimistic about the time remaining. “Sixty-three percent of doctors overestimated their patient’s survival time. Just seventeen percent underestimated it. The average estimate was 530 percent too high, and the better the doctors

² Gawande, Atul, *Being Mortal: Medicine and What Matters in the End*. (New York: Metropolitan Books, Henry Holt and Company, 2014). 35.

³ *Ibid.*, 28.

knew their patients, the more likely they were to err.”⁴ With indefinite timing, “more than 40 percent of oncologists admit to offering treatments they believe are unlikely to work.”⁵ It always seems an option to hope there is a thin thread of possibility that the experimental methods of science might find something that works, “but focusing on that thin thread, we neglect to prepare patients for the outcome that is vastly more probable.”⁶

The care of people who are dying has been greatly affected by the process of ‘Medicalization.’ In contemporary care, it is often problematic for doctors to shift their care from restorative intervention and aggressive management of disease at the end of life and focus on a pattern of care where primacy is granted to the quality of life.⁷ Nurses, with their intimate daily contact with patients, are more in tune with them and their desires. Because of this, the transition from treatment to palliative care within hospitals is a frequent area of tension between medical and nursing staff.⁸

In a study on patient perspectives on quality of life, participants were afraid of ‘lingering’ and ‘being kept alive’ after they could no longer enjoy their lives or found them without meaning. Physicians’ concepts of quality-of-life coupled with a tendency to ‘keep patients alive regardless’ seemed to fuel this fear. Patients were terrified of becoming a ‘vegetable’ or living in a coma. Study participants adamantly denounced ‘being kept alive by a machine’. They wanted to be ‘allowed to die naturally’ or ‘in peace’. Nurses should ask patients what they want, on the assumption that people know what is best for themselves, right up to the moment of dying.

⁴ Ibid., 167.

⁵ Ibid., 168.

⁶ Ibid., 71.

⁷ Ibid., 41.

⁸ Ibid., 42-3.

The claims of the patient's right to decide do not fit comfortably within the technological imperative of medical treatment, says Sarah Breier-Mackie, citing an article by Joy Ufema. Ufema's study identifies five domains of quality end of life care from the patient perspective that challenge the medical imperative to keep offering treatment: (1) to receive adequate control of pain and symptoms; (2) to avoid inappropriate prolongation of dying; (3) to achieve a sense of control generally; (4) to relieve the burden on others; and (5) to strengthen relationships with loved ones.⁹

Recent studies have documented that health care providers and family members lack the qualities to know accurately how patients assess their own quality-of-life. Patients want to retain control of their end of life care decisions. "It's my life. Nobody has any right to tell me what I want." The quality of one's life, based on rational decisions, can be measured only by the individual's own value system, an attitude that captures the true voice of autonomy, as over against continuing to fight disease at all costs. 'De-medicalizing' death via holistic care, the distinctive responsibility of nursing, renders nursing different from medicine, and through that distinction, inappropriate prolongation of dying may be successfully challenged.¹⁰

Medicalization of Death

"Since the twentieth-century medicalization of aging and dying, medicine has mainly seen itself as a means to wage battle against death, not as one of many tools with which to ease that inevitable transition."¹¹ Medical specialization such as we see with Cardiology, Neurology,

⁹ Breier-Mackie, Sarah, "Patient Autonomy and Medical Paternity: Can Nurses Help Doctors to Listen to Patients?" *Nursing Ethics* 8, no. 6 (2001): pp. 510-21. 517.

¹⁰ *Ibid.*, 518.

¹¹ Aronson, *op. cit.*, 191.

and Gastroenterology makes caring for terminally ill patients focus on one system at a time, as is typical in tertiary care settings, and fragments the process of dying into a series of medical events with little room to see beyond that one system to the whole person.¹² Focusing on a single body system has removed a sense of a person as a whole and created medical professionals who lack a view of what makes life significant for the sick and the old. They concentrate on repair of a single body part, not sustenance of the soul and the qualities that give meaning to each person as they confront their own mortality. Yet, despite this known divide between what is provided and what patients want, we have decided that our medical system, a system guided by people known for their technical prowess rather than for their understanding of human needs, should decide how we live out our waning days.¹³ “The result is that people die with chemicals in their veins, a tube in their throats or fresh sutures in their flesh, unconscious, and isolated, their lives controlled by technicians with little understanding of who they are as whole persons, or anything of their life’s story . . . a Medical death.”¹⁴

Both Dr.s Gawande and Aronson hold that the way to move from the incessant momentum of medical death to a more patient-focused natural one is with a conversation: an interaction between doctor and patient in which they share values and expectations, agree on a realistic understanding of the possible, and recognize that individual patients have loyalties and values that constitute meaningful lives and which guide their desires and wants as the end of life draws near. Gawande confesses that he and his doctor colleagues are plodding novices in facing mortality with this approach.¹⁵

¹² Breier-Mackie, *op. cit.* 518.

¹³ Gawande, *op. cit.* 128.

¹⁴ *Ibid.*, 173.

¹⁵ *Ibid.*, 193.

There are well-recognized difficulties on both sides of this conversation, but the highest hurdle is the imbalance between and long-established subjugation of patients by doctors. The origin can be traced all the way back to the founding code of medicine. Despite significant modifications in the discussions of medical ethics, and the role of doctors, a strong tradition of a doctor's authority persists today as medicine proudly traces its heritage back 2600 years to the time of Hippocrates.

II. DEFINITIONS: DOCTOR AND PATIENT

Words

Words and their meanings are critical in any discussion. Words have underlying emotions and subtle nuances and sometimes multiple definitions. They need to be selected with precision and care. In addition, the same words carry different weight, depending on who utters them. Words used in racial discussions are immediately recognized as delicate and sensitive. In the Church, the liturgy and the hymnody have been reworked and revised to accommodate a new understanding of gender reference and acceptance. The proper use of female/male pronouns is closely attended in the 21st century. The terms we use to describe doctor and patient are likewise significant and sensitive, particularly when we consider their impact on the roles each participant plays in end-of-life discussions.

The current problem with the words "doctor" and "patient" is the vast disparity between the two roles that makes it impossible for any relationship other than the clearly understood stance of the patient's subservience to the doctor. The scale is too imbalanced and the dominance too strong. The expectations of the disparate roles lead directly to a patient's resignation into a "Whatever you say Doc" mentality and precludes any meaningful face-to-face exchange.

When effective treatments have been exhausted and mortality looms, when it is time to shift from cure to care, it is time for the doctor to step back and use her skills and procedures to support what's important to the patient. The doctor's authority and the patient's submission are no longer needed. What is needed is her empathy and support through this demanding time.

What is needed is a balanced relation where the Doctor inquires, “What’s important to you?” . . . and listens.

In the 21st Century, a relation between authoritarian and subservient partners attempting to work together to solve personal ethical issues will not work. To recognize each other properly and to help create a changed relationship, new terminology is needed. Giving a new understanding to old words is not sufficient. Although progress has been made using that approach, it’s too easy to laze back into previous attitudes. As Dr. Gawande puts it, “We’re too familiar with ‘the old dance moves.’”¹⁶

A Doctor

The traditional names for the persons composing the base ethical relationship of medicine are doctor and patient, “patient” from the French meaning “a sufferer,” and “doctor” from its Latin roots meaning “teacher.” Both terms have a rich history and usage, as well as an extensive set of subtleties and innuendos that shade and color their meaning.

Merriam Webster Dictionary.com defines "doctor" as:

1. a person who is skilled in the science of medicine: a person who is trained and licensed to treat sick and injured people.

It continues and expands the definition in different settings:

- 2 a: *Christianity* : an eminent theologian declared a sound expounder of doctrine by the Roman Catholic Church - called also *doctor of the church*
- b: a learned or authoritative teacher

¹⁶ Gawande, op. cit. 143.

- c: a person who has earned one of the highest academic degrees (such as a PhD) conferred by a university
- d: a person awarded an honorary doctorate (such as an LLD or Litt D) by a college or university
- 3 a: a person skilled or specializing in healing arts *especially*: one (such as a physician, dentist, or veterinarian) who holds an advanced degree and is licensed to practice¹⁷

The Online Etymology Dictionary adds additional subtleties through the history of its use:

- c. 1300, *doctour*, "Church father," from Old French *doctour* and directly from Medieval Latin *doctor*, "religious teacher, adviser, scholar," and in Classical Latin "teacher," agent noun from *docere* "to show, teach, cause to know," originally "make to appear right."

The title Doctor is conferred as the "holder of the highest degree in a university, one who has passed all the degrees of a faculty and is thereby empowered to teach the subjects included in it." Hence "teacher, instructor, learned man; one skilled in a learned profession" (late 14c.).

The title "doctor" was used in the Middle Ages to describe eminent scholars, originally, the members of a small group of theologians who had approval from the Church to speak authoritatively on religious matters, also known as Church Fathers. Such teachers were accorded significant respect and prestige.

¹⁷ <http://www.merriamwebster.com/dictionary/doctor>.

With the forming of universities in Europe, in the 13th Century, a doctorate was introduced as the highest academic degree, awarded at the University of Bologna and the University of Paris first in Canon Law then in Civil Law. Eventually the use was expanded to include all qualified academic professionals.

Middle English also used *medicin* for "a medical doctor" (mid-15c.), from French. Similar usage of the equivalent of *doctor* is colloquial in most European languages: Italian *dottore*, French *docteur*, German *doktor*, Lithuanian *daktaras*, though these typically are not the main word in those languages for a medical healer. For similar evolution, compare Sanskrit *vaidya*- "medical doctor," literally "one versed in science." German *Arzt*, Dutch *arts* are from Late Latin *archiater*, from Greek *arkhiatros*, "chief healer," hence "court physician." French *médecin* is a back-formation from *médecine*, replacing Old French *miege*, from Latin *medicus*.¹⁸

The word doctor, meaning "a medical professional, a person duly licensed to practice medicine," was in use early in the 1400s; however, it took until the 1600s before usage was common.

When the universities in Europe continued to expand, more people started using the title "doctor." Universities conferred the degree Doctor of Philosophy (Ph.D.). Early on it was limited to professions like medicine, law, theology, and sometimes music. Increasingly university training was common in medicine and as education expanded, the term Doctor of Medicine, or M.D. was used for those trained to practice medicine.

According to the London Medical Gazette, in an effort to regulate who could use the title "doctor," at least in a medical sense, the Royal College of Physicians declared in 1860 that only

¹⁸ Harper, Douglas R. <https://www.etymonline.com/>.

those with an MD could refer to themselves as a doctor. It wasn't until the 20th century that this was reversed, with the organization noting the public have called physicians, regardless of degree, a doctor for years.

Since the rise of specialties within medicine such as oncology, orthopedics, ophthalmology, cardiology, pneumonology, neurology and the like, the name of the specialty is used and "Doctor" is used primarily in address: "I'd like to introduce our speaker today, Dr. Cooperman, an ophthalmologist who will address us on the topic of" Today a doctor is one licensed to practice medicine, based on university training and the licensure of the state. She is accorded overtones of power and status elaborated from the synonyms expert, physician, professor, scientist, specialist.

Doctor has always been the highest rank, and the most honored title, and it has always been chosen by medical professionals. In the dictionary, the lead definition is given for its use in medicine, and the second for its more historic and logical academic one. Despite a loosening of the understanding of the medical person's authority, the title "doctor" is both widely embraced and widely expected by medical professionals.

A Patient

What might we name a person capable of participating effectively in a discussion with a medical professional? Dictionary.com defines patient as:

(noun), "person being treated for a medical problem"

(synonyms), "calm, forgiving, long-suffering, imperturbable, meek, resigned, stoical, submissive, uncomplaining."

Webster's Dictionary defines patient as:

1 a: an individual awaiting or under medical care and treatment (cancer patients, psychiatric patients)

b: the recipient of any of various personal services

2: one that is acted upon

Synonyms & Antonyms for *patient*

Synonyms: (adj.) forbearing, long-suffering, stoic (*or* stoical), tolerant, uncomplaining

Antonyms: (adj.) complaining, fed up, impatient, kvetching, kvetchy.¹⁹

The Online Etymology Dictionary indicates the deeper roots of its meaning.

patient (adj.)

mid-14c., *paciente*, "capable of enduring misfortune, suffering, etc., without complaint," from Old French *pacient* and directly from Latin *patientem*, "bearing, supporting, suffering, enduring, permitting"; "slow to anger, self-restrained, having the temper which endures trials and provocations." From late 15c. as "awaiting or expecting an outcome calmly and without discontent." The meaning "pertaining to a medical patient" is late 14c.

patient (n.)

¹⁹ <https://www.merriam-webster.com/dictionary/patient>.

"suffering, injured, or sick person under medical treatment," late 14c., from Old

French *pacient* (n.), from the adjective, from Latin *patientem* "suffering," . . .

In Middle English also of anyone who suffered patiently.²⁰

The understanding is clear and emphatic: a patient is one who suffers quietly without opposing whatever is done, like the sheep who is still and quiet, without a single bleep, while the shearer shifts him around, tugging and shoving, and with large, loud, threatening shears removes his entire coat of wool. The idea of being a patient is solidly based on compliant acceptance, on being one who is designed to be submissive to whatever the other person in the relationship suggests or imposes.

However, all patients are people, human beings in their largest social context, possessors of essential humanity even when they are sick and aged. "Rather than naming aged patients as a burden to themselves, to their families, and to the community at large, economically worthless, all life would be richer and better if as a society we care for 92-year-olds simply because they are human beings, and because we as a society care about human beings."²¹ Yet we've reduced the aged, diminishing them in both body and spirit. Given a chance, we discover the aged possess a powerful humanity expressed with courage and humor and sometimes with anger or even fury.

The missing components in the definition of a patient, of a person fit to function as a proper partner in a conversation with a doctor, are status, dignity and respect, all qualities of a human being, or person. The best new word to include all of these components and to engender a new definition for patients is the word "person" as understood through a neuroscientific analysis of the formation of a human being. "Only humans are persons, enjoying existential uniqueness.

²⁰ <https://www.etymonline.com/search?q=patient>.

²¹ Aronson, op. cit. 159.

'Human being' is a biological term but 'person' refers to the further existential dignity derived from experiencing subjectivity and personal identity, seeing herself as a phenomenological 'I', with moral identity that possesses both agency and responsibility."²² A physical being has biology, but a person possesses biography, a distinctive individual history, a personal history that continues to its completion in mortality.

The doctor-patient relation with elders is complicated and demanding. It presents to the doctor complexity, multimorbidity, and geriatric challenges, while to the patient it presents confrontation, fragmentation, incoordination, and expense. The ticking clock of interaction and conversation-to-a-solution creates tensions that call for efficiency, but efficiency is a goal for systems and organizations, not one for people and human interactions. The most precious, meaningful element of the patient-doctor relationship is the human connection, a connection between two persons, direct and intimate, laden with subtleties, significance, and respect for each person's unique feelings and needs.²³ It's time to "stop the clocks" of medical incessance and allow time for everyone to be treated and respected as a person, no longer as just a tolerant, long-suffering, accommodating, enduring, lenient, meek, mild, resigned, submissive, and uncomplaining patient.

Medical ethics and medicine in general need to replace the word, the concept and the understanding of "one who receives treatment, support, and care" - a "patient" - with the word "person." Here we conceive of a person as a distinct self-determined, differentiated "I," possessing dignity, entitled to respect, worthy of the concern of another person's skills in giving care, and entitled to express the meaning of their life all the way to its end.

²² Rolston III, Holmes. (2008). "Human Uniqueness and Human Dignity," *Human Dignity and Bioethics*. www.bioethics.gov. 142.

²³ Aronson, op. cit. 219.

Doctor and Patient, or Medical Person and Person

Better names for leading medical personnel instead of "doctor" would be "physician," "clinician," "medical professional," or "medical person." Any of these would be more appropriate than "doctor," with fewer attachments to inappropriate traditions and misconceptions and a mis-placed understanding of the nature of authority. Each helps provide a better balance with a person. But "medical person" is the best, for it joins two equal persons in conversation, working together to solve a joint concern, the one with expertise in medical possibilities, the other with expertise in what is personally important and valuable to them. "Medical person" also avoids the vestiges of authority, separates the name from traditions and all its baggage, and opens the possibility to respect the dignity of each person being cared for.

Obviously, science and technology have dramatically changed not only the capabilities and tools available to fix medical problems, but also the role and the varied skills and interests needed for medical providers. Medicine today requires technical expertise and detailed, focused study of the body, but it also requires medical persons who can remain aware of the larger picture of a whole person and their historical iteration throughout their life.

A medical person in the 21st century should be competent in their specialty, but cognizant that each specialty serves a part of a whole, a whole person with needs that go beyond just the skin, or the heart, or the kidneys, or a reproductive system, or the bones . . . and that person has a whole life that lasts all the way to mortality. If a specialist does not comprehend his role as serving the whole, he cannot be effective or responsible for even his part.

The Oath of Maimonides from the 18th century commends this person-to-person relation for the clinician-patient relationship, recognizing each as a child of God working together for healing - a great prescience for the 21st century. It is this balanced relationship of equals that will

facilitate the conversation needed for the consideration of end-of-life issues to support patients and avoid the medicalization of this time of life and the pain and suffering that accompanies it.

III. AUTONOMY AS RESPECT

In the era of scientific medicine, the concept of autonomy, the right of self-determination, has gained a central place in bioethical thought. However, there remains extensive debate about what exactly autonomy is and how self-determination should be applied.

Put simply, to be autonomous is to govern oneself, to be directed by considerations, desires, conditions, and characteristics that are not imposed externally but represent one's authentic self. Autonomy in this sense is an irrefutable value, the opportunity to determine one's own personal history, especially when viewed from the perspective of its opposite, a life chosen and determined by external forces. Such external control is clearly oppression and untenable. Autonomy is also seen as that aspect of a person that is protected or ought to be protected from paternalistic interventions in an individual's life.²⁴

Autonomy was recognized in medical ethics as a counter to paternalism, a conception of the doctor-patient relation like that of parent-child, a parent devoted to the child's best interest and with superior knowledge who determines and decides what benefits the child-patient. But even with widespread acceptance of autonomy and the self-determination of a patient, the traditions of medical authority have managed to reintroduce paternity by defining autonomy as agency and decision. Thus defined, the patient's diminished capacity to make decisions due to the supposed disabling effect of illness disqualifies her and her decisions, and so the authority

²⁴ Dworkin, Ronald, *Taking Rights Seriously*. (Cambridge: Harvard University Press, 1978). xi-xii.

reverts to the doctor. In addition, it is the doctor who decides whether a patient is capable of making a decision, and paternalism is reinstated by the judgment about the patient's deficiency to properly enact their own autonomy. The principles of law entered the bioethical discussion and contributed to the requirement of informed consent, underlining and supporting again the right of patient autonomy. Obviously, in many if not most end-of-life situations, either because of natural deterioration or due to medications, a patient may not be capable of making a specific decision. So, law again contributed with the role of advanced directives. With a properly prepared document a patient could project into the future their wishes and autonomous determinations, allowing their earlier health decision to qualify going forward as their representative autonomous decision.

Some of the issues regarding a patient's decisions and her capacity to make them have been mitigated by these two legal procedures, helping patients maintain self-determination. Nonetheless the initial premise limiting autonomy to decision-making is wrong. Autonomy exceeds decision-making and the agency to do so. A person's self-determination is more than an individual decision at a specific time. Autonomy accounts for the entire person, her dignity, how she values herself, and how she is valued and respected in the context of her family and her community. The content of autonomy is the dignity of the self-chosen-lived-out-history of each human being and is supported by the obligation to respect each person's dignity. Every individual has this right without interference to live out their self-chosen-history as individuals.²⁵ The principle of respect for autonomy is larger than a single aspect of personhood, namely the right to choose at a specific point in time. A strong case can be made that the central core of

²⁵ Dworkin, Ronald, "Autonomy and the Demented Self." *Milbank Quarterly* 64, no. 2 (1968): pp. 4-16. 7.

autonomy is respect for a person and her dignity, simply because she is a human person. It is the core from which the other aspects of autonomy are derived.²⁶

The Anatomy of Autonomy

With autonomy, the physician's obligation to honor the decision/view/wish of a patient, particularly in end-of-life timing, is based on respect for the essential autonomy of every human person to shape and determine their own life. A human's story is their own story, despite bad decisions or unfortunate results. A physician's professional commitment to serve includes the commitment to respect the dignity accorded every human person, no matter their current state or condition. Both Gawande and Aronson call for respect for the elderly, simply because they are elderly, not because they have lived well, or shown great accomplishments, or earned some right, but simply because they are elderly persons. Historically, in most cultures, Confucian, Hindu, Hebrew, European, Native American . . . the elderly are respected and honored because they have gone before, gathered life experience, and simply because they are elderly. Aronson asks, "How much better and richer would life be for all of us in a society that cared for a ninety-two-year-old for the simple reason that the ninety-two-year-old is a human being, and we care about human beings?"²⁷

Ronald Dworkin, noted authority on legal ethics, referencing John Rawl's *Theory of Justice*, states "our institutions about justice presuppose not only that people have rights but that one right among these is fundamental, even axiomatic. That fundamental right is the right of

²⁶ Aronson, op. cit. 159.

²⁷ Dworkin, op. cit. 1978. xii.

equality, which is recognized as the right to equal concern and respect.”²⁸ Dworkin contends that conventional rights are derivative, not from a more abstract right such as liberty, but from the right to equality itself.²⁹ Rights may be absolute, and if absolute, there can be no reason for not securing the liberty it requires for every individual.³⁰

Dworkin contends autonomy’s value exists in the responsibility it creates for each person. Autonomy is the responsibility each person has to shape his life in accord with a coherent and distinctive understanding of character, to order his convictions and interests in some meaningful scheme, meaningful at least to that person. It allows us to lead our own lives rather than being led through them. Each of us should be what he has made of himself, limited only by a scheme of others’ conflicting rights. This view of autonomy focuses not on individual decisions one by one, but it places each decision in a more general program or picture of life that I as an agent can create and construct, a conception of character and achievement that must be allowed its own distinctive integrity.³¹

“This is why the betrayals of body and mind that threaten to erase our character and memory remain among our most awful tortures. The battle of being mortal is the battle to maintain the integrity of one’s life – to avoid becoming so diminished or dissipated or subjugated that who you are becomes disconnected from who you were or who you want to be.”³²

Autonomy is not limited to its expression in choice, but persists beyond choice and beyond the capability to make a choice. It represents the right to self-determination beyond the

²⁸ Ibid., xiii.

²⁹ Ibid., 92.

³⁰ Dworkin, op. cit. 1968. 8.

³¹ Gawande, Atul, *Being Mortal: Medicine and What Matters in the End*. (New York: Metropolitan Books, Henry Holt and Company, 2014). 141.

³² Dworkin, op. cit. 1968. 8-9.

time when an individual can no longer express that choice, especially at that time when she can no longer articulate it for herself. Even when natural death and its process leading to the end of life is well advanced, when a person has lost many of those physical features and capacities that are symbols of dignity, dignity should be respected. When self-respect is at a low ebb, and there is no reason or right to base their actions on anything other than respect for those intentions, medical persons, health care surrogates and family should follow through to its conclusion that particular human person's individual story.

Respect is due to each human being without regard to what they have done or not done, how they have lived or failed to live, excelled or failed to excel. Respect is their right simply because they are a person, and this respect of the person follows what is important in their life, what treatments they should receive or not receive. If they are not in a position to express themselves, then their surrogates decide as to what best represents and respects their wishes and intentions in the final chapter of their life all the way to its conclusion.

If there are no surrogates to represent the person, the medical person is called upon to the best of her ability to decide based on what best expresses the respect of that life. The clinician's information about the individual may be scant, but autonomy requires her to base her treatment and care on her intent to respect, as best possible, that specific individual's life as a human being – not any other value, no matter its source.

The Basis for Respect Derived from Neuroscience

Holmes Rolston III derives this same right of respect for essential dignity from neuroscience's analysis of the development of human neurology. Neuroscience derives man's idiographic uniqueness from his distinctive quality to reflect on himself and in so doing identify

what is not-himself, an entity that is similar in capability but also separate and distinct. This distinction between self and not-self superimposes on his nature a remarkable capacity to experience and to individuate separate narrative careers. Humans thus have a capacity for enacted individuality that is not otherwise known in the animal world. This individuality makes possible biography transcending the biology on which this idiographic uniqueness is superimposed.³³

As embodied humans we are limited by flesh and blood to exist in space and time, but there are no boundaries to what humans can think or imagine in their minds. The full possibilities of space and time are endlessly open to imagination, and the human brain can accommodate $10^{70,000,000,000,000}$ neural configurations. (There are only 10^{80} atoms in the entire visible universe.) Our brain capacity allows us to imagine ourselves at the center of unbounded immensities.³⁴

Humans are unique in their escalated degrees of freedom, their voluntary intentional actions, and their powers of cognition and symbolic thought, analytical reasoning, and conspicuous aspiration, all of which can constitute by its reflecting ideational narrative a biographical identity – a person that can follow her biography from cradle to grave.³⁵ While most creatures respond to somatic biological and ecological circumstances, humans are drawn from their remembered pasts through the historic construction of the present into the future as they enact visions of their fullest flourishings and their ideologies and recall the choices and the results along the way. They create and enact their lives as an interpreted story, with each person constructing for his or her lifetime an ideographic-storied-residence on Earth. Persons want “to

³³ Rolston, *op. cit.* 139-40.

³⁴ *Ibid.*, 140-41.

³⁵ *Ibid.*, 142.

retain autonomy – the freedom – to be the author of their lives. This is the very marrow of being a human being.”³⁶

As self-reflective, self-aware, self-understanding humans, we can form ideas of other minds and comprehend our own mind as it encounters them and project an estimate of their storied existence. We can form estimates of embodied mental states within ourselves and within others, and it is this capacity to reference other distinct intentional-existential selves like ourselves that gives rise to an enhanced sense of their worth paralleling our own.³⁷ It's in such activity that the possibility of dignity is gained.³⁸

The capacity for one person to take the mind of another – mind reading, as it were – produces in humans their capacity to both be insulted and belittled, or to be respected and treated with dignity. From this ideational perspective of others, we can infer their similar perspective toward us, and in so doing the relationship becomes interpersonal. We can recognize their value to us and presuppose their ability to value us in return. With that perspective, we can reflect on our status in the relationship. “I am being treated poorly, perhaps because I am poor.”

Despite the fact that a human life only makes sense from this distinctly individual point of view, science has little continuing interest in particulars once they have been included as instances of a universal type. This means a neuroscientific search for dignity in the ideographic uniqueness of humans will not be straightforward. However, an ethical account requires particulars both for their constitutive power in enriching the universal model as well as their service as places to locate value.

³⁶ Gawande, *op. cit.* 140.

³⁷ Rolston, *op. cit.* 146.

³⁸ *Ibid.*, 143.

Ethics is distinctively a product of human social behavior and language. Language is essential because the principles of ethical decision-making cannot be formed into concepts, let alone debated, without language, and thoughtful consideration and discussion is the essential form of ethical reflection. Ethics is pervasive in every human culture, a fact that looms large in human dignity. To be ethical is to reflect on principles of right and wrong and to act on them in the face of temptation. Only in human life do we expect and demand that persons behave morally and hold them responsible to do so.

Persons are unique in their capacity to reflect ethically on the difference between what ought to be and what actually is.³⁹ An ethical human being is a reflective agent interacting with a society of similar reflecting agents, knowing that others like himself are able to choose between options and to bear responsibility for their behavior. In this company of reflecting agents, there are mental-others whom one might hold responsible or by whom one might be held responsible.⁴⁰

Only humans are persons that enjoy existential uniqueness, and “personhood” refers to the further existential dignity associated with experiencing subjectivity and personal identity empowered with ongoing agency and responsibility, thus fashioning a phenomenological “I.”⁴¹ The difficulty is to understand how thoughts in the conscious mind form, reform, or, more accurately, in-form events in the brain space to construct an inhabited first person with direct self-awareness.

³⁹ Ibid., 145.

⁴⁰ Ibid., 148.

⁴¹ Ibid., 143.

Persons set up a reflective gap between the real and the ideal, and however broken that relation is, that reflective gap is needed to be moral, because it is in aligning what-is with what-ought-to-be that we find human dignity. It is the divide between what-is and what-ought-to-be that persists through past, present, and future. It is a person's narrated story line, their individual biography made possible by the gap between the real and the ideal which introspectively orients the real and produces a "persona," a lived presence to which each self has a privileged access. This ideographic inwardness becomes a proper named presence, an "I,"⁴² and it is such an "I" that confronts others as a "Thou."⁴³ This capacity for ethical interaction, the ability to distinguish what ought to be from what is, creates a dignity that requires respect for humans simply because they are human.⁴⁴

Persons are agents who must be oriented by an ethical belief system. The question is how to authorize such a system. Ethics is essential to the human genius; we cannot realize our dignity without ethics and its imperative. Ironically, even humans, when operating as scientists, are pre-ethical, but the scientific method struggles to understand how amoral nature evolved into a moral animal and struggles how to analyze homo sapiens' duty to resolve the reflective tension between the real and the ideal. Science and its methodology needs conscience but cannot justify or explain it. Humans crossed a divide during their evolutionary history and now live in a moral territory and therefore possess dignity from the double sources of both heritage and endowment. The potential of that endowment, the duty to resolve the tension between the real and the ideal, must be actualized generation after generation and in each human life. Without the imperative of

⁴² We can wonder whether neuroscience has or ever will have access to exactly how the multiple streams of perception, images, and ideas are melded into such an experiencing "I".

⁴³ Ibid., 144.

⁴⁴ Ibid., 139-40, 144.

that duty, we lose our dignity. Questions of value are sharp and painful, and how to recognize and respect human dignity is a crucial one of those questions.⁴⁵ Humans have dignity when they are able to entertain the concept of dignity, to acknowledge dignity by respecting it, recognizing it, or according it courtesy.⁴⁶

We have drawn autonomy as respect for all persons from liberty and equality, from the philosophy of law in accord with Dr. Gawande's use, and from the neuroscientific analysis of human persons and their ethical imperative in the writing of Holmes Rolston III. It is time to use this understanding of autonomy as respect in practical ways and practice respect for persons in the end-of-life medical environment, a time when the physical vestiges of dignity are eroded by the deterioration and falling apart of the natural body, headed toward an impending natural mortality.

⁴⁵ Ibid., 150.

⁴⁶ Ibid., 147.

IV. THE CONVERSATION

“A monumental transformation is occurring in this country and across the globe, people increasingly have an alternative to withering in old age homes and dying in hospitals, and millions of them are seizing the opportunity. But this is an unsettled time. We've begun rejecting institutionalized versions of aging and death, but we have not yet established our new norm. We are caught in a transitional phase. However miserable the old system was we are all experts at it. We know the dance moves . . . you agreed to become a patient, and I, the clinician, agreed to try to fix you, whatever the improbability, the misery, the damage, or the cost. With this new way, in which we together try to figure out how to face mortality and preserve the fiber of a meaningful life, with its loyalties and individuality, we are plodding novices. We are going through a societal learning curve, one person at a time, and that would include me, whether as a doctor or as simply a human being.”⁴⁷

Dr. Atul Gawande recognized in his own practice the problems that arise when doctors over-treat their patients at the end of their lives and began a search for answers, recognizing he himself

⁴⁷ Gawande, Atul, *Being Mortal: Medicine and What Matters in the End*. (New York: Metropolitan Books, Henry Holt and Company, 2014). 19.

needed to learn a better approach. He recognized the first issue was patients being subordinated to their doctors with little or no voice.

Doctor-patient Subordination

Gawande collected the results of five studies that measured the value of including patients in the discussion of what happens in the end of their lives. The studies used a variety of approaches.⁴⁸

In 2004, Aetna Insurance Company, concerned about aggressive treatment options for terminally ill patients, decided to offer options to encourage them to use hospice. Before the study, few of their clients enrolled in hospice and when they did it was only at the very end of their lives. Hospice requires a patient to agree to give up treatments that attempted to cure as a condition of enrollment. Aetna established an experiment named Concurrent Care, allowing people to secure hospice support while continuing curative care when their life expectancy was projected at less than a year. The results were striking. Use of hospice rose from 26% to 70%. Patients visited emergency rooms half as often as the control group. Use of hospitals and intensive care units dropped more than 66%. Costs dropped by 25%. It seemed giving seriously ill people someone knowledgeable to talk with about their conditions and their concerns had major positive impact.⁴⁹

Another study, “Coping with Cancer,” had similar results. Two-thirds of terminally ill cancer patients said they had had no discussion with their doctors about their goals for end-of-life care. Without discussion, patients averaging four months from their mortality were put on mechanical ventilators, given electrical defibrillation or chest compressions, or admitted to

⁴⁸ Ibid., 175-8.

⁴⁹ Ibid., 176-7.

intensive care in near-death condition. They had a substantially worse quality of life in their last week than those who received no such medical interventions. When interviewed six months later the caregivers for those patients were three times more likely to have experienced severe depression. But the third of the same group who did have those discussions were far less likely to undergo CPR, wind up in intensive care, or be put on ventilators. As they neared the end, they interacted meaningfully with their families for a longer period and after their death their families were less likely to experience depression.⁵⁰

A third study by Massachusetts General Hospital divided a group of 150 patients in half. One group received the usual oncology care while the other half got that same care and in addition palliative care. Palliative care serves persons with serious complex illness regardless of what other care they are receiving. Patients receiving concurrent care could discuss their goals and priorities with palliative care physicians and nurses planning their treatment. Those who saw the palliative care specialist stopped chemotherapy sooner, entered hospice far earlier, experienced less suffering at their end of life, and lived 25% longer. Just the chance to talk about their impending mortality made a significant difference.⁵¹

A fourth study followed 4,493 Medicare patients in hospice with terminal cancer or congestive heart failure. The general assumption going in was that hospice patients would forgo treatments, be given high-dose drugs to prevent pain, and die sooner. However, the study found persons with breast, colon and prostate cancer survived about the same length of time whether or not they were on hospice. But for some unexplained reason, hospice patients with pancreatic cancer lived an average of three weeks longer, with lung cancer six weeks longer, and with

⁵⁰ Ibid., 177.

⁵¹ Ibid., 177-8.

congestive heart failure three months longer. In this study they concluded that hospice not only didn't shorten life; in several conditions it actually extended it.⁵²

Finally, in La Crosse, Wisconsin, the ICU was filled with critically ill patients, including a young woman with multiple organ failure from a devastating case of pneumonia and a man with a ruptured colon accompanied by a serious infection and a heart attack. He was only sixty-three. This was a most unusual patient base for an ICU. None of them had terminal disease, untreatable dementia, or heart failure, and none were in the final stages of metastatic cancer. None of them were aged, at the end-of-their-lives like a typical ICU.

What was the difference? The difference stemmed from a decision made a number of years earlier by the La Crosse community medical leaders to initiate a systematic campaign for medical persons and patients to discuss together their end-of-life concerns. Talking to patients about their end-of-life wishes freed up beds in the ICU which were then available to treat critically but not terminally ill patients.

It was common practice that all patients admitted to the hospital nursing home or assisted living facility would discuss with an experienced medical person their wishes at the end of life. The conversations focused on four questions:

1. Do you want to be resuscitated if your heart stops?
2. Do you want aggressive treatments such as intubation and mechanical ventilation?
3. Do you want antibiotics?
4. Do you want a tube or intravenous feeding if you can't eat on your own?

In five years 85% of the town's residents had prepared advance directives, up from 15% when the program started. It's not that the discussions and advance directives settled every issue or

⁵² Ibid., 178.

covered every decision. What was different was that patients and families had thought about and talked about the critical decisions so that when they were caught up in the anxieties, fear, and crisis at the moment of mortality, families were more receptive to discussing such matters and had had some experience doing so. In La Crosse, the end-of-life costs dropped to half the national average.⁵³

The case for discussions is compelling. Just talking together brings positive identifiable results. Gawande concluded: “If end of life discussions were an experimental drug, the FDA would approve it.”⁵⁴

When it comes to treatment at the end of life Dr. Louise Aronson affirms . . . “the default position of the American healthcare system is to ‘do everything.’ More often than not this approach does not include ‘everything.’ It rarely includes essential conversations about a person’s future, care designed to minimize distress and maximize comfort, information about likely life expectancy, and options for treatment in a familiar environment. Each of those approaches is well studied, proven effective, preferred by many patients and families, and generally not provided in today’s technology-obsessed and profit-driven health systems”⁵⁵

The Conversation

Doctors are not trained for conversations with patients at the end of their lives. Doctors view many end-of-life issues as failures – their failure to conquer illness. Doctors struggle with uncertainty, feeling that they should appear certain in the eyes of their patients. Despite this,

⁵³ Ibid., 179-80.

⁵⁴ Ibid., 178.

⁵⁵ Aronson, op. cit. 209-10.

there is evidence that they are more certain about the results of experimental studies (which are in fact probabilities) than about mortality (which is clear and certain). Some doctors also have not come to terms with their own mortality and therefore find the subject difficult to discuss openly with their patients. Doctors define themselves with paternal authority and have difficulty relating to a patient, since patients are defined and perceived as “suffering” and “weak.” Apart from other issues, this imbalance of doctor-patient relations compounds the difficulty of a meaningful conversation. In addition to other concerns, Gawande himself admitted that “Discussing the fantasy of a very remote possibility of a positive outcome was easier – less emotional, less explosive, less prone to misunderstanding – than discussing what was happening before my eyes.”⁵⁶

Conversations are likewise hard for patients. Many want to fight their disease to the bitter end, partly because of an overconfidence in science and science’s confidence that if the cure is not already available it soon will be, and partly because confronting mortality is so frightening that they can’t bring themselves to face it. “Is there anything more you can do for me?” is not an uncommon question. Patients and their families are often caught up in crisis and feel anxious about death, suffering, concern for loved ones, and finances. Facing mortality feels strange. It’s new. One doesn’t die but once.

According to Ezekiel and Lynda Emanuel, doctors interact with patients in one of three general styles, each indicative of the relationship they choose with their patients and the role they view for themselves. First, as medical authority, with a paternalistic attitude – the priestly, doctor-knows-best model. Second, as information provider. The doctor provides medical information, and the patient decides what to do with the information presented – a consumer

⁵⁶ Gawande, op. cit. 169.

model. The doctor supplies the best, most recent results of science, and the patient decides when and how to use it. Third, as interpreter. The doctor asks what's important, what are the patient's concerns, and she then offers what treatments she believes might serve best. The interpretive style is one that shares decision making best between doctor and patient.

In Gawande's opinion, the pendulum has shifted from doctor-authoritative toward doctor-informative, but it seldom moves the next step forward to doctor-interpretive. In his experience the most common style, driven by the doctor's perception of her role as a science-based purveyor of information, is for the doctor to share the information, put it before the patient and allow the patient to use it, without getting involved or with both of them together discussing the options and choices.

Conversations are never straightforward. Both participants bring to the table the spoken, out-front comments, but usually couched in hesitant, qualified words, and both bring as well a pack-load of unspoken emotions, anxieties, and fears, including a purposeful uncertainty about mortality, and a distancing from its inescapable inevitability. If the reality of an insistent natural death and mortality can be pushed aside, and it usually can, then a desperate search for an escape haunts the entire discussion, and it seems any alternative will serve despite its improbability of success.

Words and Questions

Wrong words can trigger unanticipated, unwanted reactions and responses and sidetrack the discussion. A single word with strong emotional content can end a conversation before it begins. Words can have multiple meanings that allow participants to talk past each other without

realizing it. Words also can possess assumed or erroneous meanings that cloud and confuse understanding.

Questions are likewise difficult. Wrongly phrased, or based on inappropriate assumptions, questions can be either confusing and badly worded, difficult to answer, or at worst, simply unanswerable.

The caricature of a horrible, unanswerable question was posed to a friend by a doctor as I accompanied him to his wife's hospital room. We arrived, 48 hours after Deedee had delivered their first child, and only 24 hours after she had experienced a massive, post-delivery brain aneurysm. In the hallway, before we had reached the patient's room, her gynecologist confronted Phil and asked in a tone that disclosed his great frustration, anger, and dismay, "Do you want to turn off the machines and let your wife die?"

I could almost feel the stunning impact of the question hitting Phil's head, like the piston of a stun gun striking the forehead of a steer in a meat packing plant. Both Phil and the doctor were so emotionally charged that they were unable to interact or decide anything at that moment, so I closed the encounter by saying simply, "We'll have to get back to you on that."

Phil and I sat down and struggled to rework the question. It took some time to rethink the situation, figure out what were the circumstances, discover how they could be resolved and what he needed to know to respond to his wife's situation. When Phil was finally satisfied, the reworked question for the doctor became: "What tests will disclose whether or not Deedee's brain is completely inactive with no chance of recovery?" If that is determined, then she has died, and there is no question and no decision to be made.

In this experience the medical person was dumping his emotional baggage on the family, and likewise passing on his medical investigative and decision-making responsibility to them as

well. He even asked the question in anger and frustration, completely out of control. He seemed to feel he had failed, by allowing Deedee to die. Had he done his homework, used his medical knowledge, and determined the state of his patient to determine whether or not she was brain dead, there would have been no question and no decision for anyone. Having determined that her brain and brain stem were finished, he would shut down the meaningless equipment and share the sad news with the family. He failed his professional responsibility by not following through to correctly assess the condition of his person, a task for which he alone was responsible. He also failed by passing a question to the family that was both inaccurate and unnecessary. In addition he failed his responsibility by not completing the treatment he had started and ending a no longer viable procedure, rather than asking a family member to make an unthinkable as well as unnecessary decision. If a question seems unanswerable, the question itself might be the fault. It might be a totally wrong, thoughtless, and irresponsible question.

Difficult questions at the end of life frequently pivot on stopping treatments and ceasing support. They are often phrased with guilt-loaded implications, intentional or not: “causing death, or allowing it.” Medical personnel, no matter the level of experience or maturity, bring their own history and grief to the table. Those two emotions go with the territory of mortality, and they continue for a lifetime. Even proper questions deserve to be laid on the table as gently as possible, like tiptoeing across broken eggshells.

Questions should be addressed to the correct person. If the issue concerns a process or treatment that is no longer working, one that has no benefit, that decision belongs to the person who initiated it, not to the family. A discussion with the family to apprise them of what is happening might be needed, but the question and responsibility belongs to the doctor. If a

question concerns the family's understanding of what respects the patient's dignity, then that one belongs to the family. Questions concerning mortality are always difficult and demanding.

In significant situations, if a question is difficult to answer, the problem is likely that that question was the wrong question, or perhaps badly phrased, or maybe asked of the wrong person, or asked at the wrong time. A good question is always difficult and should be approached with care and careful preparation. A few doctors have compared preparation for a conversation with a patient to preparation for surgery.

Susan Block, a palliative care specialist with lots of experience in end-of-life issues, said, "A family meeting is a significant procedure, and it requires no less skill than performing an operation."⁵⁷ Conversations are not about what people want, nor about the doctor's facts and opinions. They are about anxiety, about death, about suffering, about relations with loved ones, about uncertainty, and about finances; such a full basket of concerns is too much for any single occasion. A conversation of this nature is always "a process, not an epiphany."⁵⁸

For a doctor and a patient to engage in a meaningful conversation, a groundwork and an emotional base need to be in place, including an acceptance of one's mortality, and as well a clear understanding of the possibilities and limits of medicine to assist and not interfere. Often, this groundwork is not available, and the ghosts of unspoken anxieties and unrecognized expectations haunt both the process and the outcome.

Meaningful conversation requires as much listening as talking, perhaps more. Keep track, Block says; if you're talking more than half the time, you're talking too much. A leader's stance, attitude or question can invite conversation, or shut it off before it begins. Both Art Linkletter

⁵⁷ Ibid., 181.

⁵⁸ Ibid., 182.

and Danny Kaye hosted variety shows in the early days of television. Both interviewed children on their shows. Art stood, microphone in hand with 10-year olds and week after week asked the same question, “What did your parents tell you not to say on the show?” They answered honestly with comments about how not to embarrass the family in one way or another, and the audience laughed heartily as the parents were embarrassed by their children naively broadcasting exactly what their parents said they should not say – but they only answered the question that was asked.

By contrast, Danny Kaye sat on the steps with a five- or six-year-old each week, his head at their level, and quietly asked an open-ended question: “Have you done anything fun today?” Then he listened. His young guests were set free to share with him and the entire audience their world of innocence and wonder, giving adults a glimpse into their fresh unspoiled perspective. It was a rare, magical gift which I still remember 54 years later. I still remember with delight a little girl named Veronica . . . because Mr. Kaye gifted her with respect and with the freedom to be herself and share her child’s perspective with all of us. That is the same respect, encouragement and freedom patients need from doctors so doctors can hear them and minister to their needs, not impose on them some medical imperative.

Listening begins with ‘wanting to hear,’ and to be meaningful and honest, it needs to be accompanied with appropriate body language, mood, and a question that invites response. Even dogs know if you stand over them you are asserting authority. If you want to relate with someone, get down on their level. Sit beside their bed, don’t hover over them. If you want to hear them, prove it by listening.

Words can miscommunicate as well as communicate. An experienced palliative specialist notes if you say, “I’m sorry things turned out this way.” You are looking at matters from a different perspective than the patient’s, distancing yourself and thereby abandoning the patient.

To engage in conversation and exchange requires assuming a view of life from the other's perspective. If you want to identify with the patient, say instead, "I wish things were different." That statement puts you clearly on the patient's side, viewing issues from their vantage point. Phrase each question with considered care to enhance communication for the best relationship and the best result.

Don't ask, "What do you want when you're dying?" Instead ask, "If time becomes short, what is most important to you?" The reflex answer to the first is universally, "I don't know yet. I've never been there." It's much easier to talk about "what is important to me" than about "what I want to do" in some unimaginable, fearful and unwanted future.

Susan Block, from her nurse's experience, suggests the discussion with a patient to help them achieve clarity should include what they understand their prognosis to be. To help deal with their fears and anxieties, ask what are their concerns about what lies ahead. To help them form their priorities, ask what kinds of trade-offs are they willing to make. To shape their expectations, ask how they want to spend their time if their health worsens, and who they want to make decisions for them if they can't make them, thus deciding on who they want to serve as their medical surrogate.⁵⁹

With these questions, the clarity of the medical situation is confirmed, and the need for additional information is identified. Fears and anxieties can be addressed. Benefits are recognized and harm can be minimized. The patient's priorities for the all-important time remaining are communicated, and who they want to represent them if and when a representative is needed.

⁵⁹ Ibid., 182-3.

When the air is cleared, when mortality is recognized, when the possibilities that medicine has to offer in those individual circumstances are understood, the choices are focused and often become amazingly clear. One patient in such a situation expressed his priorities very simply. “If I’m able to eat chocolate ice cream and watch football on TV, then I’m willing to stay alive.”⁶⁰ Often priorities are that simple when given the freedom to consider.

Conversations as mortality approaches are as valuable as they are difficult and are invaluable for the wellbeing of the patient. They allow a person to consider, reflect on and express what represents them, their dignity, and their life’s import as it is concluding. The importance of these conversations rates as the top priority for medical ethics, as significant as the most significant medical breakthrough in any disease, because a conversation is vital to every patient and addresses the most significant incident of every person’s life, the final scene of each personal history, the conclusion of life itself.

⁶⁰ Ibid., 183.

V. CONVERSATIONS—THE BEST PATH TO NATURAL DEATH

In the current division of medical specialties, there are two specialties that are designed to focus on respect for patient autonomy and have a specific interest in end-of-life care: palliative care and geriatrics. These specialties assume the same relationship between medical provider and persons as does a conversation and can therefore more easily produce the desired result. Doctors of cardiology, oncology, surgery, pneumatology, and other specialties may engage in such a discussion with their patients, but it is a rare event. Dr. Atul Gawande's study indicates that only 11% of all doctors engage in such conversations near the end of life, while most avoid that kind of involvement.

A third option is concurrent care, a hybrid approach to treatment in which a traditional specialty is combined with either geriatrics or palliative care. Under concurrent care, persons enter an interactive relation earlier during treatment, as much as a year before projected mortality, which can provide better, longer-range, person-serving results.

Palliative Care

The significant efforts to improve end-of-life care that are now burgeoning in the USA are focused on better availability of palliative care.⁶¹ Palliative care is an approach that focuses on the quality of life of patients and their families as they deal with problems associated

⁶¹ Breier-Mackie, Sarah. (2001). "Patient Autonomy and Medical Paternity: Can Nurses Help Doctors to Listen to Patients?" *Nursing Ethics* 8, No. 6. 516.

with long term, life-threatening illness. Using techniques of early identification, careful assessment and treatment for pain, palliative care clinicians seek to enhance the quality of life and focus on the preferences of the people as they approach their mortality. Palliative care both affirms life while at the same time regards dying as a normal process, intending neither to hasten nor to postpone death. This person-focused approach can be applied early in the course of illness. It uses a team approach and therapies intended to prolong life where appropriate, such as chemotherapy or radiation therapy, as well as procedures to provide comfort and relief from pain. Palliative medical persons help coordinate, better understand, and manage the combinations of distressing clinical complications while, at the same time, offer a support system to help patients live as actively as possible up to mortality. It provides relief from pain and other distressing symptoms to enhance a person's quality of life, as well as a support system for families to help them cope during the person's illness and the family's bereavement after death.

Palliative care is the patient's friend and support as soon as the path to mortality emerges in their life, an approach by which the medical community can support both curative treatment as well as respect for patient autonomy while helping to avoid the incessant medicalization of death and non-beneficial treatments at the end of life.

Geriatrics

Dan Brennan, MD describes geriatricians as primary care doctors who have additional training in treating older adults – people who have multiple or complex health matters and need specialized care. Geriatric doctors have the training and experience needed to focus on the whole person and coordinate the complexity of the various issues that arise at the end of life. With a focus on the whole person, they work with an expanded range of concerns such as arthritis,

Alzheimer's, balance issues, cancer, dementia, diabetes, depression, frailty, heart disease, incontinence, insomnia, osteoporosis, and all areas of concern that usually affect older adults.

A geriatrician can serve as a primary care clinician, a consultant, or part of a team of physicians and caretakers for older adults. Their focus is on the overall quality of life and the goals and values of the individual person. Their interaction with persons usually takes longer because they need to spend time to address all a person's issues including lifestyles, family concerns, and relations to the community in order to get a full picture of the whole life, not just their specific medical concerns.

Adult-Geriatric-Nurse Practitioner

A helpful addition to care for older adults is the new specialty of Adult-Geriatric-Nurse Practitioner (AGNP). With additional training, an AGNP adds special age-related technical skills, communication and coordinating abilities, understanding of the aging process, and training to serve as a primary caregiver for the elderly. He manages chronically ill patients and informs families about the condition and care of their loved ones. With these additional skills AGNP nurses can offer a meaningful alternative to medicalized care.

The work of palliative caregivers and geriatricians is very similar. Their specialty is to focus on the needs and interests of the whole patient. This aligns them directly with the concerns of respect for a patient's autonomy and helps assure that as she approaches her mortality, her will and her intent will be followed. It likewise assures her the quality of her life as she wishes it and enables her to avoid medically determined priorities and defaults. Training and commitments are aligned with the medical provider-person relation sought in the Conversation and with a commitment to use valid, meaningful healing procedures in conjunction with a person's

autonomy. They become powerful allies for elders to maintain their choices as they approach mortality.⁶²

Concurrent Care

Concurrent care is like palliative care with the exception that in concurrent care, palliative care serving alongside traditional treatment is introduced earlier in the course of treatment and care. It involves the same persons doing the same things, but the patient-focused palliative approach helps guide curative treatments earlier and can help mitigate pain as well as minimize non-effective and undesired treatments.

Hospice

Hospice is a frequently used pattern of support at the end of life, but hospice, in clear distinction from the three forms of medical specialties, is an insurance-funded set of supports for those who have signed off on further curative treatment in favor of only pain medications and sustaining aid at life's end. To qualify for hospice, two physicians must confirm a prognosis that life expectancy is less than six months. Since hospice is funded by Medicare, the specific care supported is reviewed annually and subject to change. Although widely utilized, and available as early as six months prior to projected death, it is commonly started only when a person is actively dying, and on average, death occurs within two of weeks of beginning care. Experience indicates if persons select hospice early, it can extend life as well as enhance the quality of their life.

⁶² Geriatrics and gerontology are often confused. Geriatrics is a medical practice of hands-on care, while gerontology is the study of elderly and aging. Both are concerned with the same group of people, but one studies, while the other provides services and care.

Dying patients who receive hospice and their families are more satisfied with the care they receive than are those who are cared for elsewhere. This reflects the skill, compassion and dedication of the people working in the hospice environment, predominantly nurses.⁶³

Nurses

A part of the Nurse's Code of Ethics includes a commitment to care for patients, while by contrast the physician's commitment focuses primarily on healing. Because of their duties, nurses spend more time with persons and are closer attuned to their needs and values. Although nurses are the medical persons directly involved with patients on a day-to-day basis, and even though the effects and consequences of carrying out clinical decisions fall on the nurses, clinical decisions are the responsibility of the physician. However, persons, confronted with the patient-autonomy/paternalism dichotomy, are often unable to verbalize to their clinicians, either because they are intimidated by the clinicians's perceived power, or because the clinicians fail to invite, listen and hear their concerns.

Nurses are in position to become persons' advocates, a most helpful function for both clinicians and people. They are in a unique position with daily contact and personal knowledge of the patient's conditions to initiate discussion regarding preferences for treatment and for quality of life. The individual person alone knows the risk he/she is willing to take and is in position to judge the specific benefits of treatments. More importantly, only patients live with the impact and outcomes of medical interventions. Persons can recognize when treatments are futile and can value when they are not worth trying in the first place. Persons should be significantly involved in making treatment determinations; however, they are seldom considered to be

⁶³ Breier-Mackie, 516.

sufficiently knowledgeable to make judgements about the probability of a treatment's success or its effectiveness to achieve their desired goal.⁶⁴

The most difficult times in caring for severely, progressively ill patients are the transitions from gravely ill, to fighting death, to terminally ill. Shifting through these transitions is not new to nurses, especially those experienced in clinical environments such as oncology, palliative and hospice care, critical care, emergency departments, and geriatric care facilities. Nurses are directly involved, on the ward, at the bedside, 24 hours a day, providing continuous care, rather than the segmented consultative care so characteristic of the practice of hospital medicine.⁶⁵

With close daily contact with persons, nurses are in an ideal place to successfully assume the role of mediator. Their daily work is hands-on care, helping patients live as normally and independently as possible, attentive to their individual desires and cares. With close intimate contact they are in position to help achieve goals defined by their patient's abilities, based on the close nurse/person relationship.⁶⁶

Due to this relationship nurses are empowered to speak with authority regarding the effects of the illness on the patient, assess the current health state, and judge how that state impacts their ability to achieve what's important to them. This nurse/person relationship distinguishes nursing from other forms of medical delivery and puts them in position to develop strategies to clarify unrealistic expectations of both treatment provider and treatment recipient.⁶⁷

Nurses are an invaluable resource for enhancing care for the elderly at the end of life. Their

⁶⁴ Ibid., 514.

⁶⁵ Ibid., 516.

⁶⁶ Ibid.

⁶⁷ Ibid.

knowledge, experience, and skills should be incorporated into the patterns of elderly care much better than they currently are.

Although both nurses and clinicians share a commitment to the principle of autonomy, nurses emphasize patient-autonomy while physicians are more likely to emphasize beneficence. It's far easier to consider a generalized good, or at least a possible good, than it is to serve the respect of the specific values and goals of individual persons. It is easier to revert to paternity and to decision by defaults than it is to discover the specifics of each individual person's concerns.

As Sarah Breier-Mackie says in commending nurses for service as advocates:

The inhibitors to patient focused care emanates from what can be defined as a 'capitalized/privatized' health care delivery system. Medical paternity is alive and well, as is patient ignorance of their rights as recipients of health care to say 'no'. To claim that patients have autonomy is to argue that they have the capacity and right to decide for themselves the values and rules that will govern their existence. This claim works only to the extent that it provides a justification to limit the power doctors exercise over patients, specifically the power to judge and make decisions without their knowledge, their understanding or their consent. When doctors exercised such power, they violate the capacity and right of patients to self-determination. Doctors' unilateral decision-making-power on the basis of medical dominance substitutes a system of medical-paternity for patient-autonomy. Nurses work daily within this ever-present dichotomy, putting them in a position to challenge the process. Assuming the role of patient-advocate they can embrace their professional power within the area of clinical ethics and make a significant and worthwhile contribution to ensuring that patients' true wishes are respected, or at least heard.⁶⁸

If a patient has information about these medical specialties and these varying approaches and does not allow himself to be structured by time worn-tradition and expectations, he can choose a path and align himself with these medical providers and nurses early on to both influence the

⁶⁸ Ibid., 518-19.

direction of care and enhance the quality of life for a longer period of time, as well as have a major say in making the best decisions along the path to mortality.

VI. AVOIDING MEDICALIZED DEATH

Elderly persons today live longer, accumulate multiple chronic diseases, and experience extended morbidity. When that happens, medical treatment is needed over longer periods of time, is more complicated, and involves multiple body systems which in turn involves multiple specialties and complex intersecting treatments. Multiple specialties involve multiple decision makers, complicating the conversation still further. The complexities and the decision making of medical treatment is expanded by geometric proportions.

Mortality is inevitable, the certain end of every person's life. Prominent medical practitioners and writers Dr.s Atul Gawande and Louise Aronson call on "medical persons" to engage with "persons" under their care to support their values and their individual biographies as they approach their mortality.⁶⁹ "Death is certain, but the timing isn't."⁷⁰ "Persons" have their own personal concerns at this time, and medical treatment is not always desired.

Mortality is the inevitable end of life. The goal is to avoid the incessant momentum of medical treatment, but once a person enters the maze of medical care, the undetermined focus and frequently changing identity of decision makers and providers makes meaningful interaction with a "person" problematic if not impossible. A "person" is moved through the multiple specialists and treatments selected, often by protocols and default. Specialists – oncologist,

⁶⁹ Gawande, *Being Mortal: Medicine and What Matters in the End*, 165.

⁷⁰ *Ibid.*, 139.

neurologist, cardiologist, emergency room physician, hospitalist and intensivist – conclude independently what is best and any input by the patient is incidental.

The momentum of tradition through the history of medical delivery has charted the classic role of doctor and patient, continuing the subjugation of patients to the superior judgment of doctors based on the doctor's knowledge, their traditions, their expectations, and the aura of their art. Despite the introduction of a “person’s” autonomy as a major principle of medical ethics in the last few decades, the forward thrust of tradition continues to provide a strong undercurrent of doctor dominance and authority.

In medical delivery at the end of life, protocols never indicate “Do Not Treat” as the choice, much less the preferred choice. Instead, the default position is: “If you have a treatment, use it.” If “Do Not Treat” comes up as an option, it is usually after several treatments have been considered and eliminated or tried and failed. The medical mantra is consistent: “Do everything you can!” It’s easier to defend “I did everything I could,” than “I didn’t think that was needed.”

Each medical specialty has its own set of protocols and preferred treatments. Treatment is assumed and expected. The only decision is which one to select from a list. Meanwhile, patients endure the results. Aronson writes, “My mother says she’d rather be dead than live in a very old age with significant dementia or disability . . . ‘lingering’ in a life without any evident benefits.”⁷¹ Most elderly patients express misery; all appear to be suffering.

There are a few religious traditions that don’t see it that way. They advocate the sanctity of life over all other values. The goal is always more, more life. A long-standing theologically based assumption is to extend life no matter how meager its quality, no matter the pain and suffering, no matter its meaning or the lack thereof. No one asks what is important to the patient,

⁷¹ Aronson, op. cit. 246.

or how a proposed treatment relates to the inevitability of impending mortality. If breath and heartbeat can be maintained by some means, then do so.

Mortality provides an anchor to hold against the tides of anxiousness and the emotions of both doctor and patient in both the discussion and decision-making. Mortality is the reality quotient as well since mortality is inevitable whereas death is only desperately hoped to be optional. It recognizes the end of life as a normal, inevitable end, not an illness that can be treated. If mortality is not recognized, treatment persists until death, snatches away the final breath, and medicine is finally defeated.

Treatment decisions, whether based on protocols or by default, are not moral because they lack any moral intent; they were decided by someone else in case a situation like this one arises with no regard for the specifics of the current patient, or the circumstances. Such treatments are morally neutral, gaining moral significance only when they have specificity and intent. Intent identifies a goal, a purpose, an expectation or a benefit, a fulfillment of a duty, or an obligation, and intent applies to an individual person and their particular condition.

Default is by definition generic. It is an act without a decision, a pattern imposed on all who fit the entry criteria. No decision regarding the patient is made. The only decision is to follow the default and the tradition. It takes place because it's what usually happens when these general circumstances obtain, treating a generalized pattern. Defaults cover many situations without regard for the current specifics, lacking relation to an individual or to the respect of that person. Treatment selection by default is because "we've always done it this way . . ." or "because in Dr. Noes' Department, where we were taught, they thought that was the best way to do it." Default lacks both specificity and individuality.

To make an individual specific decision, considering the distinctiveness of a person, takes time, and defaults are used in situations where time is scarce. But by the same token, if time is shorted without considering an individual and their situation, it thereby shorts the value and respect for that individual by not taking the time required to respect him and his individuality. The pressures of time caused by corporate-owned physicians, the structuring and selection of procedures by insurance's priorities, and the limitations on treatment determined by managed care all run counter to medical ethical standards and to respect for the individual. Burnout is an important factor for doctors today. These imported structures and the internal conflicts within medical delivery are often the cause when physicians are caught between demands of what they ought to do and what they are permitted to do – causing burn out. These dysfunctional structures and incongruities are to blame, not the pressures felt in ethical decision making. A physician's decision, whether to miscode a procedure so insurance will cover it for the patient's benefit, is not a tough ethical decision, but a structural issue of insurance-manipulated medical delivery. A physician's not being allowed sufficient time to secure a patient's input is not a moral problem for the physician, but an ethical problem of the system of medical delivery. The rug of medicine is bulging with all that's being swept under it.

Emotionally Charged Words

The discussions in end-of-life decisions are emotional enough without adding emotionally charged words such as “death,” “kill,” and “die.” The medical preference of continued life without regard to cost, continued life that continues without regard to the suffering it causes and that lacks meaning to those whose life is continuing, is noxious. Decisions to continue life based on abstract principles, or values of other persons, not of the individuals who

are suffering, are often based on the unconscious, background emotional states of the healthy: their fear of death and their loss of *joie de vivre*, states that are derived from the expectation-perspective of their years of life ahead. These are inappropriate and misplaced.

Words carry not only distinct meanings, but also significant emotions. “Death” is a harsh word apart from its meaning. It also has a harsh sound when pronounced, adding even more harshness. To speak it requires a hard-dental aspiration produced with the tongue pressed firmly against the back of the teeth, then suddenly released. “Death” sounds sudden, abrupt. It feels like intrusion, invasion, alien – a word more suited to an interruption in an ongoing process, rather than an end to the inevitable completion of mortality.

“Kill” is likewise sudden and intrusive. It feels like an attack or the end of a contest. The sound of “kill” also concludes suddenly and abruptly. It begins with an abrupt click of the tongue, like a tiger’s teeth closing on the neck of its prey and ends before the beginning sound is completed.

"Die" is softer. It has connotations of slowly coming to an end. The sound of die trails off and concludes gently, leaving the air behind with less emotion, like the smooth wake of a boat as the water returns after being gently parted.

By contrast, “mortality” sounds even more like an appropriate word for the inevitable conclusion of a process. It has four even-sounding syllables, mor-tal-lit-ty, and suggests the conclusion like a process. It represents what is happening as life ends, the end of an extended existence. The word "mortality" also sounds like the rounding off of a completed whole, with a beginning and an end. When "mortality" is used in the discussion, it tends to defuse the emotional content and allow decisions to be made on a more thoughtful level.

Treatments at the End of life

Medical ethics discusses the morality of end-of-life decisions under the principle of nonmaleficence, examining the distinctions between killing and letting die, causing and anticipating harmful outcomes, withholding and withdrawing life-sustaining treatments, and extraordinary and ordinary treatments.⁷² However according to Thomas Beauchamp, “Though enormously influential in medicine and law these distinctions are all untenable. The venerable position that these traditional distinctions occupy in professional codes, institutional policies, and writings in biomedical ethics provides no warrant whatever for retaining them . . . some of these distinctions can be morally dangerous.”⁷³ The distinctions serve civil and ecclesiastical law more than ethics, with numerous unexamined presuppositions that focus on both placing and avoiding blame where the lawyers for the defense and prosecution are both seeking emotional impact to influence a judge or jury. Medical ethics seeks not blame or assign responsibility, but rather the proper care and support for dying persons. The wording of ethical discussions needs to be selected carefully or simply a wrong word could bring about an ethically wrong decision.

All treatments in the end-of-life setting should be considered in the specific context of impending, inevitable mortality. No correctly specified treatment in this context can kill or cause death because dying is already happening; the process of incessant dying, mortality, is already in process. To consider withholding or withdrawing treatment apart from the reality of inevitable mortality is morally dangerous, intrusive and irrelevant.

A major anxiety of patients approaching mortality is the suffering produced by treatments, thus introducing a major theological tradition that holds sway in medical ethics, one

⁷² Beauchamp, Tom L. and James F. Childress. *Principles of Biomedical Ethics. 5th Ed.* (Oxford: Oxford University Press, 2001). 113.

⁷³ *Ibid.*, 120.

which values suffering as a positive good for teaching and for recompense. This tradition is noxious. It only clouds the discussion and distracts from reality. The first consideration of using quality of life as a standard immediately calls forth a prior question: “Whose life is it a quality of?” The immediate answer is “The patient’s,” which sends us back to the respect for the autonomy of the patient, disallowing the essential structure and context of the traditional concerns introduced into medical ethics by a religious tradition.

Gawande points to Juergen Bludau, a geriatrician who defined promoting quality of life as the job of any doctor to support “as much freedom from the ravages of disease as possible, and the retention of enough function for active engagement in the world.”⁷⁴ The discussions at the end of life and each decision at that time must account for the inevitability of mortality and of natural death and must be made in that context.

Since all the proposed discussions of nonmaleficence presuppose treatment of some sort or the lack of it, let’s consider the requirements of treatment if it is in any sense called for. To serve a moral end, any treatment must be specified by the goal or purpose to which it is directed. Specification includes: (1) a clear purpose or goal; (2) a specific path and expectation to achieve that goal; (3) a standard to measure effectiveness; (4) a projected time frame to evaluate effectiveness; and (5) a commitment to end the treatment if it does not meet the goal.⁷⁵

Since the priority of treatment vs. non-treatment is so instilled in the traditions of medical education, medical science, and medical service, it is very hard for a clinician to comprehend the reasoning or progress on the path to mortality without treatment and hard for them not to search

⁷⁴ Gawande, op. cit. 41.

⁷⁵ Robert Henry Crumby. (2012). *So Falls a Sparrow: Ethical Medical Decisions at the Bedside with and For the Sole Good of the Patient*. (CreateSpace Independent Publishing, Subsidiary of Kindle Publishing).

for a path to a cure. After all, healing is what medicine is all about, but neglected “care” is the third leg of a physician’s responsibility.⁷⁶ However, today, care is deemed less valuable than cure, so if there is the slightest thread of hope of a treatment possibly working, most clinicians prioritize a cure simply if it can be imagined. The value of doing nothing, and the contribution that doing nothing adds to “persons” living out their lives according to what they prefer, is never considered. Gawande cautions, “Lacking a coherent view of how people might live successfully all the way to their very end, we have allowed our fates to be controlled by the imperatives of medicine, technology, and strangers.”⁷⁷

Specified treatment serves two ends. First, it serves moral integrity by presenting a clear goal that can be evaluated in accord with its moral intent. Second, it pulls back from protocols and defaults, and supports a thought-out process with a clear expectation that can be evaluated and used for a particular situation. In addition, it requires whoever is ordering the treatment to pause, consider, and provide a clear terminus if the treatment is not effective, based on predetermined criteria. Specified treatment focuses on the moment and on the current individual’s situation. It should be based on respect for the autonomy of the patient, free of the traditional definitions, unspoken expectations, traditions and codes, and free of the unrecognized, unconscious emotions that play in the background of the psyche.

All Treatments derived from Intent

To provide a sound ethical base, in addition to careful specification of treatment, medical ethics should require a single standard for all decisions, by all involved. In end-of-life care, every

⁷⁶ Siegal, M. D. (2018) “To Comfort Always.” Letter to the Yale School of Medicine, <https://medicine.yale.edu/news-article/to-comfort-always>.

⁷⁷ Gawande, op. cit. 9.

decision should serve the intent to respect the autonomy of the person on whose behalf the decision is made. Physicians, all medical personnel, family members, and surrogates are all bound by intent, the intent to respect the autonomy of this individual person. Everything done as mortality approaches should be intended to serve that autonomy.

Intent is a firm base for moral action. It serves as a standard and starting point for all discussion. It is a clear stance imposed on everyone to respect the individual's autonomy and a meaningful representation in situations where an actual decision by the person or specific affirmation is available and likewise a clear focus of attitude and action where a personal statement is unavailable. Intent is superior to any intruded paternity of a non-parent, based on values drawn from outside the sphere of the person. Intent as an attitude lacks specificity, but when intent is focused on the effort to determine how respect would be honored, that intent becomes itself a form of honoring respect.

With intent as the measure of every action and decision, clinicians gain leverage against the unbridled self-interest of family members. Likewise, family members can call on intent to leverage overbearing treatments of a medical professional with more than a vague memory such as, "I seem to remember when I was twelve that my grandfather said . . . "

Paternalism when attempted would have to justify itself by the intent to respect the patient, a very difficult move of mental gymnastics. Emergency artificial nourishment would have to be argued on that person's specific situation, not an imported, generic "lack of food is killing the patient." The requirement for all end-of-life decisions to be made with intent and thus to honor the respect for a patient's autonomy would place all decisions in the realm of ethics where they properly belong, focusing only on respect for the person served, and disavowing decisions made by protocols and default.

In legal arguments, “intent” serves to diminish culpability from maliciousness to just negligence. Though difficult to prove in the courtroom, its importance plays a valuable role in lessening the weight of the act . . . because it was unintentional. “Intent” was also used in later versions of the Oath of Hippocrates to diminish the culpability of harm. In the AD 245 version of the oath, the phrase regarding “harm” was modified. The adjective “intentional” was added . . . "I will abstain from all intentional wrong-doing and harm."⁷⁸ Both these uses were to indicate a lack of malevolent intent; the subject did not intend to harm.⁷⁹ “Intent” needs to be reintroduced into today’s ethical discussion as a positive, a call to both physician and family to intend to respect the patient’s autonomy at a time when his specific needs are hard to anticipate and other avenues for determining them are not available. To use “intent” in this way would require a significant rework of current medical delivery, and at the same time make a significant contribution to medical ethics.

Specificity of treatment and requiring intent to respect autonomy as the base of all end-of-life treatments and procedures would make a major contribution to issues with the critically ill in the ICU. That should at least slow if not end the incessant imperative of medicalized death and restore the values of natural death, allowing medicine to forgo treatments and serve what is valuable to patients and their families as they approach the end of life.

Euthanasia, Assisted Death and Suicide

⁷⁸ Sokol, Daniel K. (2013). "'First do no harm' revisited". *BMJ* 347: f6426 347.

⁷⁹ “It is often said that the exact phrase "First do no harm" (Latin: *Primum non nocere*) is a part of the original Hippocratic oath. Although the phrase does not appear in the AD 245 version of the oath, similar intentions are vowed by, ‘I will abstain from all intentional wrong-doing and harm.’”

The most controversial issues at the end of life are euthanasia, assisted death, and suicide. When the names for these three acts at the end of life are properly named in relation to mortality, the approach to each is clarified and some of the tensions of confronting them are eased. The emotional naming in the term should be replaced. Speak not of "euthanasia" - literally, "good death" - but instead of "good mortality." "Assisted death" is more aptly titled "assisted mortality," and "suicide" is titled "chosen mortality" or "mortality by choice."

Mortality is a given, an inevitable end to all life. It will happen. We can affect the timing of mortality by good diet, good exercise, and good emotional balance. With these extended procedures we can also affect the timing by bad diet, lack of exercise, and tumultuous emotional states. All the above activities are conscious choices of an autonomous person. What is the difference between those self-determining choices, and the conscious choice of an autonomous person to choose to ingest chemicals that will in a similar manner only affect the timing of mortality? Unless we are prepared as a culture to require persons to follow every rule of good health and wellness, why should we in this special period intervene and try to prevent an autonomous person from adjusting the timing of their inevitable mortality? Is there an ethical rationale for society to intervene in one case and not in the other?

After a check to assure the person had accurate information regarding his condition, and that he is competent to make a thoughtful decision based on his best interest as he perceives it, why is that person not free to make that choice, a choice that respects his dignity as autonomous? A more carefully chosen word, "mortality," to better represent the reality of what is happening, makes a significant difference.

The same analysis holds for assisted death. Assisted mortality is likewise an adjustment of the timing of mortality, the kind of decision we make every day, with much less intent or

planning, as we go about our lives. If it is the choice to respect one's own dignity and self-determination made freely and with personal intent, then any assistance properly requested or rendered is covered under the decision of the person choosing autonomously and is thereby ethically sound. Such a decision is ethically valid, unlike a clinician's decision to withhold or provide treatment based on her paternal role and superior medical knowledge.

Chosen mortality has different implications. It differs from good mortality and assisted mortality in that it comes before end-of-life issues and therefore with significantly different implications, but like the others when considered as it relates to mortality, it is cast in a significantly different light.

With mortality as the inevitable given, all considerations at the end of life are based on timing and on the respect for the person who is mortal, maintaining their intrinsic dignity as they conclude their distinct personal life history. It is the ethical responsibility of all involved - family, medical personnel, judges, everyone - to adopt the intent to serve the autonomy of that person and their dignity, putting aside all their other values and considerations.

In the 21st century, there have been advances in curing diseases, but many more advances in stopping and slowing the progress of diseases. Elders live longer with more disabilities than in the past. We have more understanding and help for relieving pain and suffering and for assisting people to cope with their disabilities than ever before. Yet our social structures and living conditions, our medical procedures, and radical changes in family styles have left elders more isolated and alone, with less personal support and assistance through family and community than was formerly available. We have progressed in our abilities to cure and to extend life, but the obligation of care is missing from both social and medical support. When the zenith of cure is reached, purveyors of medicine too often retreat from the field, leaving people on their own, or,

much worse, continuing to inflict treatment when treatment is futile, blindly medicalizing death and abandoning the respect for the dignity of the person and what's important to the person entering their mortality.

Until medical practitioners have the integrity to recognize the limits of treatments before impending mortality, until medical practitioners have the courage to confront their own anxieties about their own deaths as well as the death of their patients, until medical practitioners have the wisdom to move beyond their treatments and embrace the third standard of medical practice – care – and gain the opportunity to experience shared moments-of-humanity with their patients, the incessant momentum of the medicalization of death will continue.

In Edward Livingston Trudeau's trilogy on medical practice from the late 19th century, he stated the purpose of medicine:

“To cure sometimes, to relieve often, to comfort always.”⁸⁰

A cure is not always possible, but when it is, it should be pursued. Relief, if available, should be embraced . . . often. Comfort, the bedrock of all human relations, is always possible in every situation, especially in medical ones. Comfort is always available to relieve and support.

⁸⁰ Siegal, op. cit.

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