Medical Aid in Dying

A Message by the Rev. Angela Herrera and Aroop Manglik, MD
First Unitarian Church
Sunday, September 30, 2018

Angela: This is the last Sunday of the month, which means it is our last Sunday reflecting on this month's topic of vocation. I'm pleased to share the speaking today with someone who is in a different vocation than mine. Dr. Aroop Mangalik is a member of First Unitarian, and is an oncologist and ethicist. Having retired from clinical practice in 2013, he now teaches ethics at UNM's medical and law schools.

He is the author of a book called "Dealing with Doctors, Denial, and Death." Some of you may have attended one of our Adult Religious Explorations sessions in which he shared wisdom accumulated from his decades of practice, as well as personal experience... wisdom about the way doctors are trained to deal with the inevitability of death.

Our message today is not the usual sermon format, but more of a conversation. It's a conversation about a topic that affects us all: death, which is both a medical and a spiritual experience.

Aroop, will you tell us a little more about you, and about the training physicians receive in regard to death?

Aroop: I graduated from medical school in 1958 and completed my training in Hematology and Oncology in 1966. I was involved with treating and taking care of patients with serious, even fatal, diseases for 50 years.

In my early years, I was focused on the treatment of the disease. In retrospect, I feel that I paid less attention to the whole person I was treating. I was also fairly heavily involved in clinical trials and experimental treatments.

I cannot give a specific time that I changed my emphasis. But gradually, I became more concerned about the person along with the treatment of the disease.

One reason for the emphasis on the disease was the training I received. The same training that most medical students and doctors receive. Medical training at all levels emphasize the pathology, physiology, pharmacology etc. and that is necessary. Doctors are also told that they have to be the best and that they cannot "fail".

Not failing is a phrase with many connotations. But failure is used when we think of the treatment of a patient. Of course we want to help the patient feel better and control or cure what ails them. If the treatment the doctor recommends and uses does not achieve its goals, that is not failure. Of course, one must check and be sure that the correct treatment was given. It is the nature of the disease and the available treatments for that situation that determines whether a treatment is effective or not.

The attitude translates to "If the treatment I gave did not achieve its goal, it was a failure on my part". Doctors often try other treatments just because they are available even if there is a small chance of benefit and the burden of treatment is high. This is often what leads to poor quality of life and suffering before death. It is now more accepted that all treatments will not be effective and patients, people, will die. At UNM Medical School, we have now added this perspective in our teaching. I am happy to say that more recently, I have noticed that this approach is bearing results. I see a more realistic approach to serious illnesses amongst young doctors.

This is allowing patients to receive treatment when needed, but equally importantly to receive care when appropriate. It is being accepted, more than before, that there are limits to what medical science can do and there is value in changing from treatment of the disease to care of the whole patient.

Angela: This is something that impacts all of us throughout our lives because we all must deal not only with our own deaths, but with the deaths of loved ones also.

Aroop: I'd like to return the question of training back to you, Angela: how are Unitarian Universalist ministers trained to think about death? Is there a spiritual tendency to avoid the subject also?

Angela: Well, the short answer is: we ministers spend quite a bit of time studying and thinking about death, and... it's also true that there can sometimes be a tendency—maybe it's a human tendency—to avoid it.

In seminary, one of the most formative classes I took was Buddhist Approaches to Death and Dying. In that class, I met Roshi Joan Halifax, the founder of Upaya Zen Center in Santa Fe. She flew back east to lead our class in a workshop about being present with death. We had to first come to terms with our own mortality.

Roshi Joan led us in meditations where we visualized our bodies moving through the life cycle, from birth and growth all the way to picturing our bodies wearing out and beginning to shut down—Who did we imagine would be there? What did we imagine it would look and feel like?—and then visualizing the moment of death and our bodies after death.

What would happen to our bodies? At what point would they cease to look like bodies, and be returned to the earth in some form?

It was a very graphic meditation.

Aroop: "It sounds like it!"

Angela: At first it was unsettling... but then, a feeling of peace came over me. I saw clearly that every negative or stressful experience is as impermanent as life itself.

By overcoming our avoidance to these thoughts, we began letting go of anxiety. We let the reality of death be present to us now and therefore, we became more present

with others who were dying. Often fear of our own mortality scares us away from being present to dying in others.

In my chaplaincy internship at an urban hospital, I saw many deaths. Some were difficult. Some were beautiful and peaceful. Those tended to involve medical care geared toward comfort rather than prolonging life when death was already near.

A conundrum ministers sometimes face when a person asks us to pray for them to be cured and we know it is very unlikely. We want to join them in that prayer—100%—and at the same time we want to support them in being spiritually prepared for death if a cure is not to be. So we have to find a way to hold both of those things together. In my experience Unitarian Universalists tend to be open to those conversations. But UUs, like everyone else, could do better at speaking about death before the end of life is near. In the most recent issue of our denomination's magazine, UU World, there's a story about a minister and her grandfather.

They had spoken openly about the eventuality of his death. She had told him how much she would miss him. And he had shared that he felt he'd lived a good life, and was ready whenever the time should come. They had this conversation now and again for fifteen years. Then one night, when he was 96 years old, she went in to check on him and observed that he was having some kind of cardiac episode.

When she called her parents in to be with him, one of them said, "I'll call 911!" but she asked them to reconsider. She explained that once medical intervention began, it would be very hard to stop it, and that resuscitating a ninety-six year old man's heart was unlikely to lead to lasting quality of life afterward. He had expressed that he was ready. Maybe they should allow the process to unfold naturally, as long as he was not suffering. They did, and hours later he died peacefully. Most of us do not have that kind of clarity with our loved ones, and we may not even be sure what the law says about such things.

Aroop, a moment ago you mentioned the idea of treatment versus care. How do you see the difference between the two?

Aroop: There is no sharp distinction between treatment and care. But treatment attempts to control the disease like fixing a broken bone or improve the function of a failing heart. Care of course must be given along with treatment of the disease.

Once, after due deliberation and discussion, it is decided that the disease cannot be controlled, the emphasis changes to relieving symptoms and the reducing of burdens that the patient has and to care for the whole person.

Angela: And when death is certainly near, there's another option, called Aid in Dying. Tell us about that.

Aroop: If the burdens of living cannot be relieved despite the best efforts of the providers and patient when the patient is expected to die in the near future, there is

another option that the patient can have. The option of hastening their death. The patient can voluntarily stop taking fluids and food. This hastens the death process.

People who have used this method have been found not to suffer from thirst or hunger.

Also there is the option of Aid in Dying. If the patient chooses that option, the medical provider can help by providing a prescription for a lethal dose of a drug.

Angela: So with Aid in Dying, the doctor provides a prescription, but they don't actually deliver the drug to the patient themselves?

Aroop: Correct.

Angela: It's up to the patient to decide when and if they ever use it. And I know there's quite a process around it. Not just anyone can get such a prescription.

Aid in Dying is something many states and some other countries have considered. When I lived in Oregon in the 1990's, we were referring to it as assisted suicide. Opponents called it euthanasia. Why do you say "aid in dying" instead of assisted suicide or euthanasia?

Aroop: It is not suicide because death was coming in the near future. It is not euthanasia because the doctor only writes the prescription. The patient self-administers the drug.

Angela: I see. I know one concern about Medical Aid in Dying is that if doctors are allowed to write those kind of prescriptions, maybe it will happen in the wrong circumstances, or people will make that decision based on the high price of medical care, rather than as a deeply considered, true personal choice. I agree that we cannot let that happen.

But most Americans support the idea that when

- a person's condition is not curable,
- and they face a painful death in the very near future,
- and *they would like* the option of a prescription to end their life when they are ready,

it is most compassionate for society to include a carefully considered option for honoring that request, rather than declaring it always illegal.

And in fact, I've noticed that people sometimes find ways to make this choice without their doctor's assistance.

Sometimes I've done memorial services where, when I interview the family, I get the feeling the person might have done this. But the family isn't sure if they can tell me the truth, and I'm not sure I can ask them, because if they helped their loved one in

any way, then asking about it might also mean asking them to reveal that they have broken the current law.

Aroop: Yes, I have heard many patients say that they will secretly hoard their medications and take a large dose at one time. If Aid in Dying is not legal in a given state, this has been done.

The unfortunate reality is that patients may survive this attempt because they do not understand the many ramifications of such an attempted overdose and their suffering is magnified. Further, to protect their family and friends, they go through the process alone and are lonely.

There is another method to hasten a patient's death. It is a method used by some physicians. If a patient is very sick and suffering from pain, the doctors can put them into what is called "Terminal Sedation". The doctors give the patient large doses of sedatives and pain killers, by an intravenous infusion. The patient's pain may be relieved but they are helpless. They cannot interact with their family and they are vulnerable to pneumonia and bedsores.

After days, maybe a week or two, they die. The family just sits and watches helplessly.

Angela: It would honor life more if we could have these conversations, and consider the options, before we are in a place of defaulting or feeling helpless. And it would honor families if they could share openly without fear of repercussions.

Honoring life and honoring families is why talking about Medical Aid in Dying is a vocational issue for me. Death is part of life. It is an important and deeply spiritual event in a human life and in a family.

The Unitarian Universalist Association supports Medical Aid in Dying and has for many years. A resolution in support of it was passed at the General Assembly in 1988.[i]

Unitarian Universalism does not regard it as a sin in any way, rather the belief is that because life is a precious gift and death is a natural part of it, it is not right that anyone should be forced to prolong life at its natural end with unnecessary suffering and medical interventions.

The United Church of Christ and the United Methodist Church[ii] are two other denominations that have expressed support. In addition, individual religious leaders from a broad array of traditions have also affirmed that in certain cases, Medical Aid in Dying can be an ethical choice. Desmond Tutu is one example.

Aroop: Acceptance of death is not easy. Of course, we all know it is going to happen but somehow we have a disconnect.

As a doctor, I need to work with living people, some healthy and others with medical and health problems. It is common that I deal with the transition from the living to

the dead. My aim and hope is to make the transition as comfortable as possible both physically and spiritually. I have unfortunately seen many times when this did not happen. Mostly, it is because the doctor or patient or both are unwilling or unable to accept that death is near.

I would like to briefly describe my father's death. He had been in excellent health and developed progressive shortness of breath and died in six months after his first symptoms appeared. Through that period, we never talked about what was happening and what was going to happen. He died a lonely man even though the whole family was there with him.

It is this acceptance of death that I have become aware of and try to help patients by making that transition easier. It is often said that Aid in Dying goes against the Hippocratic Oath. The line that is used in this context is "do no harm". That is a very broad generalization and I agree with it. My point is that pain and suffering is also a harm. If Aid in Dying reduces the duration of pain in suffering, it does not go against the Hippocratic Oath.

Angela: What have you noticed about the role of spirituality in your patients' thinking?

Aroop: The prevailing practice in medicine was not to discuss spirituality or religious beliefs. Only if the patient brings up the subject was it discussed. The discussion was just to support the patient. More recently, it has been found the acknowledging the patients spirituality helps them accept the reality of a bad situation more easily.

(To Angela) What have you noticed about the role of doctors in patients' thinking?

Angela: I've noticed that sometimes patients seem to need support in "breaking the news" that they are dying... to their doctors. In other words, it's hard to start a conversation about deeply considering the costs and benefits of treatment. But the best medical care happens when there is an honest and trusting relationship between doctor and patient.

What is the current state of Aid in Dying laws in NM? In the US?

Aroop: Aid Dying is legal in eight states in the country. In NM, the judicial system was petitioned to make the process legal. It was supported by a lower court but the State Supreme Court ruled that it was the purview of the Legislature. In 2017 it was debated in the NM House and Senate but narrowly lost.

A bill called End of Life Options bill will be presented to both houses in 2019. There is broad support for the option but the passage is by no means certain. The support comes from both Republicans and Democrats. We have sponsors in both chambers.

We are seeking more support for EOLO by informing people in different demographics, professions and religious groups about what EOLO is and what it is not. To repeat and clarify some points.

1. A terminally ill patient requests the doctor for Aid in Dying.
2. The doctor verifies that the patient is an adult and is mentally competent.
3. The doctor reviews the medical record to confirm that the patient has a short life expectancy.
4. A second doctor needs to confirm the above information.
5. After a waiting period (2-3 weeks), the physician writes a prescription for a lethal dose of drugs.
6. Patient has the option of taking or not taking the drug, which is self-administered.

Data from Oregon on patients who requested and availed the lethal drug under the law are available. There were no instances of misuse or suggestion of coercion. Many people asked for the prescription as a backup – in case their pain could not be controlled.

Angela: What do you most hope the congregation will take away from this conversation?

Aroop: I hope that those who were not aware of Aid in Dying have learned of a potential new option for those who are dying. I hope that those who had some reservations and misinformation that has been clarified and I hope you will talk to your family and friends. Ask them to let their senators and representatives know that EOLO benefits dying people and their families and harms no one.

Angela: An interesting thing about the issue of Aid in Dying is that liberal and conservative lawmakers (and regular people) have been able to come together around it. The City Councils in Santa Fe and Albuquerque have both passed bipartisan resolutions this year in support of Aid in Dying.

If you'd like to explore the issue further, or for help planning conversations about end of life care, one place to start is the website CompassionAndChoices.org. Compassion and Choices is a non-profit that has been providing resources and advocacy in the US for over thirty years. So there's lots of good info there.

Whatever our wishes or situation might be, the time near death is a part of life that can and should be an experience of care and support. By talking about it with love and thoughtfulness, may we make it so.

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[i] https://www.uua.org/action/statements/right-die-dignity

[ii] https://www.compassionandchoices.org/wp-content/uploads/2017/01/FS-Faith-Based-Perspectives-on-Medical-Aid-in-Dying-FINAL-1.9.17-Approved-for-Public-Distribution.pdf