A Question of Mercy: Contrasting Current and Past Perspectives on Physician-Assisted Suicide

Mahala Yates Stripling, Ph.D.

Keywords: right to die, assisted suicide

The right-to-die debate was cast into the spotlight on November 1, 2014, when Brittany Maynard, a beautiful young California woman, took her own life by a doctor- prescribed lethal dose. Maynard, in her October 7, 2014, CNN article, "My Right to Death with Dignity at 29," describes what led up to this decision. 2 Married just over a year, she and her husband were trying for a family. However, after months of suffering from debilitating headaches, she learned on New Year's Day that she had brain cancer. "Our lives devolved into hospital stays, doctor consultations, and medical research," she states in her article.

Nine days after the diagnosis, she had a disfiguring partial craniotomy and partial resection of her temporal lobe to stop the growth of the tumor. When her aggressive tumor came back three months later, she was given a prognosis of six months to live. She opted out of full brain radiation that would leave her scalp covered with first-degree burns. "My quality of life, as I knew it, would be gone," she admits in the CNN article. She ruled out hospice care because medication would not relieve her pain or forestall personality changes, including verbal, cognitive, and motor loss. Withholding treatment or removing life support—decisions made in America every day—were not an option for her. Whatever life she had left in her strong young body was mitigated by a deteriorating brain. She did not want for herself or her friends and family that dire reality in the few remaining months. Choosing to live her brief life as fully as she could, without the fear of intolerable pain, she uprooted her family, moving from California to Oregon, where the Death with Dignity Act was passed in 1997. 3 The Act allows terminally-ill Oregonians to end their lives through the voluntary self-administration of lethal medication expressly prescribed by a physician for that purpose. The harrowing burden facing death, for this woman and her family, besides finding a new home and a physician willing to prescribe a lethal medication, was compounded by the need to establish residency. She had to get a new driver's license and change her voter registration.

She met the strict patient eligibility criteria of being at least 18, mentally competent, and with a terminal illness, defined as less than six months to live, confirmed by two independent physicians.4 Two oral requests were made with a 15-day waiting period in between, and she made a written request that was witnessed. A prescription for the lethal dose she needed was written no less than 48 hours after the receipt of the written request, and she had to prove that she could self-administer the medications (i.e., have the mental and physical capacity to take the medications on her own).

Brittany filled the prescription but did not take it immediately: "I am not suicidal. I do not want to die. But I am dying. And I want to die on my own terms," she affirms in the CNN article. She chose how and when to die. After finishing her bucket list, including seeing the Grand Canyon and celebrating her husband's birthday, her condition worsened. She laid in her upstairs bedroom surrounded by her husband, Dan, mother, Deborah, and stepfather, Gary, and died peacefully, rather than in a cold hospital room in intolerable emotional and physical pain during a time dominated by fear and uncertainty.

© 2015 Stripling. This is an open access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction, provided the original author and source are credited.

Her situation brought national attention in People magazine as well on her own Facebook page on November 1st: "Goodbye to all my dear friends and family that I love. Today is the day I have chosen to pass away with dignity in the face of my terminal illness, this terrible brain cancer that has taken so much from me . . . but would have taken so much more." And so, in dying, Brittany Maynard revitalized the right-to-die debate.

In sharp contrast to her story, and seven years before Oregon's first Death with Dignity law in 1997, three men conspired in secrecy in a seventh floor New Haven apartment. Richard Selzer, who had left an active surgeon's life in 1985 to write full-time, was drawn into a prickly situation, as he relates it:

"A man I know here at Yale, a poet, called up and asked if I would see these two gentlemen. One had fullblown AIDS and the other was a faculty member here. The sick man wanted me to end his life. I talked to them, and I of course said, 'No. I'm not practicing medicine anymore.' He implored me to go and visit them. I did, and I became involved in their plight."

In diary entries from January 14 through February 15, 1990, Selzer recorded each visit to the apartment, a ten-minute walk from his house. The doorman, a former patient, greeted him warmly and lifted his shirt to show the doctor how well his gallbladder incision had healed. The action unfolding in real time is set out in Selzer's subsequent publication, "A Question of Mercy," and in it he describes the dramatis personae. First, there is the "almost too handsome" Lionel, a man in his late 30s who is an ordained minister. Second, his lover of six years, Ramon, also in his 30s, is a short, delicate man "with a neat lawn of a beard," who was a public health physician specializing in "women's problems, birth control, family planning, and (AIDS)."5

Acquired immune deficiency syndrome, or AIDS, was first identified as a disease in 1981. Since AIDS had an unknown etiology, if Ramon had known about his infection while he was on the job, he had to conceal it or be fired. Locally, the doctors at Yale-New Haven Hospital double-gloved when treating an AIDS-infected patient; nationally, almost everyone was afraid to be near someone with the disease, believing that contracting it was a death sentence. Christian conservatives cultivated fear, saying AIDS was a punishment from God for deviant sexual acts. So being outed at this time was tantamount to receiving both a social and physical death.

Selzer was unknowingly in the cross-fire of the two national debates relating to AIDS and physician-assisted suicide (PAS), long advocated by Michigan pathologist Jack Kevorkian, who first publically assisted in the suicide of an Alzheimer-stricken woman on June 4, 1990.6 Even with so much uncertainty about the nature of AIDS and the public controversy surrounding PAS, Selzer, right then and there in that room, was the compassionate former doctor who understood that the man's suffering was "worthy of Job" 7. Plain to see was Ramon's fatigue, depression, and fulminating Kaposi's sarcoma in the left naso-orbital region, the pain of which was exacerbated due to his pride in his appearance. Soon he would be blind. The foul odor in the room was evidence of his intractable incontinence. The doctor took him into the bedroom where he examined Ramon's ulcerated hemorrhoids more closely: "His anus is a great circular ulceration, raw and oozing blood. His buttocks are smeared with pus and liquid stool." Lionel tenderly bathed and dressed him in a fresh diaper. "Even though I have been summoned here," the doctor thought, "I feel very much the intruder upon their privacy."8 And yet he was convinced that this man wanted to retain his dignity in death.

Lionel had undoubtedly read Selzer's confessional story, "Mercy" (1980), which emboldened him to contact Selzer ten years later.9 The story describes a doctor whose 42- year-old patient had the unrelenting pain of end-stage pancreatic cancer. "I won't let you suffer," the doctor said. The man, his wife, and mother wanted the doctor to administer a fatal dose of morphine to end his life. When that did not work, the doctor could not take that extra step by putting three minutes of pressure on his patient's windpipe. Now Selzer, given another opportunity to end the suffering of a human being, was again reluctant. But he thought, "If I would do it for myself, why not for another?"

Ramon, Lionel, and Selzer were joined by a fourth person, Melanie, a supportive friend sworn to secrecy.

Feeling like conspiratorial criminals, they were all aware of the sense of impending doom that filled the air. They must tell noone. And yet they all wondered how they would handle the gravity of it. Ramon was suffering and wanted to die. Lionel, although a minister, had never seen death before. His religous beliefs of the afterlife were unspoken, but he feared the premature death of his friend and lover. The compassionate Selzer, caught up in the drive for Ramon's assisted suicide, faced a dilemma. He was in the midst of opposing ethics in an existential crisis. He was trained as a doctor in the Hippocratic Oath—"I will not administer poison to anyone where asked," and I will "be of benefit, or at least do no harm."10 Being sworn to preserve human life, he now found himself in an action to alleviate prolonged suffering by taking one.

The silence in the hall outside the apartment was in marked contrast to the noisy horn-tooting cars of Yale students on the street below as the plan took shape. Ramon, who was Columbian, expected to receive a sufficient supply of barbiturates from a Columbian doctor he knew. Selzer instructed Ramon on how the pills should be taken at intervals with sips of water, being careful not to get too full too early or he would not have the capacity to absorb the lethal dose. He should also add a codicil to his will, which Lionel was the sole beneficiary of, that his mortal remains should be cremated. The blood work at autopsy would reveal the overdose.

Selzer had a prescient dream that things went terribly wrong, and he was arrested for murder. That fitful urgency caused him to test Ramon's and Lionel's resolve once again. He hoped they would allow Ramon to die naturally of thirst. It also concerned Selzer that Lionel was too sensitive to bear any of Ramon's suffering and that he would not be able to tell any necessary lie. They both relied more heavily on Selzer who had grown weak in the knees. The reality hit that a compulsory autopsy would confirm Ramon's use of barbiturates and someone seeing Selzer enter the building would suggest his complicity. So Lionel let Selzer back out, unbeknownst to Ramon.

Three weeks later, on the appointed day, Lionel and Melanie, whose absences would make them above suspicion, took the train to New York for the night, while at 6 P.M. in New Haven Ramon began to take his pills. The man, alone in the apartment, was so weak that he could not take the final lethal dose. He did not know that Selzer, afraid of being charged with murder, would not be there to help him by injecting the morphine. That act of omission—something that would not have happened if PAS were legal and Ramon had met the medical criteria, caused the attempt to be botched. Lionel returned to the apartment to find Ramon unconscious but alive. He called an ambulance. "What else could I do?" asked Lionel. Placed in the hospital ICU, Ramon was put on a respirator and had his stomach washed out. As related in "A Question of Mercy," Selzer went to see him.

"Ramon!" I call out. He opens his eyes and looks up, on his face a look that I can only interpret as reproach or disappointment. He knows that I was not there. Lionel the Honest has told him.

"Do you want to be treated for the pneumonia?" I ask. He cannot speak for the tube in his trachea, but he nods. "Do you want to live?" Ramon nods again. "Do you still want to die?" Ramon shakes his head no.11

Standing on the dark threshold of death, life became more precious to Ramon. But twelve days later he died in the hospital. In the close-knit community of Yale elites, everyone seemed to know about it. Whether or not Selzer's desire to help was brave or foolish, dying and death was not a new arena for him, but public exposure regarding the hot issues of AIDS and PAS was. 12

Ten months after the incident, Selzer says a reporter at the New York Times, who had heard about it, asked him to write a piece on physician-assisted suicide, a topic that was increasingly in the media due to Jack Kevorkian. He replied, "No, that's not my subject." He had repressed this experience because it was so negative. He then reconsidered and went back to his notebook and typed out the entries as he had written them in longhand. In his haste, he did not change the names and location enough to offer anonymity. He met Lionel at the library and asked him to read the manuscript before he sent it to the Times. "He did so in my presence," Selzer says, "and said that of course I should publish it--that it would be pro bono publico. And so, with Lionel's blessing, I allowed the Times to publish the story."

Selzer is no stranger to controversy but he could not have anticipated what lay ahead. His true and unflinching account of attempted physician-assisted suicide, titled "A Question of Mercy," was published on September 22, 1991. The hot national issue had considerable letter-to-the-editor follow-up. Although Selzer had changed the names, all of the characters lived in New Haven, and "the survivor told everybody," Selzer says. "So everyone at Yale, where I live, knew who I was and who they were. It was common knowledge. It was extremely uncomfortable for me."

When the diary account appeared, "Lionel had a change of mind, and bruited about Yale that I had unfairly used his tragedy for my own purposes," says Selzer. There was to be a meeting to discuss this, but Lionel canceled, and they never spoke again. Selzer does not know of any personal or professional ramifications felt by Lionel as the surviving partner, except that he left Yale for another university.

It did not end there. At a reading of Selzer's work sponsored by the Program for Humanities in Medicine, "Everyone knew that he was going to talk about it," says Howard Spiro, the program director, "and there was a lot of animus about Dick that he unwittingly identified one of the men as a gay man and outed somebody who did not want to be." Some of the other program organizers wanted to call the event off, but Spiro, instead, moved the program from the smaller Beaumont Room to the Hope Building, a place that could be easily defended by the Provost's security. Based on the buzz in the community, Spiro worried that a crowd of enraged people would tear his friend Richard Selzer into pieces. "It was sort of like the day the Black Panthers came to march on the New Haven Green," recalls Spiro, "and the FBI and the National Guard came out. We expected Armageddon but nothing happened. It was a similar attitude—in a smaller way—but I don't think there were even a lot of heated questions from the audience."13

But anger spread like a tsunami throughout Selzer's community. He was a well- known surgeon who had operated on many of them, and now they wondered if he had lost his empathy for patients in favor of being a vampire artist needing to feed. Broader questions arose having to do with whether or not Lionel, who was not Selzer's patient, should be concerned about being "exposed."

Selzer felt the consequences of his actions. New Haveners, who thought that Selzer had prized being published over maintaining confidentiality, shunned him. 14 Long-time acquaintances, who would normally greet him with, "Hi Doc," offer a smile and friendly wave when meeting him on the street, crossed to the other side. Selzer, who ostensibly had the thick-skin of a surgeon, was underneath a sensitive soul who avoided the spotlight. This painful scrutiny, on top of being adversely affected emotionally and psychologically by the PAS attempt, matched the suffering of the other survivors in the days following it. "A Question of Mercy," which describes a volatile situation and its aftermath, ends with everyone involved in this failed plan sucked into a quicksand of their own making. It is a cautionary tale that asks, Whether PAS is legal or illegal, could you, as a family member, friend, or health care professional, help someone die and live with the consequences of your actions?

The medical climate has changed a great deal since the complicated and muddled situation described in Richard Selzer's "A Question of Mercy." For those who meet the criteria, the right to die is simply about free will and choice, if you reside where it is legal. In the 24 years that separates the two cases, a great cloak of conspiracy shrouded the events of Ramon's last days, but the national media broadcasted Brittany's story. The cause of death on her certificate was not suicide or euthanasia but "brain tumor."

Oregon, Washington, and Vermont have legalized assisted suicide through the legislature or popular referendum. In Bernalillo County, New Mexico, and in Montana it is legal through court decisions; and New Jersey's House has passed legislation legalizing assisted suicide. Bills in Connecticut and California are under review with their state legislatures who are now debating the issue.15

The profound impact of widely- legalized PAS is that it alters the very foundation of the doctor-patient relationship. A terminal patient's right to alleviate suffering by choosing death, called autonomy, creates a tension when doctors are trained to see human life as an inherently valuable. While in a Gallup poll conducted May 8-11, 2014, before Maynard's story went public, nearly seven in 10 Americans said they believed physicians should be able to "legally end a patient's life by some painless means," the American Medical Association and the American Geriatrics Society oppose assisted death. 16 Will the groundswell of popular opinion and the consequential state-wide movements to legalize physician-assisted suicide cause them to reformulate their current ethics?

Among the arguments against PAS, the most zealous come from people who uphold the religious tradition of the sanctity of human life. In fact, controversy erupted when Pope Francis and the Vatican denounced the right-to-die movement as showing a "false sense of compassion" and a sin against God, who determines when we die.17 The Vatican's top bioethicists took it further, calling Brittany Maynard's actions "reprehensible." Brittany Maynard's mother immediately responded in a letter written to Compassion and Choices, a no-cost end-of-life resource center for the terminally ill. She rejected this religious doctrine of God's perfect timing for eternal life versus her daughter's earthly relief. Believing that God should never have entered this conversation, she said: "My 29-year-old daughter's choice to die gently rather than suffer physical and mental degradation and intense pain does not deserve to be labelled as reprehensible by strangers a continent away who do not know her or the particulars of her situation."18

Still others see Brittany Maynard's precedent as being on a slippery slope. The downside includes, a physician who might inadequately treat pain or make a mistake in diagnosis or prognosis; because aid-in dying is less expensive than end of life care, its availability could affect decision making at the insurance, doctor, and patient levels, and vulnerable populations who become a burden to families may be coerced into it; and, not the least of which is, as more doctors use PAS in their practices, the way it will change the integrity of the doctor-patient relationship and how the public views the profession. 19 Whatever else happens in our lives, our final journey may become a spiritual quest, and some may find meaning in their own suffering; however, not all will. There are the faithful who adhere to ancient beliefs of life's end; removing God from this equation does not unravel society's morality is another viewpoint. Modern medicine has opened the door for everyone to reconsider that a terminal illness can have a more peaceful end.

Once more, pertinent literature on the topic of PAS, such as Richard Selzer's "A Question of Mercy," offers historical, cultural, and spiritual perspectives for bioethicists considering contemporary problems. 20 In the end, one of Brittany Maynard's last wishes has been fulfilled: her final illness shines a light on the Death with Dignity movement, impacting public opinion and the passage of laws in the near future.

PDF available: Mahala Stripling, "Question of Mercy," Voices in Bioethics (2015).

References:

1 This is partly excerpted from Chapter 12,"A Deep Black Hole," of the forthcoming Mister Stitches: the life and arts of Richard Selzer, M.D. All Selzer quotations, unless otherwise noted, come from interviews with author.

2 "My Right to Death with Dignity at 29." CNN.com October 7, 2014. Updated November 2, 2014. http://www.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity/.

3 On October 27, 1997, Oregon enacted the Death with Dignity Act. It requires the Oregon Health Authority to collect information about the patients and physicians who participate in the Act and to publish an annual statistical report. Providers may decline to prescribe medication under the1997 Death with Dignity Act.

STRIPLING, A QUESTION OF MERCY, VOICES IN BIOETHICS, VOL. 1 (2015)

http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Page s/index.aspx

4 "The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals." http://www.ohsu.edu/xd/education/continuing-education/center-for-ethics/ethicsoutreach/upload/Oregon-Death-with-Dignity-Act-Guidebook.pdf

5 Selzer, Richard. "A Question of Mercy." The Exact Location of the Soul. New York: Picador, 2001: 13

6 Jack Kevorkian (1928-2011), called "Doctor Death," championed a terminally ill patient's right to die via PAS, saying: "Dying is not a crime." Between 1990 and 1998 he helped 130 people take their final action, such a pushing a button on a machine that released drugs, resulting in their deaths. Things heated up in 1999 with his direct role in voluntary euthanasia, a second-degree murder offence sending him to jail for eight years of a 10-25 sentence. In 2010 CNN's Anderson Cooper asked Kevorkian, "You are saying doctors play God all the time?" Kevorkian's reply: "Of course. Anytime you interfere with a natural process, you are playing God." Anderson Cooper 360 (CNN). April 16, 2010. Kevorkian, Jack. Prescription Medicide: The Goodness of a Planned Death. New York, Prometheus Books, 1991.

Job's faith in God by causing him to lose his family, wealth, and health, including having excruciating sores all he Book of Job. Satan tests over his body reminiscent of Ramon's. Although cursing the day he was born, the blameless Job remains devout. "Naked I came out of my mother's womb, and naked shall I return: the Lord has given, and the Lord has taken away; blessed be the name of the Lord." Job 1:21. A story about human suffering and God's sovereignty, Job is rewarded for his loyalty when God restores to him his health, happiness, and prosperity.

7 "A Question of Mercy", 134. References to the Old Testament in the Bible are often seen in Selzer's work. Here he refers to the intense emotional and physical pain felt by Job, as told in t

8 "A Question of Mercy", 137. writings about them must be devoid of patient identifiers or they must have permission from the patient involved in the writing. In today's reality, blogs or Twitter feeds that release information instantaneously are a real concern.

http://www.hhs.gov/ocr/privacy/hipaa/administrative/statute/hipaastatutepdf.pdf

9 Selzer, Richard, "Mercy." Letters to a Young Doctor. New York: Simon & Schuster, 1982: 70-4. It is ethical for a doctor to alleviate the suffering of a patient even if it hastens death as an unwanted side effect, but this scenario approached the level of active euthanasia.

10 Internet Encyclopedia of Philosophy. http://www.iep.utm.edu/hippocra/

11 "A Question of Mercy", 146.

12 Selzer renews his narcotic license every year. "It is within the law to do so, although I have never used it to procure drugs for the purpose of physician-assisted suicide. I am a proponent of PAS as a choice to relieve suffering under the strictest controls. I have advised very ill and symptomatic pre-terminal patients on a couple of occasions on how to end their own lives, but I have never taken an active role à la Dr. Kevorkian, nor have I been present at the time of death. With more liberal laws, I doubt not that I would be among those who would ease the hopelessly ill out of their agonies." And, he may need it someday "to kill myself easily," he adds, "should the occasion arise."

13 Sprio interview with author 9 May 2001.

14 Since Hippocrates patients' stories have been used to teach, first in the closed society of medicine but now they entertain and instruct the general public. Like Selzer, William Carlos Williams felt sandbagged when New Masses asked for a contribution, and he sent them one he had simply filed away. "The Five Dollar

Guy," published in 1926, was about a woman friend who was propositioned by the owner of a local oil company. Williams did not change the names or location, and New Masses did not vet it for possible libelous material. They were sued for \$15,000—in 1926 three years of Williams' salary— but settled for \$5,000 and a promise never to print the story again.

Mariani, Paul. William Carlos William: A New World Naked. New York: Norton & Co., 1981: 254-5

15 "Physician-Assisted Fast Facts." November 26, 2014. Includes timeline. http://www.cnn.com/2014/11/26/us/physician-assisted-suicide-fast-facts/ In The Netherlands, Belgium, and Luxembourg doctors, under strict conditions, can euthanize patients whose medical conditions have been judged hopeless and who are in great pain. In Canada, in a unanimous decision, the Supreme Court ruled in February 2015 that doctors can help the gravely ill end their lives but the decision does not immediately allow physicians to assists patients in their deaths. Existing legislation and regulations will remain in place for one year to allow the federal government, which enforces criminal law, and provinces, which administer health care, to adopt new measures.

16 Swift, Art. "Brittany Maynard's Story and Americans' Views on Assisted Suicide." http://www.gallup.com/opinion/queue/179159/brittany-maynard-story-americans-views-assisted-

suicide.aspx

17 "Pope Francis: Assisted Suicide is a 'false sense of Compassion.'" Christian Science Monitor: Nov. 15, 2014. http://www.csmonitor.com/World/Latest-News-Wires/2014/1115/Pope-Francis-Assisted-suicide-is-a-false-sense-of-compassion

https://www.compassionandchoices.org/2014/11/18/brittany-maynards-mother-responds-to-vatican-other-critics-of-her-daughters-end-of-life-choice/

18 "Brittany Maynard's Mother Responds to Vatican, Other Critics of Her Daughter's End-of-Life Choice." November 18, 2014.

19 These and other arguments are made in "What are the Arguments against physician aid-in dying (PAD)?" "Physician Aid-in Dying." Ethics in Medicine, University of Washington School of Medicine. Revised April 2013 by Helene Starks, PhD, Denise Dudzinski, PhD, and Nichole White, M.D. http://depts.washington.edu/bioethx/topics/pad.html

David Rabe, who adapted Selzer's essay, "A Question of Mercy," into a play premiered in New Haven at the Longwharf Theater in 1998, took a position on PAS, saying he fears PAS becoming legal through "authorities"— rather than being helped by a personal physician—and that's when "anything that becomes bureaucratic ultimately is corrupt. I just see an endless area of danger with insurance companies or families who want to get rid of someone. That is my fear about legalizing it." Quoted in "Life to Stage," an interview by Frank Rizzzo in the Hartford Courant 2-15-98: G4.

*A talkback panel following the premiere was led by Roland Clement representing the New Haven Chapter of the Hemlock Society. Speakers included several doctors, a rabbi, a chaplain, a psychotherapist, a bereavement specialist, a lawyer, the director of pastoral care at a CT hospice, and the director of education for the AIDS project in New Haven.

20 With writing medical narratives now an industry, doctor-writers must add enough unique expression to a patient's case history to make it their own. Lapses in confidentiality cause harm to patients in the admittedly cannibalistic act of writing. When Selzer published "A Question of Mercy" in the Times in 1991, The Health Insurance Portability and Accountability Act of 1996 (HIPAA), setting out patient privacy standards, had not been enacted. Today doctor-writers must take care in divulging information about their patients.

STRIPLING, A QUESTION OF MERCY, VOICES IN BIOETHICS, VOL. 1 (2015)