INTRODUCTION

In this essay I explore the ways palliative care — treatment given to a patient at the end of his or her life — can be enlarged to include a humanistic approach that takes into account both the patient and the medical team of caregivers. The goal is to enhance patient care by bringing together medical science and the humanities. It is at this intersection that the “whole person” can be attended to in the most meaningful sense of patient-centered care.

Numerous important books on palliative care have been written by surgeons. How We Die [1], The Best Care Possible [2], and Being Mortal [3] come immediately to mind. These works stress the human side of the study of individual needs at life’s end.

The science side of this health care story has been brilliant: Many of our outstanding advances in science are the remarkable advances in medical care. Treatments, procedures, medications, and public health have extended life expectancy annually over the last seven decades. There is every reason to believe that patients’ lives will be extended for our children and grandchildren. However, even in our lifetime, new drugs and remarkable operating room procedures have introduced novel problems. Patients now live longer, but with bodies that are diminished by old age, and often experience unintended reactions to life-prolonging, complicated treatments.

END-OF-LIFE CARE

Historically, end-of-life care was provided in two parts. The first took the form of informal conversations between patients and their nurses and physicians, and sometimes family members. Today, these may include family members, as well as others such as social workers, clergy, and hospice staff.

In earlier years, the second part of the dying sequence primarily took place after death: wakes, memorial services, Shiva, eulogies, obituaries, biographies, and other narrative recollections.

A critical problem with our current system is that it only tangentially includes the patient, a flaw rendered all the more poignant in light of new medical procedures and treatments that extend life beyond the timeframes of historical precedents. The system of informal conversations with patients before death and post-death memorials has been put under significant stress and, ultimately, has proven to be inadequate and incomplete for both patients and caregivers.

NARRATIVE MEDICINE

What I am suggesting is that the patient should be at the center of attention. I believe a void in approaches toward patient-centered, end-of-life care has developed as societal needs and medicine have changed. My argument supports the creation of a secular, humanistic way of looking at mortality and thinking through the different commitments that should be required of us to truly care for one another’s frail moral being.

In order to accomplish this and go through a meaningful, transformative experience, patients, their families, caregivers, and physicians need to re-conceptualize
their roles at the final stages of life. Many people fear pain without necessarily fearing death.

Plato suggested that the role of the doctor is to alleviate pain, not render someone immortal. Narrative Medicine is one way to join health care providers and patients in the end-of-life care process, and to fill the void that has emerged at this crucial crossroads of life.

In recent years, Narrative Medicine has come to be recognized as a critical component in patient care, improving health care quality and outcomes, as well as fostering more comprehensive clinical competency for physicians and other providers [4]. Narrative Medicine’s aim is to attend to patients comprehensively, to recognize and interpret their stories of illness by integrating into training and practice the intersection of the humanities with primary care medicine [5,6].

The goal is to strengthen the physician-patient relationship by providing more humane, ethical and effective care, making the principle of patient-centered care more meaningful.

A competency in Narrative Medicine also enhances communication, collaboration, and professionalism, humanistic skills mandated by the Accreditation Council for Graduate Medical Education.

LISTEN TO THE STORY

In a 2001 article in the Journal of the American Medical Association, Dr. Rita Charon, who leads the Narrative Medicine Program at Columbia University’s College of Physicians and Surgeons, states, “Sick people need physicians who can understand their diseases, treat their medical problems and accompany them through their illnesses” [7].

In essence, by attending to peoples’ stories of illness, we enhance the lives of patients and health care providers, bringing greater dignity, trust, and confidence to medicine.

The journey of improvement in medicine has introduced a more urgent need for palliative care and placing the patient at the center of the discussion. As life is being extended, the outcome remains the same: We still die at the end.

Our goal has never been immortality, but it has been, and remains one, of coming to grips with our own mortality. Coming to grips with questions such as: What is the meaning of life? What is my life story? Has my life been worthwhile? Who am I?

For humans, life is meaningful because it is a story. A story has a sense of a whole, and its acts are determined by significant moments where something happens. The peaks are important and so is the ending. I will have more to say on this later.

In the early years of life on Earth, death tended to come quickly and early. With the advances in medicine, society, and education, our experiences with death tend to be drawn out with an ever-extended loss of human abilities as we age into our 60s, 70s, 80s, 90s, and even into our 100s. Extended periods of less physical ability to care for ourselves have given us more cognitive time to reflect on our lives. This has created a psychological need to address the isolation from time and loss of faculties to interact with family and society.

THE JOURNEY AND THE TERROR

Today, swift catastrophic illness is the exception. For most, death comes after a long medical struggle with an unstoppable condition or with the march of old age. In all cases, death is certain — but the timing is not.

Medicine’s goal is to extend life: You may sacrifice quality of life in a trade to gain time later, but in this process, the patient’s importance as a human being is often minimized, while “success” is interpreted solely in terms of treatment of a medical condition.

The final stretch is like descending the mountain of life. The doctors know the trail and guide you. The journey has many forks, with risks that need to be evaluated. The destination is the valley below, where one closes out the story of his or her life.

The path proceeds and discussion moves to a philosophical level with the question of how to face mortality and preserve the feeling of a meaningful life. We want autonomy for ourselves and safety for those we love. Humans need something to grab onto beyond mere existence. Too often, our elderly are left with a controlled and supervised institutional experience, a medically diagnosed answer to unfixable problems, a life designed to be safe but empty of anything they care about. In its worst form, it is a life of boredom, loneliness, and helplessness.

The fear of sickness and old age is not merely the terror of the losses one is forced to endure, but the terror of isolation. It is not riches and more power that people desire in their final days: In their isolation in the last chapter of their lives, human beings ask only to be permitted to keep shaping the story of their lives — in the world — to make choices and sustain connections to others according to their own prerogatives.

Atul Gawande has observed that, the “only way death is not meaningless is to see yourself as part of something greater: family, community, society. If you do not, mortality is only a horror. If you do, it is not” [3].

There is no escaping the tragedy of life. What we are looking for is a coherent view of how people might live successfully all the way to their very end.

SPEAKING FROM EXPERIENCE

I will never forget the outpatient experience I had about 10 years ago. I went to the hospital for an ablation to correct an irregular heartbeat. My wife accompanied me and expected to take me home in about three or four hours.

I woke with a blurry view of someone leaning over me saying, “We nicked the wall of your heart during the
procedure and we need you to sign this release for us to go in and sew up the side of your heart.” I was in no position to reason through the merits of this request.

The journey toward terror began.

As I learned later after talking to my family and friends who sat with my wife, I had open-heart surgery and was in intensive care for eight days, during which I developed a severe infection raging through my body. Our grown children were summoned home after the doctor told my wife that I probably had 72 hours to get the infection under control.

Along the way I developed pneumonia and double vision. I lost all sense of time, not knowing what was going on and was very uncomfortable with a tube in my mouth, cutting off any way to speak and ask questions.

The perpetual night of isolation was dreadful. A sense of terror seeped into my world. I desperately wanted a drink of water. It seemed hours went by without anyone coming to see me. Figures would be next to the bed but no one spoke, they just looked and walked out.

I began to see bugs crawling on the walls and ceiling. They were very real to me and I questioned why the walls or the tube came away. They were very real to me and I questioned why the walls or the tube came away. Finally, they went away.

The tube was in my mouth for days and I still remember (I have never told anyone until now) that the discomfort of not being able to talk or drink water was so severe, that I reasoned that death would be better than having to carry on.

The senses of isolation coupled with terror were palpable. I never want to experience it again.

I was not proud of this whole episode and put it in the far reaches of my mind. For one who took pride in considering himself a successful, in-control person who brought resolution to situations of disorder and confusion in his private and professional career, it was a real comeuppance.

I can reflect on my experience, and muse on what doctors and the other health care workers might have done to ease my terror and isolation — not just attending to urgent medical matters, but to the fuller consequences that patients like myself experience.

I do not think that I could have written on this subject without having such a life-threatening episode. The critical remembrances were stored in the far reaches of my memory and subconscious.

Now that I have come to grips with, and written about, my suppressed feelings about choosing death, I feel released in a personal way to write on the subject of “end of life.”

A NEW OUTLOOK

My vision of the intersection of medicine and humanities is clear. I can define my own questions about what a doctor could have done to acknowledge, and maybe even diminish, my sense of fear and isolation.

The medical cohort and the patient need a new concept of the protocol of interacting with patients during the final stage of life.

My fear was not a condition that my doctors put on a chart with data about my medical status, but the recognition of the isolation that I encountered was an essential element in my health crisis, as well as part of my recovery. Telling this story some 10 years later reveals how important it was to my health and well-being.

One could imagine how different training of the medical staff treating me might have helped correct how alone I was with my desperation. Surely I am not the only patient having had such an experience.

In the last year, the case for palliative care has caught the attention of many medical institutions and writers. Several medical centers have created Palliative Care Departments and dedicated physicians and nurses to be the core group attending to terminal patients. Even Medicare has announced that it will reimburse for a doctor’s time involved in developing “a patient’s story.”

This is a good start, but I imagine a master plan that embraces the entire cadre of caregivers and physicians in these institutions. What seems to be missing is any program that brings the attending physicians, surgeons, and others into the loop of training for palliative care.

To make this program successful, hospitals have to engage a broad range of professionals. A single department for palliative care seems to be a good first step, but not a final destination.

When patients are told they have a life-ending disease, all sorts of questions can come to mind. Suddenly patients reflect about what their life has been. At this point, the doctor or other health care professional can be an agent of the mind — soul if you will — to convey sincere interest in the patient’s life. For this to happen, all the doctor has to say is, “Tell me your story.”

Every person has his or her own personal narrative. The capacity for reflection expands as we age and gather experiences. Also, reflection is taught, learned, and accomplished through emotional and psychological operations. It is an interior state that uses cognitive effort, affective imagination and creativity.

It means to perceive and represent in language — spoken, oral or otherwise — and thereby to undergo one’s lived experiences.

Narrating through reflection can result in presence, identity, self-awareness and ethical awareness. In short, it allows one to ask and respond to the question, Who am I?

Representing one’s experiences in language is a forceful way to render them visible and therefore comprehensible. The medical profession is truly at the most important, and most likely the final, intersection of the humanities and sciences in human life.

Let me return to Narrative Medicine, which aims to develop skills in visualization and interpretation in both
the doctor and the patient to discover the whole person being telegraphed by their physical bodies.

It is founded on the observation that valuable information can be gathered not just from the physical state of patients, but also from patients’ stories. Incorporating a patient’s lived experiences into a doctor’s file helps in improving diagnoses and care.

Considered as a shared action, reflective writing and storytelling help bring together the patient, the doctor and other caregivers, resulting in more informed diagnoses and better outcomes [8].

The doctor may say, “I need to know about your body, your disease, about yourself and your life.” When a person tells their story, it requires skills in how to listen, how to transcribe and how to solicit additional knowledge. In this way, doctors and patients learn about one another through the use of stories.

Patients develop their own narrative toward answering the questions, Who am I? What is the meaning of this life I have lived? And through doing so, they not only re-experience their personal story, but also develop confidence in the doctor as a reader of their life.

On the other side of the relationship, the doctor gets insight into patient history, lifestyle, and ethical values. Knowledge of these dimensions can exponentially improve diagnosis and treatment, resulting in a better outcome by replacing the patient’s fear with cooperation. Health care professionals trained in Narrative Medicine gain a sense of the vastness, loneliness, and meaning of being a patient.

Replacing fear with a sense of cooperation is one of the critical facets of this approach to medicine. Quite often the specialists one sees at the end of life are anonymous, often disease-focused, and short on human kindness.

The patient’s fear and anguish can hurt health outcomes despite the doctors’ best efforts, but replacing them with acceptance, compassion, and a sense of harmony at life’s end has the power to produce positive results.

Narrative Medicine builds on this more comprehensive approach to care and its concomitant health benefits by developing the ability to recognize, absorb, and interpret the stories of illness. It is fundamentally an effort to interweave feelings and empathy into the treatment of illness and disability.

CONCLUSION

Unsympathetic or alienating medical treatment at the end of life is something none of us should take for granted. At some point, we are all going there. By attending to the sense of story a patient has of his or her own life, death can become less frightening, less isolating: It is death that gives our lives meaning, death that becomes a part of our life’s story.

Would that we could say, along with Oliver Sacks, as noted in a piece he wrote shortly before his death, “I find my thoughts drifting to the Sabbath, the day of rest, the seventh day of the week, and perhaps the seventh day of one’s life as well, when one can feel that one’s work is done, and one may, in good conscience, rest” [9].

Storytelling is a gift. It is a forest of understanding and meaning, because it emerges from our innermost values and experiences. Nothing can be more crucial for a patient than to feel his or her life has been meaningful. Doctors have not often played a strong role in advancing this aspect of illness and healing.

But they can.

It is time for our medical system to prepare all of its participants, surgeons, oncologists, and others who come into contact with patients at the final stages of their lives for this intersection of science and the humanities. Our task is to make the inevitable death, as the last chapter of life, into a more meaningful and humane experience.

Acknowledgments: Gerhard Casper, Gary Tomlinson, Bob Shulman, Ann Speltz, Bruce Dunn, J. William Schopf, Matthew Ellman, William Sledge, Anna Reisman, Janlori Goldman, Sarah Nuland, and Tyler Griffith provided encouragement, recommendations, and personal stories.

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