

Grand Valley State University presents



The Ethics of Physician-Assisted Death

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Distinguished Service Professor of Medicine
Chief, Section of Palliative Care and Medical Ethics
Director, Institute for Doctor-Patient Communication
University of Pittsburgh School of Medicine
Medical Director, UPMC Palliative and Supportive Institute

Timothy Quill, MD
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March 27, 2017

Cook-DeVos Center for Health Sciences • Robert C. Pew Grand Rapids Campus

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DeVos Medical Ethics Colloquy

The Bi-Annual DeVos Medical Ethics Colloquy Series was started in March 2005, at Grand Valley State University in Grand Rapids, Michigan, by a generous endowment from the Richard and Helen DeVos Foundation. Richard and Helen DeVos saw the need for a forum where subjects of medical and ethical significance could be discussed under the guidance of a learned speaker, with opportunity for participation by the public in general. The proceedings of the Colloquy are printed and distributed free of charge to institutions across the continent and interested individuals.

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Transcription: Sheila Guston

Editing: Philip Jung





(Moderator)

**Paul Reitemeier, PhD
Corporate Director, Clinical Ethics
Beaumont Health, Royal Oak, MI**

Paul Reitemeier, PhD, is currently serving as the corporate director of clinical ethics at Beaumont Health in greater Detroit, MI where the clinical ethics consult service averages 18 cases a month. Prior to that, Reitemeier served as an associate professor of philosophy at Grand Valley State University (2003-2015) and served as chair of the Grand Valley Internal Review Board for 10 years. Other positions include clinical ethicist and IRB member at the University of Nebraska Medical Center in Omaha; clinical ethicist and chief communications officer for the VA National Center for Ethics, and associate professor of medicine at Dartmouth-Hitchcock Medical Center in Hanover, NH. Reitemeier has presented a variety of training and other sessions at both the American Society of Bioethics and Humanities (ASBH) and the Public Responsibility in Medicine and Research (PRIM&R) national conferences for the past 30 years.

INTRODUCTION

Dr. Reitemeier:

Thank you all for coming. As Jean Nagelkerk noted, this is a very complex topic and we can't possibly address it in all its complexity this evening, so we won't try. We will, however, give you an opportunity to hear two of the most thoughtful people in the country on this topic. And their remarks I think you will find very instructive, even illuminating.

I am not a physician. I am a medical ethicist, and I was trained as a philosopher. But when philosophers fill out their IRS form under professional expenses, we don't really have much of an opportunity to write stuff down. A few pads of paper, some pencils, a lot of big erasers, that's about it because we don't need a lot of technology to do our work in philosophy. But we do need language, and we use language extremely carefully to communicate effectively about very sensitive and highly-charged topics, especially those involving life and death. Language is our tool. It is our only tool. And words matter. Most of us recognize that we're not thoroughly rational, at least in our thoughts and our deeds, despite our efforts to the contrary. Frequently the narrow rational pathway on which we begin fails to keep us steady and the winds of emotion will drive us from side to side. Controlling the terms of language that we use to discuss these sensitive topics, these weighty moral matters, has been key to winning arguments through persuasion. Without a common denominator for reference, and hopefully one that is value neutral, the discussion frequently becomes a shouting match because the speakers use incompatible and sometimes incendiary language and they end up talking past each other.

That will not happen tonight. Questions concerning the ethical permissibility of tonight's topic, *The Ethics of Physician-Assisted Death*, therefore require descriptors that do not sneak in prior ethical judgments about the moral acceptability of the actions under consideration. The terms

suicide, killing, euthanasia, and their sort have such long social histories of embedded and implied negative moral judgment that they probably cannot be used in a truly value-neutral sense even if we stipulate and insist that that's how they're to be understood. But like most tensions in clinical ethics, mere distinctions do not do the work of moral reasoning. Careful arguments are required because at issue when discussing moral standards is not the terms of the language, but it's meaning. Our speakers rejected the term "physician-assisted dying" because that refers to compassionate palliation and that's long been part of good medical care. But more importantly, it has never been ethically controversial. The controverted point is not physicians assisting with the dying process, which can take many forms, but rather their knowingly, intentionally, willingly, and deliberately bringing about the very end of the dying process, the patient's last breath that occurs at one moment rather than another later moment.

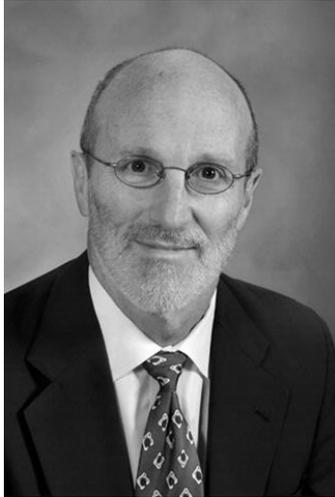
Professional standard setting, to the degree it's used in medicine, is unique among the professions and, as used in this country, unique among all nations. In these United States the private sector of medicine is regulated to a degree, but it is not controlled by the state. Physicians continue to enjoy the freedom of self-direction, and they voluntarily use standards in their own self-governance as an expression of their responsibility and their free accountability to the society which permits their professional freedom. Standards are established for entrance to medical school and residency training, for accrediting specialty programs, hospitals, and care facilities; and individuals of notable accomplishment are certified by their peers and none other.

Beyond these standards that can be defined with some precision, are the standards of behavior and performance that make up the professional code of ethics and beyond that a second set of standards, a set of values by which physicians are judged by the society they seek to serve. Since the art and science of healthcare is special, society will permit that activity only by

those whom it trusts — and trusts with its very life. But the patient wants more than the application of clinical knowledge and skills to her problem, she wants help or relief from her fears and concerns; and even more she wants the assurance, the evidence, the expression of her physician's dedicated service. Physicians understand that the most compassionate act they can perform is to provide the correct diagnosis and the most effective treatment of the disease of the patient. The science of medicine and its benefits must always be evident in the action of our physicians, but science alone can never be the fulfillment of their responsibility to the patient. Physicians also have an obligation to care about the patient and his needs and to do so with compassion. Here our attention is extended to the humanity of the patient.

Physicians then have two areas of service: their science and their compassion. If they so choose, to each of these areas they can give a still greater dimension, a dimension of proficiency. Proficiency in science is self-evident by examining the outcomes of their efforts in terms of their ability to benefit their patients. Proficiency in compassion, however, requires thoughtful consideration. The old adage to cure sometimes, comfort frequently, and to care always, presumes a personal proficiency in compassion – just as the traditional meaning of an attending physician is to attend to, to be present with, the patient and never to diminish the personal importance of being present with the patient.

So our speakers now will lead us on their very thoughtful journey to help us better understand how they have come to understand their own professional proficiency in both the use of medical science and in attending compassionately to their dying patients. Dr. Quill.



Timothy Quill, MD
Georgia and Thomas Gosnell Distinguished Professor in Palliative
Care; Professor of Medicine, Psychiatry and Medical Humanities
Palliative Care Division, Department of Medicine
University of Rochester School of Medicine

Timothy E. Quill, MD is a professor of medicine, psychiatry, and medical humanities at the University of Rochester Medical Center (URMC). He is the founding director of the URMC Palliative Care Program and a board-certified palliative care consultant in Rochester, New York. Dr. Quill has published and lectured about aspects of the doctor-patient relationship, focused on end-of-life decision making. He is the author of several books on end-of life and numerous articles published in major medical journals. Dr. Quill was the lead physician plaintiff in the New York State legal case challenging the law prohibiting physician-assisted death that was heard in 1997 by the U.S. Supreme Court (Quill v. Vacco). Dr. Quill received his undergraduate degree from Amherst College (1971), and his medical degree from the University of Rochester (1976). He completed his internal medicine residency in 1979 and a fellowship in medicine/psychiatry liaison in 1981, both from the University of Rochester School of Medicine and Dentistry. Dr. Quill is a fellow in the American College of Physicians, an ABMS certified palliative care consultant, and a past president of the American Academy of Hospice and Palliative Medicine.

Dr. Quill:

Thank you for inviting me back here again. I've been here once before and I had a lovely time interacting with you all and I'm looking forward to this interaction. I also want to thank Dr. Tomatis, who was here last time I was here, and Dr. Reitemeier, Dr. Nagelkerk, and the DeVos family for making this happen year after year. It's quite an extraordinary event nationally to have such a colloquy occurring yearly.

What I'm going to do first is present a case to you, because one of the things that I try to do in these conversations is to keep us grounded in real clinical experience. Of course, it's not going to be an easy case because why would I present an easy case to you? None of the cases in this area are truly easy. This was a thirty-year-old medical resident. He was a wonderful medical resident. He attended all of the palliative care lectures and was going into primary care when he finished. He was about three months from ending his training when he developed chest pain which got quite severe quite quickly. He did what many doctors would do under those circumstances, he went and got a chest x-ray without seeing a doctor. It turned out his chest x-ray showed that he had a very large mass in his chest. So he went to see his preceptor because he didn't have a personal doctor. His preceptor was a good doctor by reputation. My resident liked him a lot, but it turned out the preceptor didn't prescribe opioids because he was worried about addiction. My resident was having to make the biggest decisions of his life, but he couldn't think straight because he had 10/10 pain. So he realized at that point he needed to get a real doctor, and he came to see me.

Now again, believe me, this is not something you step up to eagerly – taking on a resident who is training under me as a patient who is extremely sick. But there weren't a lot of other people to step up. So I treated his pain, referred him for a biopsy and provided support. He was understandably overwhelmed by what was going on. To make a long story

short, the biopsy showed a yolk sac tumor. Some of you may know about this. I was a primary care doctor and a palliative care doctor. Yolk sac tumors are rare and I had not had experience with them. But I looked it up and it turned out yolk sac tumors have a 40% chance of cure. Pretty exciting, right? The only trouble is, what's the down side of a 40% chance of cure? A 60% chance you aren't going to be cured and will die from the disease in a fairly short period of time. This patient knew what these statistics meant.

I made arrangements for him to see the regional specialist in this disease because it was a rare tumor. But my patient also wanted at the same time to explore some other things like the "what ifs." Believe me, if you had cancer like this, you would be wondering about the "what ifs." So what were his what ifs? He wanted to make sure that if he didn't respond to treatment that he wasn't going to suffer too much. He wanted to make sure that he could have an escape if he had really bad suffering toward the very end. He was surprisingly ready to talk about these things. In fact, he needed to talk about them because they were very much on in his mind. And it might be big in your mind or mine under the same circumstance. He needed to have these "what ifs" settled before he could devote himself wholeheartedly to treatment, and the treatment was not going to be easy. This was very aggressive chemotherapy that he was undergoing. Of course, predictably, not only did he under aggressive chemotherapy, but he had every side effect possible, so he was in and out of the hospital a lot during chemotherapy. I have a brief interview of him talking which I which I will show you on video.

(Begin video)

Patient/Resident:

We talked about my fears about end of life and I told her (his wife) that this was one of them, that I was going to get to this point where life was not

worth living, and I really felt I wasn't going to have someone there who could help me intervene or deal with that.

Dr. Quill:

Had you thought about those issues before at all, or probably in an abstract sense?

Patient/Resident:

Never before becoming sick, but constantly after becoming sick. It's been at the forefront of my mind, especially during the time period when we felt like this cancer that I have might be something that might not be very treatable. But even later on when we found out the diagnosis was actually germ cell tumor, which is somewhat treatable with some degree of success, even then one of the most important things in my mind has been how I can maintain control, even through the end of life, should this become an end of life kind of issue.

Dr. Quill:

You personally, in your own conscious control, be the person in charge?

Patient/Resident:

Right, exactly. I feel like I'm in the driver's seat of this body, and I want to make the decisions about what it goes through. And if I can't make those decisions, that would be one thing that would make life not worth living. But maybe more poignantly, I want to be able to decide that life is not worth living and to end my life, if it comes to that point; and that's one decision I think that's often what we don't think about, as being necessarily someone's prerogative. I think most people would agree it's my prerogative, my decision, whether or not to take treatment or something, and I think that that degree of empowerment is given to me. I talked with

my wife and my friends a lot about this and I made it clear to them I really wanted to be empowered if I got into an end of life kind of situation to be able to judge on a day to day basis if I wanted to continue my life based on whatever, my nausea, my vomiting, my fear level, and the aggregate of all of that pain.

(End video)

Dr. Quill:

So I can guarantee you I did not want to be having this conversation with this man at this time, but this is what he brought to me and this is what we're asking you to think about when you face situations like this with patients that you really care about. And I really care about this young man. I'm going to turn it over to Bob.



Robert Arnold, MD
Distinguished Service Professor of Medicine
Chief, Section of Palliative Care and Medical Ethics
Director, Institute for Doctor-Patient Communication
University of Pittsburgh School of Medicine
Medical Director, UPMC Palliative and Supportive Institute

Robert M. Arnold, MD, is a professor in the Division of General Internal Medicine, Department of Medicine at the University of Pittsburgh and in the University of Pittsburgh Center for Bioethics and Health Law. He completed his medical school training at the University of Missouri-Kansas City and residency at Rhode Island Hospital. He serves on the faculty at the University of Pittsburgh. He is the director of the Institute for Doctor-Patient Communication and the medical director of the UPMC Palliative and Supportive Institute. He is clinically active in palliative care. Dr. Arnold has published on end-of-life care, hospice and palliative care, doctor-patient communication and ethics education. His current research interests are focused on educational interventions to improve communication in life-limiting illnesses and better understanding how ethical precepts are operationalized in clinical practice. He is currently working with the UPMC Health System to develop system-wide, integrative palliative services. He is the past president of the American Society of Bioethics and Humanities as well as the American Academy of Hospice and Palliative Medicine.

Dr. Arnold:

I'm also really pleased to be here and thankful to Dr. Tomatis, and I do have to say I'm a little nervous because Dr. Quill said it was the second time he was here, and that meant that he was debating someone the first time and they didn't get invited back so that made me worry this is a little bit like *Survivors*. So I'm a little nervous about this, to be honest with you. So, I'm going to ask you guys some questions to help me calm down a little bit. How many of you are not clinicians in any way? About a third of you. How many of you are physicians? How many of you are nurses? How many of you are social workers? How many of you are chaplains? Physical therapists? Now it feels like *Family Feud*, right? Oh, good, there was a physical therapist. Lawyers? Because that'll interfere with about half my jokes.

The other thing that I should say is that I know that this is often a point-counterpoint format, and the reason we're giving you one set of slides is that Dr. Quill and I probably don't disagree except for at the margins. I haven't, as far as I know, participated in physician aid-in dying although there have been a couple of people who I have been treating and given opiates to who have died relatively suddenly, and I wouldn't be shocked or amazed if their family came to me and said that there was some intentionality in it. I don't believe that in general if I was the philosopher king that it would have been a public policy that I thought we should promote. On the other hand, I want to say that 20% of Americans now can participate in physician aid-in dying, and to a certain extent, I think whether it's a wise public policy or not isn't the question. When 20% of the public can do it, it means that all of us are going to get asked about it if we're clinicians. The real question is how do we think about this issue? How do we develop public policy to make it to a certain extent — and, I'll argue, as infrequently as possible — and how do we, when it comes up, provide the best care for those patients?

So, first let's just do some definitions. We agreed to call it physician-assisted death, although many people would argue that it is suicide. We stayed away from the word suicide because psychiatry has tried very hard, for very good reasons, to argue that suicide is as a clinical event that should be prevented. Assisted means that the physician provides the means at the patient's request, but the patient must carry out the final act, and that potential escape is important to many. The physician's moral responsibility is to us, as an accomplice, very similar to what some might argue the pharmacist's involvement is as well. And those of you who are pharmacists might want to talk about that.

VOLUNTARY ACTIVE EUTHANASIA

Main Elements

- Physician both provides the means and carries out the final act
- Requires request and consent from a competent patient
- Physicians more reluctant about this than PAD
- Requires physician presence at the time of death
- Allows a response to a wider range of suffering than PAD
- Illegal in US and much more likely to be prosecuted than PAD

Figure I

It's very different from voluntary active euthanasia (AE) (Figure I) in which the physician provides both the means and carries out the final act. It does require the consent from a competent patient and, in both the ethics literature as well as the literature on physicians' opinions, physicians are much more reluctant to perform active euthanasia. AE requires a physician

be present at the time of death and it allows a response to a much wider range of suffering because it doesn't require the patient to be physically able to swallow medications. It's illegal in the United States and more likely to be prosecuted.

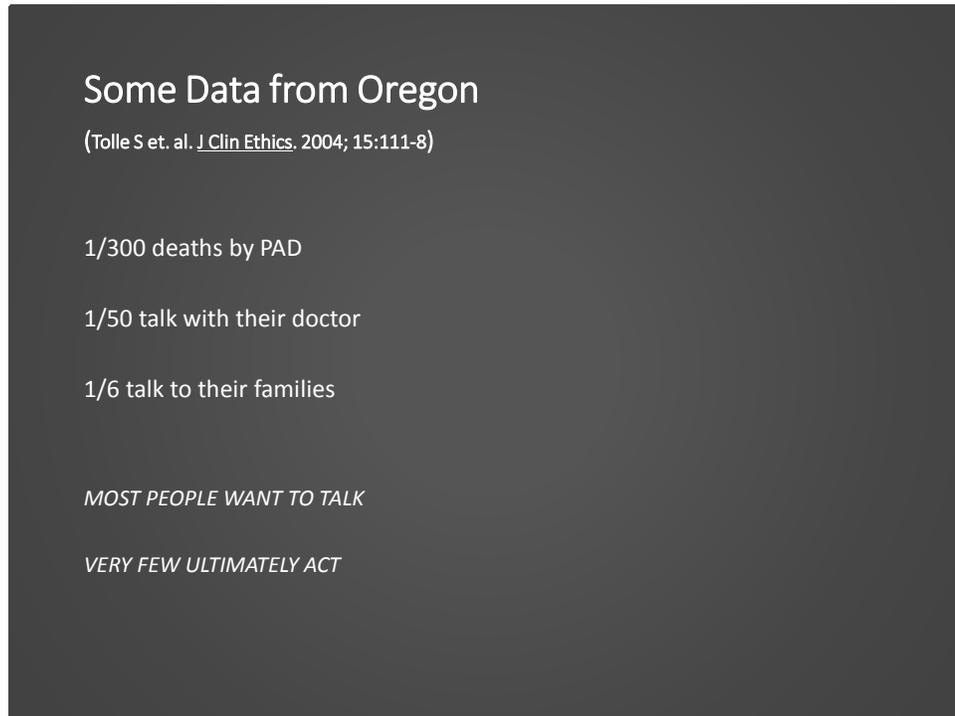


Figure II

I want to be clear that most of our data is currently from Oregon (Figure II) and from Washington. My guess is in five years if you invite Dr. Quill and me back, which would make me feel really a lot better, the data largely will be from California.

First we should note that a lot of people want to talk about it. One in six or one in fifty people talk to their physicians and, in fact, up to 70 percent of physicians say that patients have asked them about this. I've been asked about it as a palliative care physician and a physician who took care of HIV positive patients.

The fact that people talk about it doesn't mean that people do it. In fact, very few people ultimately act on this. Even if they're given the medicine, most people don't act on it.

I'm going to start off talking a little bit about the ethical issues, although I'm going to argue relatively quickly that if you believe in the norms that have guided physicians in end-of-life care in hospitals across the country for the last twenty years, it gets really hard to argue that physician aid-in dying is unethical. The three major arguments for physician aid-in dying are: autonomy, that is that autonomous patients ought to get to decide what they do with their body, much again like we saw in the video; mercy, that is if we can decrease peoples' discomfort, we should — either their physical suffering or their existential suffering; and physicians' non-abandonment, that we will stick with people regardless of what happens to them to the end.

The argument that I find the most convincing is the lack of difference between physician aid-in dying and foregoing life-sustaining treatment. That is, I probably saw fifteen patients in the ICU who decided that, given where their disease was, they wanted the machines turned off. It was pretty clear to all of us that in about five percent of those cases there was no way that they would live when you turned the machines off. We can say that we didn't intend to end their lives, but it seems to me that, given we knew that when you tried to wean them, within five minutes — in fact, often within two minutes — they desaturated; or, as I was turning an LVAD off, it seems hard to make an argument that I didn't know that they were going to die. And to say that I didn't intend it seems to place way more weight on the importance of intentionality than I or most philosophers think is appropriate.

The argument against physician aid-in dying is that intentional acts to shorten a life are wrong. I think none of us believe that without some sort of caveat because, for example, if I pulled out a gun and wanted to kill you, it would be appropriate for you to shorten my life.

We worry that it might scare patients into thinking that we're urging them to end their life, and while that's true, I think, as a risk – it seems to me a much greater risk lies to the fact that almost all deaths in the hospital in fact are planned deaths where we in fact turn technology off. If people are going to be scared it seems to me they should be as scared of forgoing life sustaining treatments in hospitals. It could undermine palliative care because of public controversy, e.g. death panels. It could lead to slippery slopes, and I'm very worried about slippery slopes. My hope is that we'll talk about that at the end of the discussion.

Rule of Double Effect and PAD

Intent has to be good

Bad effects can be foreseen but not intended

Proportionality – Suffering must be severe enough to warrant the risk

Bad effect cannot be the means to the good effect

(Figure III)

There is an argument about the Catholic rule of double effect (Figure III). The rule of double effect for those of you who forget, and that would be almost all of us, is that the intent has to be good. The bad effects can be foreseen but not intended; the suffering must be severe enough to warrant the risk; and the bad effect cannot be the means to the good effect. This rule is often used to not allow physician aid-in dying because the intent (causing death) is not good and the bad effect that is shortening the life cannot be means to the good effect, which is ending the suffering.

Now, there are challenges to the rule of double effect. One is it's unclear how we evaluate intention and ignore the philosophy of causality, that is we like to say that what killed the person is not turning off the ventilator but the person's lung disease. But when we are absolutely sure that turning off the ventilator will result in the death; it seems to me that we begin to have angels dancing on the heads of pins in a way that is not very philosophically satisfying. We also have the problem of things like palliative

sedation (Figure IV), which is in fact legal. The intent is to escape suffering, so we sedate someone so they're no longer conscious. It seems to me that also becomes very hard to distinguish from physician aid-in dying.

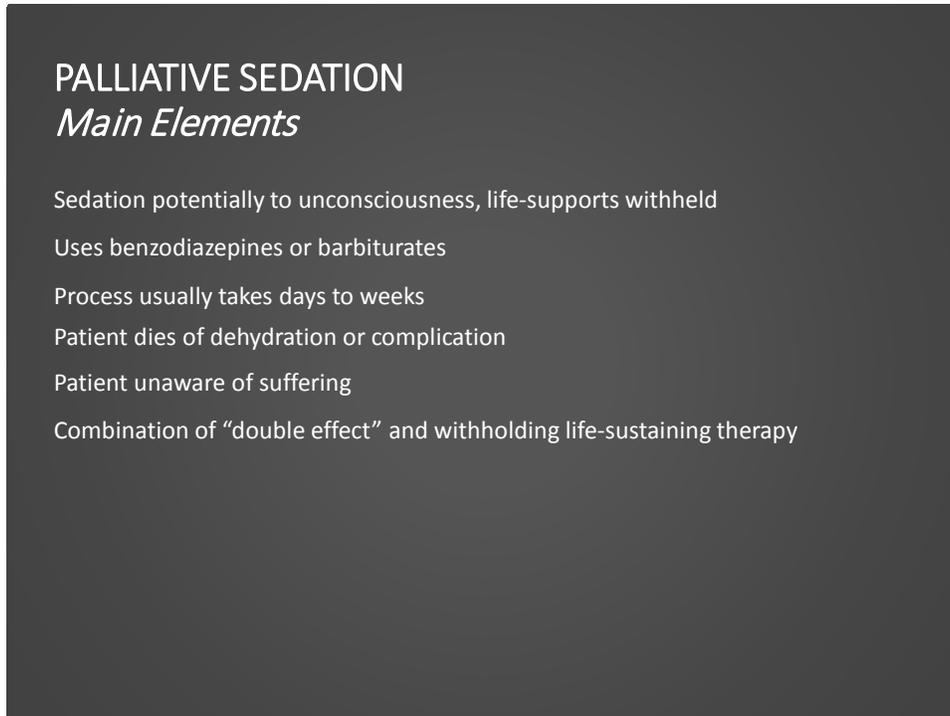


Figure IV

Given that, you might suggest that I think that under some circumstances physician aid-in dying is ethical, and you'd be right. That doesn't mean that I don't think it should be as rare as humanly possible. And I think to make it as rare as humanly possible, it means that we need to do a much better job of doing palliative care. Now, I'm old enough that when I was a medical student there was no such thing as palliative care. In fact, that's probably true of Tim, who is even older than me. There was no palliative care. In fact, I did HIV care for fifteen years, and we just called it good medicine for really sick people who are likely to die. Yet I think that in the last twenty years the education and the awareness that in fact palliative care is really important, is an important part of what you hear the resident in the video talking about. I was sometimes unclear how much he wanted

to be in control of dying and how much he was really scared of suffering and wanted the clinicians to do a good job caring for his symptoms. I would argue that regardless of what your ethical view is regarding physician aid-in-dying, it should be as rare as possible and so we should do a better job of doing palliative care.

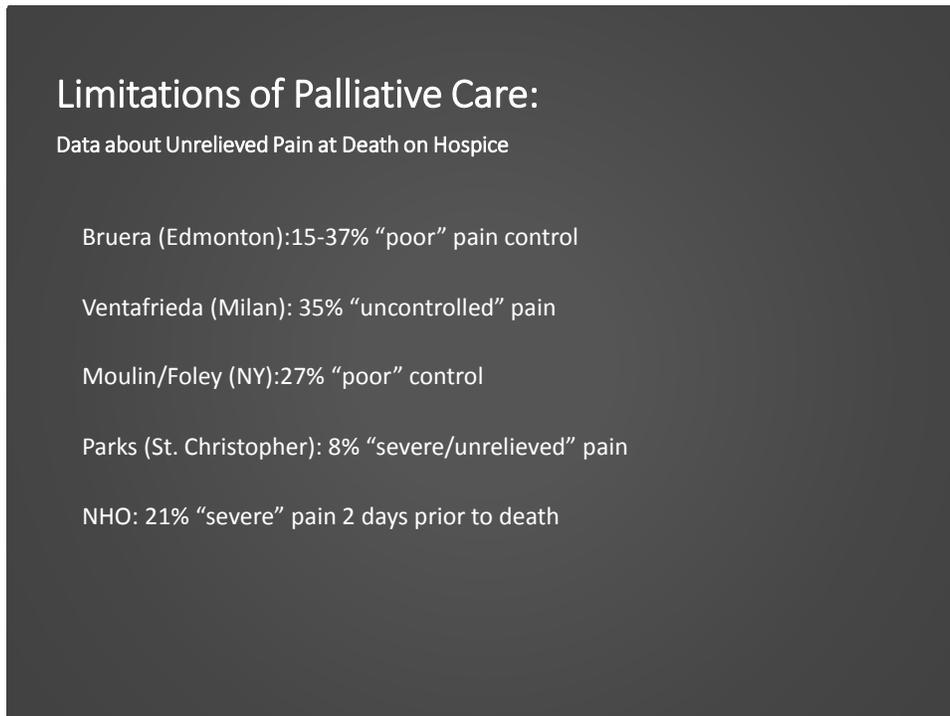
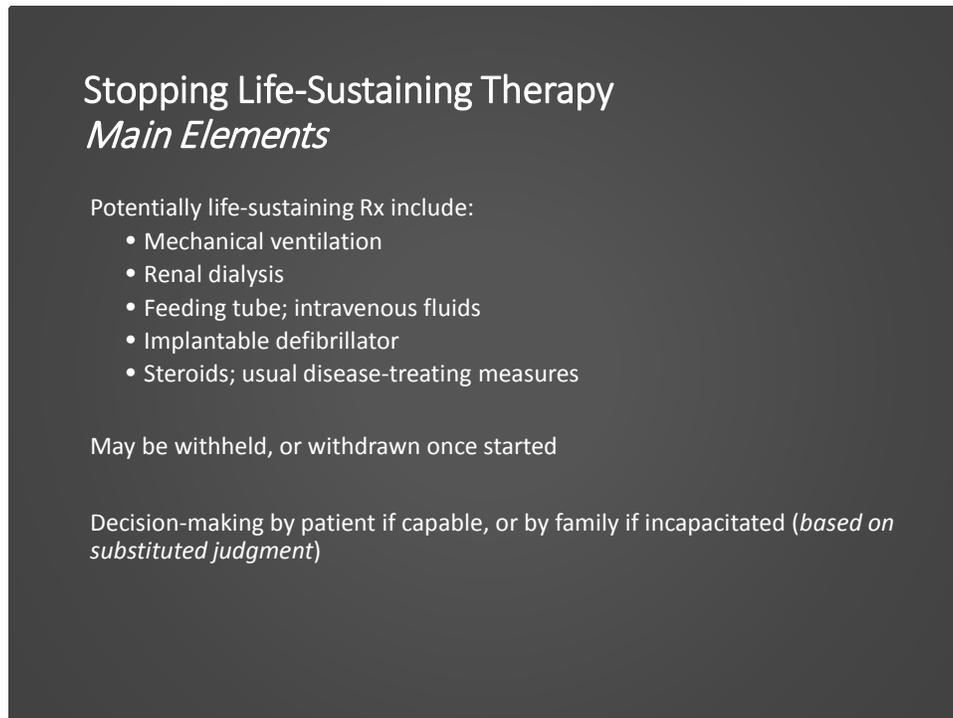


Figure V

The problem is that even though palliative care improves quality of life, as these slides (Figure V) show, there are still 20 percent of people who we don't do a great job of controlling their symptoms. Part of that is that we don't have very good tools. If you look at the NIH budget, less than one percent of it is focused on pain relief. Very little of the NIH budget is focused on treating, in fact, most symptoms for seriously ill patients. There are no studies, for example, that look at how to treat nausea, which is a symptom that makes my patients absolutely ballistic, except for chemotherapy-related nausea. The amount of data on any other kind of nausea is almost missing. If you believe that one of our jobs is to decrease

the frequency of physician aid-in dying, part of what we would do is we would do a way better job of spending our money and trying to promote good palliative care.



Stopping Life-Sustaining Therapy
Main Elements

Potentially life-sustaining Rx include:

- Mechanical ventilation
- Renal dialysis
- Feeding tube; intravenous fluids
- Implantable defibrillator
- Steroids; usual disease-treating measures

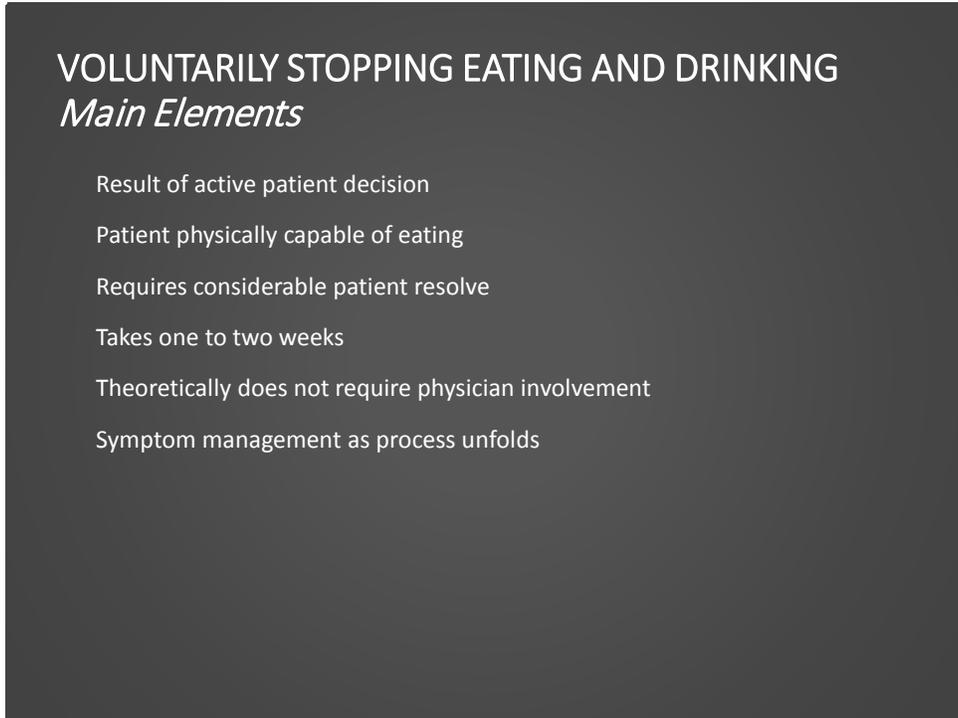
May be withheld, or withdrawn once started

Decision-making by patient if capable, or by family if incapacitated (*based on substituted judgment*)

Figure VI

The other thing we would do, if you believe that physician aid-in dying is a cultural or societal hot spot, is we would make sure people know about other last resort options (Figure VI) and are able to utilize those options to try to decrease physician aid-in dying. Things like stopping life-sustaining treatment. I think that often doctors don't talk about them. There's pretty good data that, for example, for pancreatic and other kinds of cancer, there isn't a discussion that one of our options is to focus only on quality of life and not engage in treatments. I think that most clinicians believe in what they do and so we often promote what we do in ways that might constitute overselling. And it's not just physicians, it's society in general. I don't know what your television ads are like, but the television ads from the healthcare

systems in the city where I live all talk about there's a miracle coming in the next fifteen minutes.



VOLUNTARILY STOPPING EATING AND DRINKING
Main Elements

- Result of active patient decision
- Patient physically capable of eating
- Requires considerable patient resolve
- Takes one to two weeks
- Theoretically does not require physician involvement
- Symptom management as process unfolds

Figure VII

We don't talk about voluntarily stopping eating and drinking (Figure VII) and for many people who are worried, that is an option of something that they can do to give themselves control, although particularly at the beginning it's hard for people to do and it's hard for their family to watch

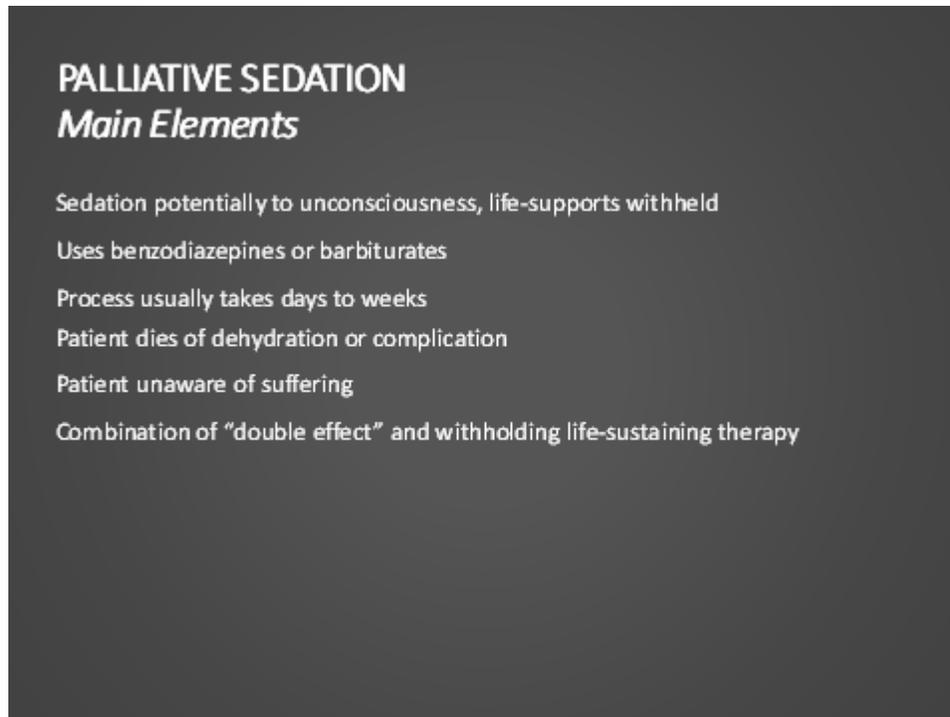


Figure VIII

them do it. Things like palliative sedation (FIGURE VIII), which is another option that is somewhat controversial; but I think in many states, and in the 80 percent of states in which physician aid-in dying is not legal, it is something that doctors need to know more about and that patients and families need to have as something on the table.

So, that’s the ethics. And yet one of the real questions is —I do a lot of teaching of palliative care physicians who want to know clinically what happens when someone brings it up? I think doctors’ initial reaction when someone brings it up is say, “Ooohh, we don’t do that. I’m really sorry, I don’t do that.” That’s bad in almost every situation because when a patient brings something up to me such as, “If I get a lot sicker, could I have something to end my life?”, my real job is to take a really deep breath, calm myself down, and try to figure out what’s going on. That is, rather

than reply yes or no, my job is to sort of say huh, I wonder why it's coming up and become curious about the story, not the answer.

What are they asking me, and when are they asking for it, and what are the issues that lead to it? Because I have to tell you, sometimes it comes up just because people don't understand what the dying process is like because we've medicalized the dying process and they've never seen it. I've had people say to me, I just don't want to be a vegetable for months or years. What do you mean? I just don't want to be alive for years if I'm not awake. That isn't going to happen. I mean, tell me what's important and once you get to not be sort of in the quality of life that you like, we'll stop a lot of the things that we do and for most people they'll die relatively easily in days to weeks to months. And just saying that for many people, it's like so I'm not going to be just lying in a nursing home for years? No. They're like oh, okay. Because they may not know.

Rather than view this as something that makes me really uncomfortable, as might some other questions such as "What religion are you?" or "Will you pray with me?", my initial job is to take a deep breath, slow myself down, and try to figure out what's the question behind the question. Are they asking me to die now or are they asking about it in the future? If it's in the future, they may just be reassured that I'm going to continue to have this conversation with them. That I'm going to help them prepare and be with them. That's the non-abandonment that came up before. Because again, many people haven't thought it through. They haven't thought such difficult questions as, "Where would it happen? Would my family be involved? Would my family not be involved?" So, a relatively small number of people will really want to activate and the question is – "Why now?" And what's the issue about what happened now? And is it something that's going to blip and get better or is it going to be consistent?

I need to talk to them about what they're afraid of. I need to figure out with them what do they think death will look like. I need to have a

commitment to be with them if things don't go the way they want. Sometimes what they really want is my cell phone number. No, seriously. Because they want to know if they get stuck who do they call? Often talking about this will then allow them to worry about more mundane matters.

If they're talking about physician aid-in dying now, I need to assess their competency. Sometimes people are just really depressed. If they're really depressed and they don't have capacity, I need to then talk to whoever their surrogate would be. I need to make sure that I've done as best I can, treated their symptoms, their suffering, and their depression, and I need to think a little bit about their social supports.

I need to be aware of the legal environment. In the state of Pennsylvania, it's not legal, and I need to have people that I can talk to that will give me advice. I've had some difficult cases and one of the things that's most reassuring to me is that I can pick up the phone and call someone who is older and wiser and smarter than me and say, "Hey, can I run this by you? Am I thinking about it correctly? What have I missed?" – so that I can get support and help – and I have to tell you, the one case where the person really stuck with the issue, in the end when I said, "You know I really can't do that because I really like being a doctor and it is illegal," that patient was in fact quite kind about it and said, "Oh doctor, I would never ask you to do something that would cause you to lose your license." And we came up with another solution that may have not been the best solution for him, but he was okay with.

At the end of this, and I'm now going to turn it over to Tim, there are questions that are going to come up that are in the slippery slope angle, and I hope we have a chance to talk about them. Questions such as what about physician aid-in dying for only existential distress? What about physician aid-in dying for patients who were competent but now have lost capacity and so they can still take their pill because they're demented, but they're really not competent anymore? How much should we have to talk

about this with all patients at a certain point, for example when they get into hospice? Should we require a palliative care consult for everyone who wants physician aid-in dying? That isn't currently the case in Washington, Oregon, or California. What would that mean both for access and maybe for improved care? I'm now going to turn it over to Tim so he can talk a little more about the legal issues and a little bit more about what happens in other countries.

Dr. Quill:

Thanks, Bob. We're really actually so close to being on the same page, but we do have some areas where we will differ, so we'll see if you all can identify them. I'm going to talk a little bit about the current state of practice with regard to physician assisted death. When you ask terminally ill patients about their views about this it turns out a fair number of them will support this option in theory (Figure IX). So 60 percent will say they wouldn't mind having access to that option, and 10 percent might say I really want access for myself as an individual.

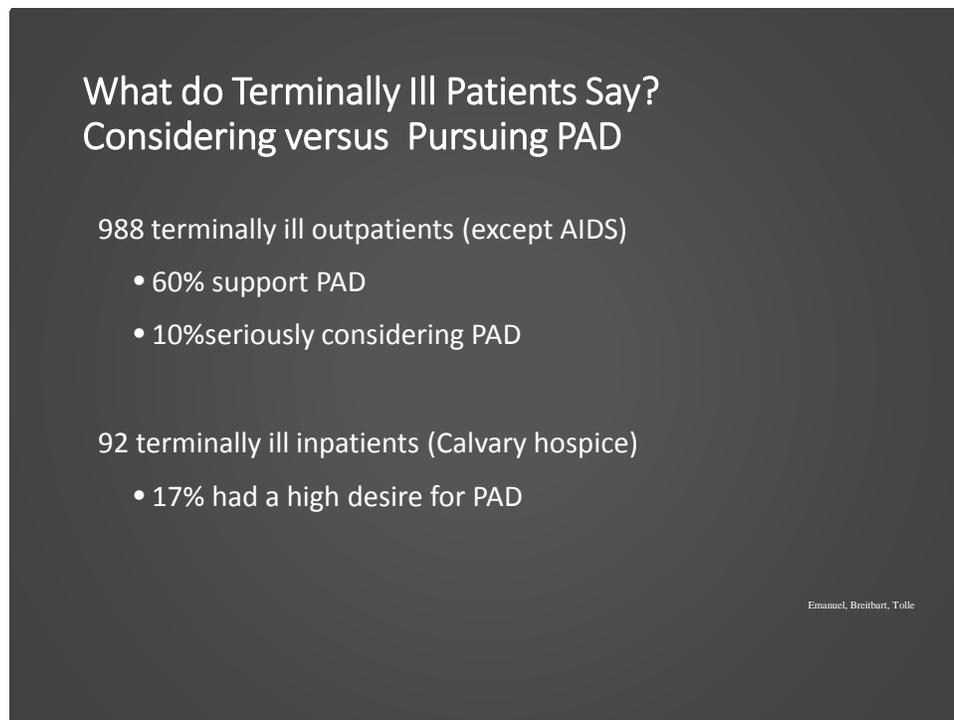


Figure IX

These data speak to the strong interest and public support for physician aid-in dying as a general idea — I wouldn't mind having access to it — but relatively few will actually really want it in earnest. In a study at a Catholic hospice of 100 terminally ill patients, 17 percent had a strong desire for this option. Does that mean that they would actually activate it? Probably not. But it means that they would like to have access to it.

Who are the people who are interested? They're often patients with cancer but also patients with neurologic diseases, particularly Amyrophic Lateral Sclerosis (ALS or "Lou Gerig's Disease"). Any of you who have patients with ALS or might know someone who had it, you have a lot of time to think about things when you have ALS when you can't move around normally and you're worried about being in charge of yourself. People who are interested tend to be white, Western. They tend to be the haves, not the have-nots. The have-nots are not at all interested in this issue. They're interested in getting access to more medical treatment. Most patients considering physician assisted death have access to hospice. So it's not an alternative to hospice for them. Some patients don't like the dependency experienced in the late stages of hospice care. I personally am a hospice devotee, but it's an acquired taste. It's not for everybody. Not everybody can adapt to the path of being cared for all the way through. For a lot of folks that does not have a great deal of appeal.

Some Data from Washington State Motivations for Seeking a Hastened Death

Illness-related experiences

- Feeling weak, tired, uncomfortable (69%)
- Loss of function (66%)
- Pain or unacceptable side effects of pain meds (40%)

Threats to sense of self

- Loss of sense of self (63%)
- Desire for control (60%)
- Long-standing beliefs in favor of hastened death (14%)

Fears about the future

- Fears about future quality of life and dying (60%)
- Negative past experience with dying (49%)
- Fear of being a burden on others (9%)

IT AIN'T PAIN, AND IT AIN'T SIMPLE

(Pearlman / Starks in *Physician-Assisted Dying*, 2004 J Hopkins Press 91-101.)

Figure X

Some data about people who are seeking access to a hastened death are above (Figure X). They're feeling weak; they're tired of dying. It's not too often that people want this option when actually experiencing severe, overwhelming, physical symptoms. It's really much more existential, psychosocial issues than untreated pain, and pain, as Bob was saying, is our best-case scenario. We can actually relieve almost all pain, particularly if people are willing to let us give them doses that might make them sleepy at the very end. Most of the time good pain management prolongs life. It's only rarely at the very end sometimes when we have to give huge doses. So the underlying motivation for assisted death is not pain and it is not simple.

Other ethics/public policy issues

In Oregon PAD legislation associated with improved eol care

- High percentage of deaths at home
- High rates of hospice referral before death
- Relatively strong opioid prescribing
- State-wide approach to DNR/DNI (POLST)

A wake-up call to physicians

- Physicians attend POLST and palliative care training
- Strong physician commitment to palliative care

Figure XI

In Oregon, where they've now had legalized physician aid-in dying for over twenty years, there have been some interesting changes (Figure XI). Examples include: a high percentage of deaths at home compared to the rest of the nation. (So many of the "slippery slope" concerns that assisted dying might replace hospice have actually not come to pass in Oregon.) High rates of hospice referral before death. Relatively strong opioid prescribing practices. And they are a leader in terms of commonality of do not resuscitate, do not intubate recording across settings. The legal option of assisted dying also been a wakeup call for physicians in Oregon when you start giving training sessions on pain management before and after legalization of physician-assisted dying. I will tell you when you give pain conferences, how to manage pain in states other than Oregon, and you take a look at who attends, it's by and large nurses. Maybe doctors are 10 percent. In Oregon when they started after POLST came along and aid-in dying came along, doctors started to attend the palliative care conferences

because — my interpretation is, they thought if I'm going to have to do this, I'd better get better at providing basic palliative care.

It's actually now legalized in six states, and the District of Columbia is under consideration. There is a lot of movement. About one-sixth of the US population has legal access to physician aid-in dying. So it's a changing environment.

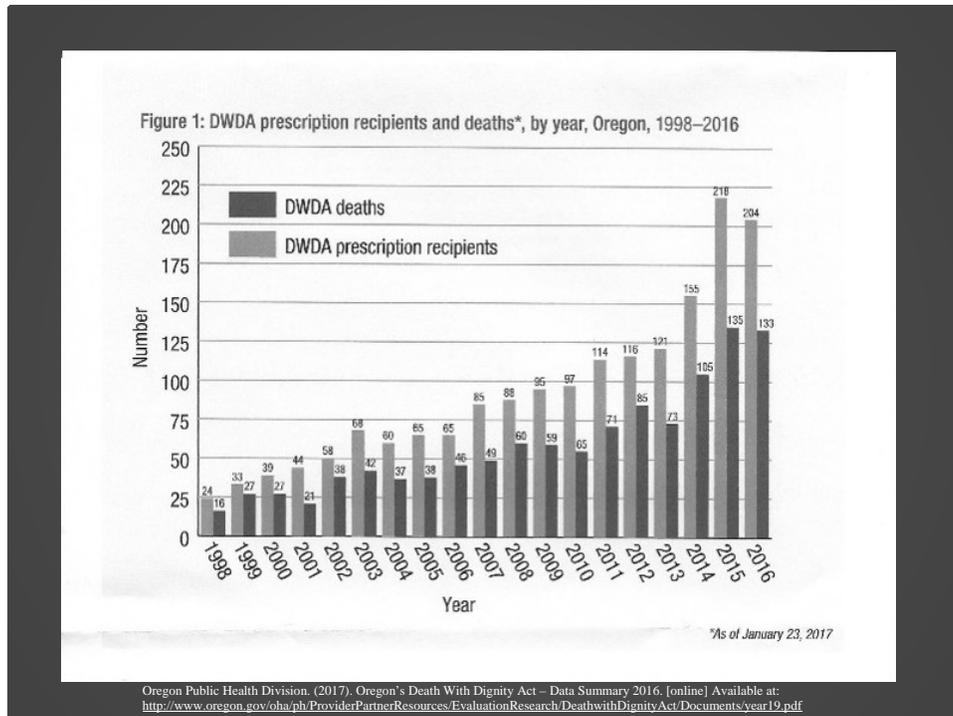


Figure XII

Here's the data from Oregon (Figure XII) about how the practice has evolved since its origin. There has been a moderate increase in the frequency of patients who actually activate this option. Quite a few more, about a third more, prescriptions than actually people who take them. About a third of people who get the prescription put it in their pocket, they're very reassured by it, but they end up not taking it.

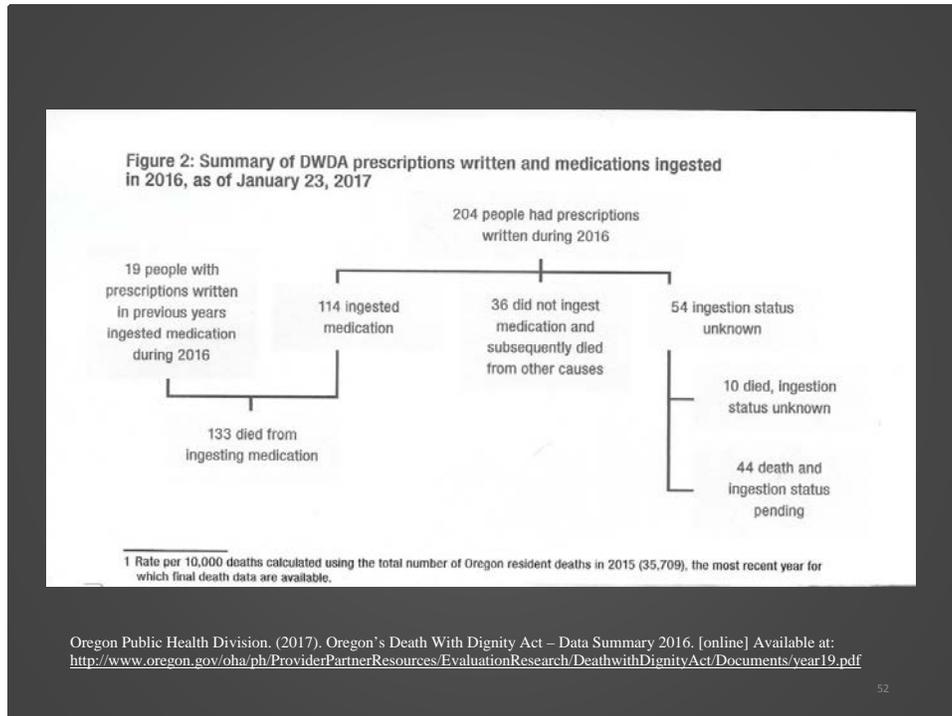
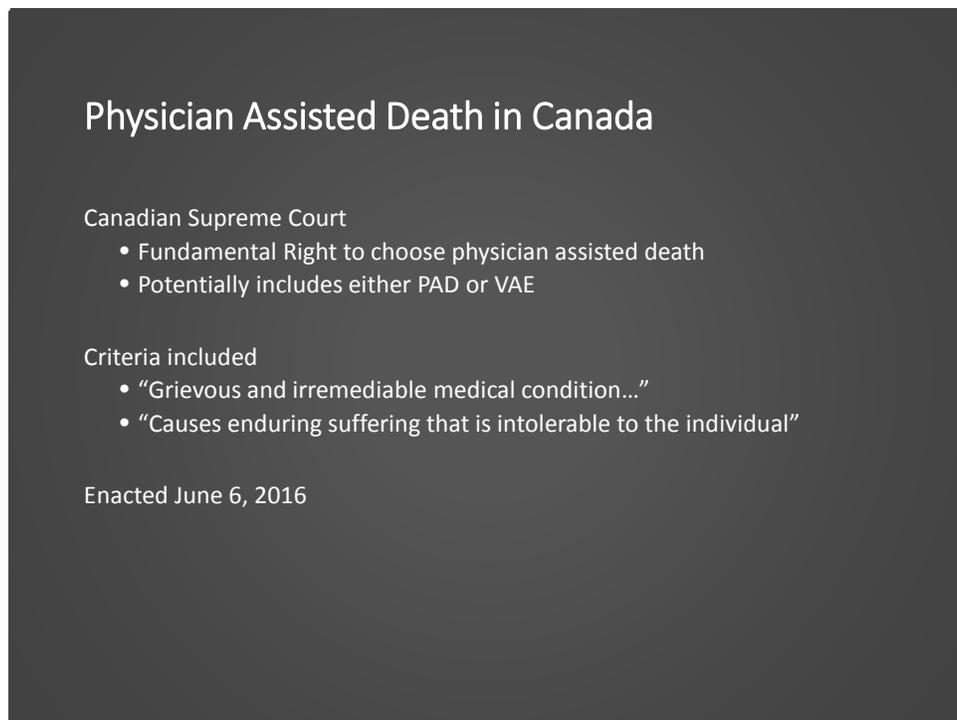


Figure XIII

So this is some more data about the prescriptions (FIGURE XIII). Again, 204 patients had prescriptions written in 2016: 114 of those ingested, 36 did not ingest, for 54 it's unknown, and there were some people from the prior year who had had their prescription in their pocket who ended up taking it in the following year. Again, they are able to track this. Now think about this: what data do we have from Michigan or New York about this practice? We have nothing because it's completely secret. If you are considering providing this assistance in a state where it is illegal, you don't write about it, you don't document it, you don't get a second opinion. We do know from older studies that there is a secret practice virtually everywhere that good doctors — or maybe bad doctors, who knows? — give a prescription to a patient or two within their practice perhaps in their entire career.

Additional data from Oregon: Most of the patients are white. Almost all had insurance. Most had cancer. They're relatively well educated. They often had long battles against their disease, so they weren't shortcutting the process. Fully 90 percent enrolled in hospice and all had access to hospice, so it wasn't that people didn't have access. The folks who did this tended to have access to everything. Uncontrolled pain was not the main motivating factor. Loss of autonomy, loss of dignity seem to be bigger factors, and it's been relatively stable, relatively low rates over fifteen years.



Physician Assisted Death in Canada

Canadian Supreme Court

- Fundamental Right to choose physician assisted death
- Potentially includes either PAD or VAE

Criteria included

- "Grievous and irremediable medical condition..."
- "Causes enduring suffering that is intolerable to the individual"

Enacted June 6, 2016

Figure XIV

What about Canada? Canada came almost out of nowhere last year? The Canadian Supreme Court (Figure XIV) found a fundamental right to choose physician assisted-death that would include physician aid-in dying, which allows doctors to provide medication that the patient takes by their own hand. But it also allows for voluntary active euthanasia, so that the doctor can actually deliver the medication. You don't necessarily have to be

terminally ill, so the terminal illness boundary is not present in Canada. You have to have a grievous and irremediable medical condition that causes enduring suffering that is intolerable to the individual. That is a pretty broad law, very different. Nobody knows how this is going to go, what kind of data they are going to get, but this is the law of the land now in Canada.

Legal status of physician assisted dying (PAD) and voluntary active euthanasia (VAE) in other countries as of June 2016	
Country	Legal status of PAD and VAE
Netherlands	PAD and VAE legal for adults and competent children older than age 12
Belgium	PAD and VAE legal for adults; euthanasia permitted for terminally ill children of any age
Luxemburg	PAD and VAE legal for adults and children older than age 12
Columbia	PAD and VAE legal for adults
Germany	Assisted suicide (not by physicians) is legal for competent, uncoerced adults, but the German Medical Association prohibits physicians from assisting on grounds that they have a duty to rescue
Canada	PAD and VAE legal for adults, subject to guidelines established under directive from the Canadian Supreme court as of June 6, 2016
Switzerland	Assisted suicide legal for adults if performed by someone with no direct interest in the death; some clinics will accept nonresidents

PAD: Physician-assisted dying; VAE: voluntary active euthanasia

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Figure XV

In Western Europe, particularly the Netherlands and Belgium, physician aid-in dying and euthanasia have been legal for quite a period of time (Figure XV). The boundaries are soft around this so it's not all just adults. Sometimes in competent children, sometimes in children over age of 12, in places like Germany, doctors are assessing patients but not delivering the medication, so that's another option. The doctors who are evaluating patients are not the ones who provide the medication. This is a changing dynamic in Western Europe.

Table reproduced with permission from: Quill TE, Battin MP. Physician-assisted dying: Understanding, evaluating, and responding to requests for medical aid in dying. In: UpToDate, Post TW (Ed), UpToDate, Waltham, MA. (Accessed on March, 23, 2017.) Copyright © 2017 UpToDate, Inc. For more information visit www.uptodate.com.

In the current state of practice, what currently counts the most? Where you live ... a good principled way to make decisions – no! The values of your physician – well, that’s what we want to count on, right? Can we count on the willingness of our physician to take a risk on our behalf? Are they willing to prescribe the effective medicine and dosage? Are they fully sensitive to the nature of our condition? What should count the most? (Figure XVI) Clearly the values of the patient should be the foremost in this process. So should the availability of hospice, because this really shouldn’t be an alternative to hospice. Hospice is the standard of care for people who are dying. It should be for those cases where hospice stops working or the dying process is still unacceptable despite hospice. And then the values of the participating physician if they are going to participate. So again, physicians in all of these areas where it’s legal do have an opt-out clause.

Summary: Current State of Practice

What currently counts the most?

- Where you live
- Values of your physician
- Willingness of you physician to take risks
- Particular nature of your condition

What should count the most?

- Values of the patient
- Availability of hospice
- Presence of unacceptable suffering despite hospice
- Values of the participating physician

Figure XVI

Here are some key interlocking policy questions underlying this issue. Clearly we need to improve access to and delivery of palliative care services

to all dying patients. Hospice should be the standard of care for dying patients. Palliative care should be part of the equation for patients who still want to have some ongoing medical treatment of their underlying disease. Palliative care and hospice represent the floor. Once we have the floor, how do you then respond to those infrequent but troubling patients who are dying badly despite excellent care? It's potentially fine to say "no" to physician aid-in dying but then how should we respond to these troubling patients? Because I will tell you at a bedside, if you're a requesting patient or a family member, you care about this question. And simply saying "doctors shouldn't do that" is not good enough. You have to figure out how then do you want doctors to respond? Should they respond to individual cases in secret underneath the radar screen or should we create public policy to provide guidance out in the open? What's a better approach? This is one of the key questions.

So if you are going to allow physician aid-in-dying to respond to difficult patient situations there will be need for safeguards to protect the vulnerable from error, abuse, and coercion. We want to make sure there is access to palliative care as a baseline, and that its implementation adequate. The risks cited, as Bob was mentioning, for physician aid-in dying are also present for the other last resort options. People on life supports are our most expensive patients, and yet we do allow life supports to be stopped even if people directly say they're ready to die now. We do that very forthrightly. How do we do that? Across the country, we get our best minds together. We get palliative care consults to ensure symptom management is optimal. We get a consult in the specialty area of the patient's main underlying disease has been properly treated and no medical stones have been left unturned, and we document everything that we're doing. You can go into a medical chart and find out exactly why that life support was stopped because it's a big deal to do that. But we don't say you can't do it. We don't force people to stay on life supports because

stopping them is difficult to do. The safeguards need to balance flexibility and accountability, and also privacy and oversight.

Palliative care has to be accessible and found to be ineffective. There must also be rigorous informed consent as well as diagnostic and prognostic clarity about the disease and its prognosis. Ideally an independent second opinion by somebody who knows the disease and who is an expert in palliative care should also be part of the process with full review and documentation of findings and decision-making.

What are the risks of "Don't Ask, Don't Tell?" It means that access is very uneven and unpredictable. It discourages explicit conversation. Unclear messages such as "*don't take too much of this or it might kill you*" can be completely misunderstood. What in the world is the doctor saying to me here? Is he giving me a green light to go ahead or is he telling me not to? There is a frightening risk of misunderstanding when we don't have very explicit conversation. In fact, this should be the most explicit conversation you ever have. It involves life and death. Without it there is no safeguard to ensure adequate palliative care and adequacy of informed consent. If you are assisted in the secret system, you and your family and your doctor all have a big secret on your hands that they then can't talk openly about. So there's potential for additional bereavement problems.

So what about the risks of being explicit about last resort options? It's going to frighten some people. If this is an openly available option, some people might be frightened. What are my doctors capable of? Are they going to be ending my life in the ICU? Might this option lead to pressure to prematurely choose death? It might also undermine progress in hospice and palliative care, and it could undermine fundamental physician values. I think these are legitimate concerns.

What are the advantages about it being explicit about all the last resort options? They acknowledge a problem. Patients, like our patient

here, will have less fear that they are not going to be left on their own at the very end if their suffering gets really bad. Reassurance that there could be an escape can potentially free up energy as in this case to fight his disease, to commit to the treatment process, and to be less afraid of what could happen at the very end. It reinforces the physicians' imperative to be responsive. Non-abandonment is to me extremely fundamental value here. If you have somebody who is a medical partner, who is committed to see the process through no matter what happens, then you are way ahead of the game. If you don't have that partner you may well be vulnerable because some of the future challenges are likely to be difficult. We want people to get help if they need it. So if they're stuck, they don't know how to approach a given medical problem, we want them to be seeing clinicians with expertise in palliative care who are committed to the patient's well-being. In Oregon most people want to talk about their end of life options but very few actually access physician aid-in-dying.

Bottom line, physician-assisted death, as well as the other last resort options that we agree as a society are permissible, are only sensible in the context of excellent palliative care (Figure XVII). These options are currently unevenly and unpredictably available. I believe they should all be subject to similar safeguards, and in my opinion open processes are more safe, predictable and accountable than secret practices.

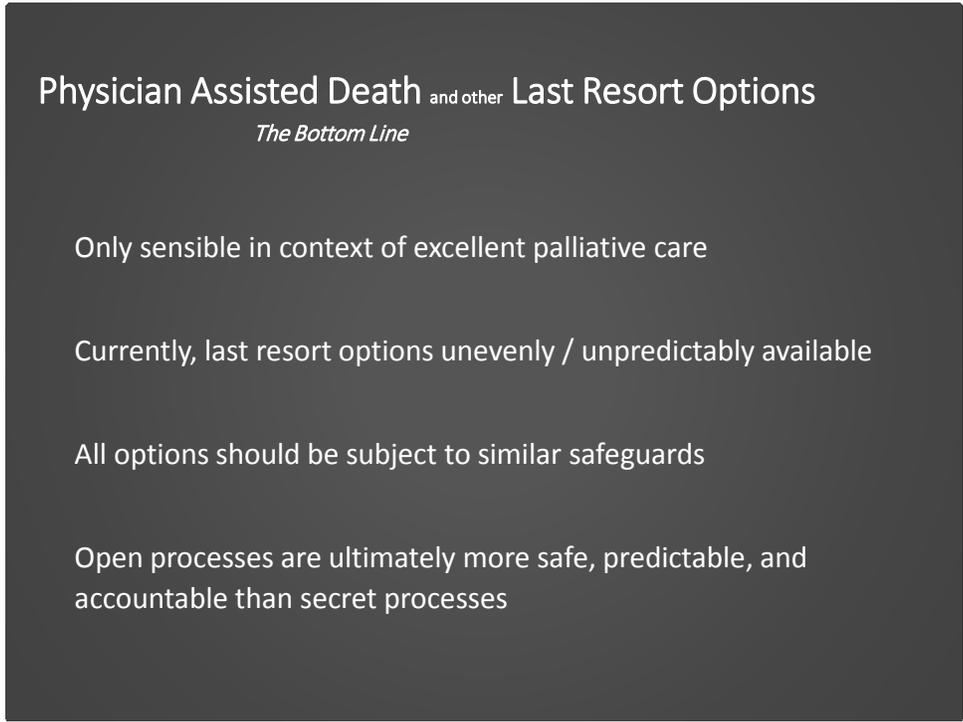


Figure XVII

Clarity (Figure XVIII) about which options are available and under what circumstances would be beneficial because it would reassure those who fear a bad death, increase responsiveness to extremes of suffering, provide greater ability to address unique circumstances, and ensure more accountability when suffering persists.

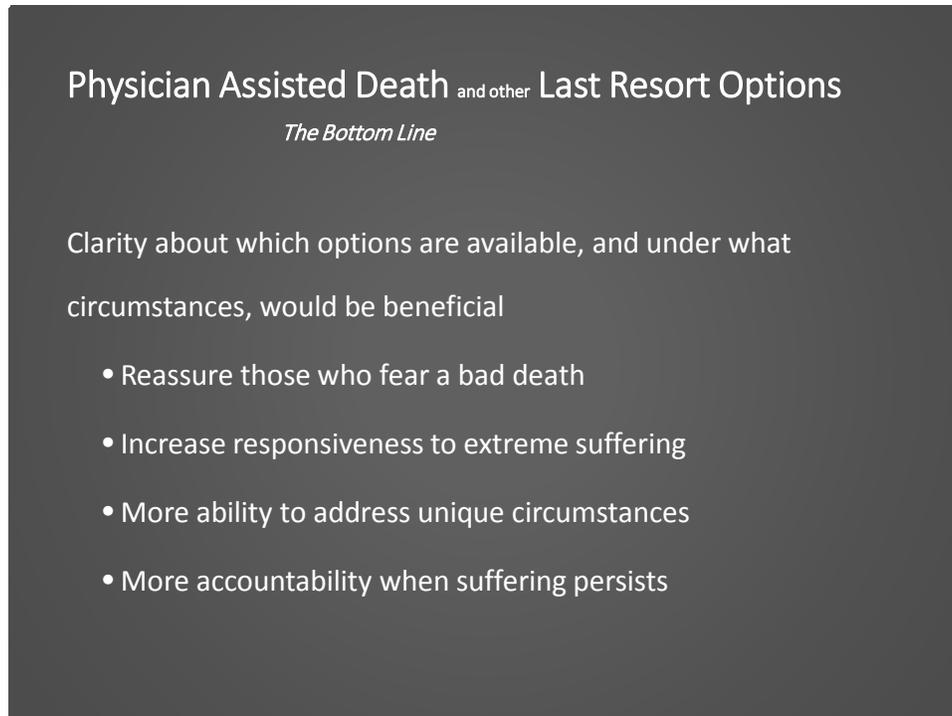


Figure XVIII

So now we'll return to our patient. He went through multiple cycles of chemotherapy and spent a large amount of that time in the hospital. He experienced almost every complication that is possible. He became septic, had infected intravenous lines, and all kinds of very challenging problems. He had four cycles of very aggressive chemotherapy and then when we went to check and see if he was cured, he still had a good size mass in his chest, so he was in real trouble. Because it was a rare tumor we wondered what else can we do? We called around nationally and found a real expert in this rare condition in Indianapolis. Go figure. We sent our patient to

Indianapolis. I was on board for this referral, but it also worried me because you can find enthusiasts in all areas of medicine many of whom never know when to stop treating. And that's not always a good thing to do. But this specialist really had an excellent reputation. He suggested that we needed to surgically remove the rest of it. I talked to other specialists I knew locally and nationally about whether this was a good idea, and they all agreed it was worth trying, but with no guarantees. Given that dying was the other option, the patient himself was willing to go for it. He then had surgery and again had every complication possible after the surgery. But remarkably after a very long recovery he ended up being cured! So I'm going to return and have you listen to him talk at the end of this process a little bit more.

(Begin Video)

Patient/Resident:

I thought more about the idea of hospice and the difference between taking my own life and allowing myself to be in the care of others at the end of life. My thinking did evolve in some ways in that issue toward kind of softening my view on it in that I would probably accept the option of heavy sedation or something if it ever came to that, if I knew that it would be done with dignity and not drawn out in any sort of lengthy way. That sort of option became less scary to me. I think as time has gone on I've sort of allowed myself to entertain that option.

Dr. Quill:

Your fear was that it would go on for a long, long time and kind of be undignified, and the reassurance came when you learned that we would be in some sense more aggressive, and have some time limits associated with it.

Patient/Resident:

Absolutely. The time frame definitely was a major, 80%, of my thinking on that. The idea of heavy sedation at the end of life, I think, and the idea it could be more aggressive definitely softened my view on it a little bit.

Dr. Quill:

We also had a talk about sleeping medication and having some just in case for you. How did that feel after we had that conversation?

Patient/Resident:

Yeah. My view hasn't really changed on that. That's something that I want for myself, I think. I want that ability and control. I want that ability to make that decision for myself at the end of life if life is no longer worth living and my life has definitely kind of played itself out and it's clear that I'm not going to be living that much longer. I want to be empowered to make that decision and having sleeping medicine on hand or something like that is a very comforting thought to me that I, with my wife and whoever I've chosen to be there, can make that decision at any point, holiday or weekend, when no one else were around if something kind of came to a head, some kind of issue came to a head such that I realize that life is not going to be worth living any longer. What concerns me about that option is that I might not be able to do it well, particularly in the situation I'm in now. I vomit so easily that I may not be able to take sleeping medicines well enough to induce death and that concerns me, but it's sort of an imperfect approach. More final-type approaches, more brutal approaches, just wouldn't be my personality. I do have concerns about that approach. But the fact that I could have at least some choice and some control even in the privacy of my own home is very important to me, even though I feel like the hospice option or the heavy sedation option might be even a better

route in some ways, having the control there. There's just a difference in the way I feel about my life, a difference in my comfort level.

(End Video)

Dr. Quill:

So this is twenty years ago. He is out in practice and doing well. He really made it through. Whether having the possibility of a physician assisted death was pivotal in terms of keeping him going or not, who knows? But it clearly was an important question for him. It occupied a huge amount of his energy, and knowing that he could have an escape freed him up to focus his energy on other things. You could say he shouldn't want that, but I think you would have had a hard time convincing him that he shouldn't want it. I think with that we'll stop and take questions, interaction.

Q & A

Dr. Reitemeier:

Before we get started with that, please join me in thanking both of our speakers for a very stimulating and – the cards are coming up. Do we have a question for either of our speakers? That's surprising. I have one that I'll exercise the moderator's prerogative and put it to both of you in sequence. You've both been writing and teaching on this subject for quite a while. Has either of you experienced a change of mind or opinion on this over the years of working with it and teaching about it?

Dr. Arnold:

I was more against physician aid-in dying when I started than I am now. I still think, and I think this is someplace where we disagree, I think that it has the potential in American society to have the tail wag the dog; that is, if you look at the percentage of people who need physician aid-in dying versus those who need palliative care, we in our society, and particularly in bioethics, like to talk about the hardest, most difficult, most unusual cases. And yet it seems to me as a society and as a matter of public health we don't focus on what most people in America who have a serious illness and who die go through. So, as a matter of public policy I would rather we spend a lot more time and energy debating how do we get good palliative care to all physicians rather than about physician aid-in dying.

On the other hand, I think I have become more willing to acknowledge that in hard cases we need to think about physician aid in

Dr. Quill:

Out of residency I became a hospice medical director as a piece of what I did. This is back in the days when hospice was just getting started, so we didn't know what the heck we were doing. We were just doing the best we could by the seat of our pants and learning as we went along, and to some degree that's still true. There's not a huge amount of data here. But I do remember as a hospice medical director, if we had fifty patients on our program at any given time there was always one or two, despite our best efforts, for whom things were not going well for and we were racking our brains about how to respond. We were trying to find ways to help them die better. This is where we come to palliative sedation. We come to stopping steroids with people with brain cancer. In these infrequent but very troubling cases we were finding all kinds of ways that could indirectly help them to die because they were dying really badly and it was very distressing for everybody, families especially, staff. Even though it's one or two percent of hospice deaths (meaning that hospice is effective enough in 98% of cases), that one or two percent has enormous impact on a lot of people who witness it. It's that entire person's family. It's all the healthcare providers who have had contact. Talk to hospice nurses about tough cases. They will tell you about patient situations they have encountered that will make your hair stand on end. So I've always known there have been tough cases. Diane, the woman I wrote about in the *New England Journal*, was the first case that I had helped by providing a direct physician assisted death, but I had helped a lot of people to die indirectly over the preceding years who had influenced the way I was thinking. So even though it is not that common, I had previously talked to a lot of people about these issues and I had indirectly helped a lot of people to die as part of my work in hospice. And, by the way, good hospice and palliative care doctors do this all the time. We find indirect ways to help people to die who are dying badly. Right?

Dr. Arnold:

I think there is some advantage to the indirect way.

Dr. Quill:

I agree, except when it doesn't work or when it's inadequate or when people are challenging us in ways that Diane, or this gentleman, was. Would I have helped him if he was dying really badly? You bet I would have. Again, most likely it would have been through heavy sedation because he would have been suffering severely from a disease that was physically overwhelming to him. He probably would not have been able to take the amount of medicine all at once to achieve a physician assisted death. But I would have found a way to help him escape severe suffering that was unacceptable to him.

Dr. Arnold:

Do you worry a little bit about the fact that if it was too easy that a doctor who wasn't as dedicated as you were in going to find an expert in Indiana would have said well, those other options are OK? Much like the data in Japan that looks at palliative sedation and seems to suggest that the doctors who knew the least about palliative care were the most willing to do palliative sedation?

Dr. Quill:

We don't have to look to Japan for variations of palliative sedation. Look in Rochester or Pittsburgh. You're going to find huge variations in how quickly people pull the trigger toward sedation. And that variation unfortunately does not have to do with patients or their particular suffering. It has to do with our values as physicians. My personal view is that the best protection against abuse is not to prohibit it or make it secret, it is to make sure that you require a palliative care consult if you're going to do this by

somebody who knows what they're doing. In big places that's easy to do. As you get more rural, it's hard to do.

Dr. Arnold:

We hope we've talked enough that now you have some questions.

Dr. Reitemeier:

Yes, I do have some. Dr. Arnold, this is for you. Most of your argument seems to be saying that the majority of interest in and the request for physician aid-in dying are really requests for some other tool to ease the process of death. If we set aside all of those misplaced requests, would you accept that the remaining cases are legitimate requests for physician aid-in dying?

Dr. Arnold:

I don't think any of this is about illegitimate requests. I would say yes, they're legitimate requests. There are legitimate requests for all sorts of things. That doesn't necessarily mean that one needs to accede to those requests. Again, I think that as a matter of ethics I am willing to say that in very rare cases it is ethical for physicians to practice physician aid-in dying. I wish we would have spent as much time writing and talking about all the 99 percent of cases and how to do a better job in those 99 percent.

Dr. Reitemeier:

A question asked by a couple of people has to do with the Western value of control and asks why it's so important that it trumps everything else. Hasn't that desire caused the slippery slope problem in the Netherlands? And how do you feel about the situation in the Netherlands?

Dr. Quill:

How many people in this audience are a little bit on the “control freak” side of the spectrum. Let’s just have a quick show of hands. When people go into the helping medical professions across the board they tend to be people who like to be in control, and they are in part trying to control death and disease among other things by doing this. The notion that people want to be in control of this process – I don’t know if this gets at this question ... but we have also really monkeyed around with the dying process. When was the last time you saw a natural death? What does that mean? I’m not opposed to fighting death; I’m just saying it’s got consequences. We have learned how to keep people alive longer and longer and longer. Men on average to 80; women on average 85. That’s average.

I’m going to digress and talk briefly about the compression in morbidity theory. The hope was people would live healthy quite a bit longer, live sick a little shorter, and then die peacefully. This is not the way it’s going. We are living healthy a little bit longer, sick a lot longer, and at the end of sick often the wheels are falling off and people are in trouble, or they’ve gone on so long that the parts of life that have meaning for them has gotten so small that they’re ready to call it quits. So the probability of having to make an explicit decision about readiness to die has gone up significantly. It’s very challenging and some of it is of our own creation. We’ve learned how to keep people going so long and they’re used to making choices along that way. This is one choice in that continuum in some sense.

Dr. Arnold:

And it’s a societal problem in that we have an immense belief in medicine and in science to cure things where the reality is we basically trade one disease for another disease a lot. We don’t really cure that much. It’s clearly a problem in the last twenty years. Until the 1950s-medicine had no impact on longevity of Americans. What has impact on longevity of

Americans are social determinants of health, clean water, those kinds of things. It's only been in the last twenty or thirty years that medicine prolonged lives, and yet we have an immense belief and trust that the next scientific advance is just around the corner that will allow us to make death optional. The head of my healthcare system has become quite enamored with immunology and the recent data involving rats, that if you give old rats young rats' blood they get young. This makes me a little scared because he's got a lot more money than me, although I'm not so young that I would be of help to him. But it is this sort of fantasy that Americans have that death is optional. We, as a society and as a healthcare, we promote that.

We did this study where we looked at advertising in cancer centers. It's all about not quitting, fighting to the end, getting your miracle. It's no surprise that people — and this is, I think, more American than it is in other societies — have this belief that we can beat death, so we have these tensions of control, and so if I can't get back to normal, and they can't cure me, then I want to end it quickly. We have little ability, I think, to live with uncertainty and angst and to find meaning in uncertainty and angst.

Dr. Reitemeier:

So that's a good segue into this pair of questions having to do with personal beliefs. Most major religions do not support suicide and physician aid-in dying. Tell me your understanding of integrating one's faith in this issue and the related question: Have you studied people or treated those from Eastern religions who don't fight a disease as much as learn how to live in harmony with their illness? Do they use palliative care and hospice to the same extent and do they also sometimes ask for aid in dying?

Dr. Quill:

So I'll give this a try first. There's no simple answer to this. You take a look at Catholic theology and you say well there's no way a Catholic is going to want this and then you survey Catholics. It turns out that they are an imperfect bunch, like the rest of us. About half of Catholics would like to have access to a physician assisted death if their suffering becomes extreme and un-relievable. It varies a little on the survey. And then different religions have different takes on this. Unitarians and Buddhists are open to this issue. What really counts, in my opinion, are the religious beliefs of the particular patient and the particular physician if the physician is going to help. So the patient's values and religious beliefs count the most, and if somebody who was asking about this option was a Catholic I would then ask them how do they make sense out of this option given Catholic teaching. They would teach me how they made sense out of it. If I were a Catholic physician or a religious physician who thought this was something that was not permissible and that I couldn't live with participating in, I would not provide it. What would I do? I would try to find other options — and I do that anyway —like sedation or other things. If I couldn't find common ground, I'd refer him to a colleague like Bob and ask them to struggle with it.

Dr. Arnold:

I have to say; I know of no data that looks at Eastern religions and their attitudes. I have to say that my clinical experience is that what people say their religion is and what their actual spiritual beliefs and hopes are do not correlate very highly. I take care of a lot of people who believe that they will go to heaven and yet are willing to go through lots of things to keep from going there as long as humanly possible. So, to think that there is this simple relationship between one's religious beliefs or what the doctrines tell you what you should do and what happens when you sit down as a clinician and a patient — I think, as Tim pointed out, it doesn't work that way.

Dr. Quill:

What does count? Having a conversation about how people have died in your family is really a worthwhile thing to do. And going back in the family tree. I will tell you that bad deaths where people died suffering in serious ways have a huge impact on families and how they think about this issue and how they approach the end of their lives. That bit of history-taking is important for each of us as family members and also for our patients is a really useful thing to do.

Dr. Reitemeier:

Both of you have accompanied a number of patients on the journey to the end of their life. Would you comment on whether, in your opinion, a patient can be wrong in judging how much physical suffering they can actually bear. And is the same true about emotional suffering?

Dr. Arnold:

I think that we often can be wrong about what our futures will look like and what we're able to go through. I don't think we have to look at death; all we have to do is look at childbirth. It's unclear which self we should listen to.

So, you're an OB. You talk to a woman who says she only wants a natural birth. No pain medicine. So now she is in the middle of labor and she's willing to sell her husband for an epidural. So, you do the epidural and then you go back to her and she says I wish you hadn't listened to me.

I think it's really complicated to know what "real beliefs" are and what's true. I have a lot of people who go through things and find meaning in their experience that they never would have thought they would find meaning in, and they're willing to put up with suffering because of positives that they never would have expected.

And I've had others who seem to be doing well with their pain and then you tell them they have cancer as a cause of their pain and their pain gets thirty times worse. I'm surprised, and it seems to me that my surprise doesn't matter. What matters is how physical and mental phenomenon combine into a patient's experience.

Dr. Quill:

My observation of suffering is a composite of both these things both existential, social as well as physical. I believe it's very worthwhile trying to tease out the various components of suffering in a particular case because there are pieces of suffering that we can fix or address or try to ameliorate and that's really worth doing. The part of suffering I feel most confident about is pain, shortness of breath, and even nausea and vomiting. Even though we don't always have good answers for those things, I have a way of thinking about them that works and there are some good data about the effectiveness of various approaches. But for my patients it's often also a real mix of sadness, despair, hope, and frustration; and witnessing those people's experience and listening to their stories is the name of the game. I would say the more a patient's suffering is on the existential or spiritual domains, the more I feel like as a physician I'm out of my depth. If a patient's suffering is predominantly in those areas and somebody's talking about wanting to call it quits, I've got to get some help. So I will find my most experienced chaplain or a really good psychiatrist who is experienced with severely medically ill patients, and see if they can help. Some psychiatrists are really able to get into those issues and others are not, but this really takes a skilled person. So we're really trying to unbundle and understand the patients unacceptable suffering, and see what can be fixed and what can't. But ultimately we're really trying to listen and have them really teach us what's acceptable to them and what is not.

Dr. Reitemeier:

This next series of questions has to do with the legalization of physician assistance in death and asking you to speculate on the future trajectory of it. Do you see any national adoption of this movement with the success of it in the six states that have adopted it? What's holding it up from moving forward more quickly? And a related but sidebar question: Do you believe that if it gets legalized it will lead to the disincentivization of research into debilitating diseases that lead individuals to opt for this choice?

Dr. Quill:

The processes of legalization within states are incredibly varied. In states that have strong referendum processes, where it's the "will of the people," I think there is a reasonable chance you can have movement in those areas. In states where its legislators are having discussions like what we're having nationally right now, I think it's completely off the table. It is way too easy to demagogue this issue, and we've got demagogues in all parts of the political world right now and they're not able to talk about sophisticated things like this. You have to have people who are really willing to suspend the demagoguery and talk about what's meaningful and that's not going to happen. In states where referenda are legally possible, I think legalization can happen, but there are not that many left. Then you can have case law. You can have a particular case that might go to court and see if a precedent can be set, but that is risking for the litigants and logistically difficult give the pace of disease and the pace of the legal system.

Dr. Arnold:

I think that would be interesting. I think for the Supreme Court to make it a right and short circuit the referendum process or the process of individual states making decisions, has a very high risk of leading to a backlash both about physician aid-in dying and about palliative care more

generally. I would think that would be not a wise way for public policy proponents to proceed.

Dr. Quill:

We're in total agreement about this by the way. First of all the Supreme Court — I don't even want to think about them taking on this issue right now. Even if they did and they decided it one way or the other — I mean basically the Supreme Court did decide this issue to a degree already. It was nine to nothing basically saying we're not going to set the law of the land in this domain, but it also said they we're not going to interfere with states. If states want this, they can move forward as has happened in Oregon and six other states. If and when you start getting two-thirds of the states that allow this practice, then you have another Supreme Court question. But we're a long way away from it.

Dr. Reitemeier:

How about within medical education itself? Are you seeing a shift toward palliative care as a focal point of emphasis?

Dr. Arnold:

So, there are two things. Someone asked about whether the NIH should spend less money trying to treat diseases because of physician aid-in-dying. No. That isn't the way the NIH works. The NIH will spend less money if the budget changes and they have less money. Otherwise, they're going to spend the money they have because the NIH is made up of scientists and the role of science is to try to change what currently happens in the world and/or understand it.

I think medical schools — as well as nursing schools and social work schools — are becoming way more interested in doing teaching about palliative care. That isn't to say that there isn't much more that can be done both about symptom management and about communication processes. I

think that, because California has a physician aid-in dying law, many more medical schools — even if they're in states that don't have such laws — will do some teaching about this because so many residents end up going to California. I think the open question is how do we change what happens, once you're out of medical school and in residencies and fellowships and practice, to set up environmental structures that promote palliative care.

Dr. Quill:

This is a bit of a digression, but if we could double the number of palliative care doctors in the country right now we could probably find jobs for them. Palliative care is a growth industry. Palliative care is on the map. The problem is there are not near enough palliative care clinicians to take up the jobs and the opportunities that there are. Basically, what we're going to have to do is train good doctors to do the basics of palliative care. Bob and I have talked about this a lot. We're totally on the same page about this.

Dr. Arnold:

It would be better if we wouldn't call it palliative care. If we would just call it practicing good medicine for seriously ill elderly adults. The problem when you ghettoize it by calling it palliative care, then people say well, we'll just send you to the palliative care specialists, and that will never solve the problem. Or it won't solve it by the time that I need it, and that's what I really care about.

Dr. Reitemeier:

So it might be that a lot of the audience is not really familiar with palliative care, palliative medicine, and a couple of the questions reflect that. There have been a few comments on the need for palliative care consult in relation to a PAD request. What do you hope to glean from the palliative care consult?

Dr. Quill:

It's pretty clear. First of all, you want to make sure that you understand the reason for the request? Let's say it's unrelieved pain, the easiest scenario. Then you'd want to make sure are the requesting patient is getting the best possible pain management. You want to make sure palliative management is optimal for whatever the main driver for the request. Then you're also going to ask the question are they depressed? Are they thinking clearly? Do they have a clear diagnosis and prognosis that is fully understood? If they're depressed clinically, maybe we should treat their depression before answering this question. I saw a lady on psychiatry who wanted us to stop life support. So it wasn't physician-assisted death; she was on several life sustaining therapies including dialysis, and she was profoundly depressed. I made a deal with her. I said look, let us treat your depression for a month and if you still want to stop, then you can stop. We treated her depression and she didn't want to stop dialysis.

There is a lot of room for careful assessment that should be part of this process. That's why, in my opinion, bringing it out of the closet and out in the open is so important. There will be cases if we bring it out in the open where people are saying I'm done, I've had it, and you need to listen to me. If we don't mind hearing that, then we should bring it out into the open. Most of the time we'll be able to find palliative care options.

Dr. Arnold:

Part of the problem is that people don't like having these conversations. Some of you might be saying well, it's just talking to patients, how hard can it be? And yet the data that's out there about clinicians talking to patients is that we don't do a very good job in having really emotionally difficult conversations. There is no reason to believe that physicians should know how to do it just because they're physicians. In addition because these are topics that are emotionally hard, they require you to be interested in

probing. It's the kind of thing that if you don't teach people how to do it, they'll never do a good job. I would argue that regardless of what we do with physician aid-in dying, we need to teach people how to have these conversations because that patient in the earlier video was lucky that he saw Tim Quill at University of Rochester. If they would have been in many other places where there wasn't a palliative care doctor, that's a conversation that their nephrologist should be able to have with them or their primary care doctor should be able to have with them. One of the things that's sad is that in our society we spend way more time and energy focusing doctors on how to give pills, partly because it's quick and it's easy and it's remunerative, than we do in teaching them to have really tough conversations.

Dr. Quill:

Let me just digress for one moment and turn the tables on you all. Think about within your own families – whether your parents, or grandparents, or children. Have you had these kinds of conversations? Not necessarily the assisted-dying conversation. The what-would-you-want-if-you-got-super-sick conversations. The advanced directive kind of conversation. If you have not, you are contributing to the problem.

Dr. Arnold:

Right. Or even worse, if they come to you and they say I want to talk about what if I get sicker and you say oh, you're doing fine, what do you mean talk about when you get sicker? Let's go out and do something; let's go bowling. It's the kind of thing that when people come to us, our immediate reaction is ooh, why do you want to talk about that? Let's talk about something noncontroversial like what's going on in Washington.

Dr. Reitemeier:

We have a question about how do you approach these decisions with parents of pediatric patients, both those who are mature minors and those who are too young.

Dr. Quill:

We have a hard time having these conversations with our ninety-year-old grandparents, right? So think about a nine-year-old or a nine-month-old or a nine-day-old, and you almost don't even want to imagine it. It's got to be so freaking hard. When we started out with our palliative care program we didn't have a pediatric separate program, so we did it because nobody else was doing it. From a decision-making point of view, the details of symptom management of palliative care – like, I was really flying by the seat of my pants then with pediatric patients, but the decision-making part, although it was emotionally wrenching, it was similar decisions. The little ones don't have any capacity, right? What's the ethical principle when people don't have capacity? You can't say what would he want if he could understand this completely, because they don't have capacity. They never had it. So we're trying to figure out what's the right thing to do? What's the best thing to do? It's really, really, really hard. It's going to turn a lot on the values of the family and how they see these things, and it's wrenching.

As kids get older, as they get to be adolescents, we are going to involve them. Even though their parents have a say in this, particularly a lot of kids who have been really sick, they're mature minors and they need to have a voice in how much is enough and what they want to do. The parents have to sort of go, they're in the game, so I think those are even more complex. These questions will come up for these folks, and if we do allow this for adults will we allow it for mature minors because mature minors have certain kind of capacity. I think you can see in Western Europe; they are struggling with this and they do it on a, by and large, case by case basis.

Western European countries are like super less litigious than our society. They're used to trying to find common ground, using common sense and all that stuff, that we've kind of thrown out the window legally. I don't know whether what they're doing is right. Although what do we do with these cases here now? It's not like we don't have them, right? Again, we muddle through and do the best we can. It's not ethically clean and it's not legally clean.

Dr. Reitemeier:

How do you respond to a patient who is concerned about their future pain or suffering and wish to address the option of assisted death before they lose their personhood?

Dr. Arnold:

Sometimes just mentioning the fact that I wish we could be in control of everything and pointing that out to them is helpful because it allows them to take a deep breath. I'm more than willing to talk about XYZ option. I sometimes worry that talking about every option down the road distracts them from being able to appreciate where they are now. Part of what I would think in those cases is well, I want to deal with that. I also want to see if they can get enjoyment and meaning out of their life now, and I worry a bit about people who are trying to cross every bridge.

Sometimes what helps is making a commitment that you're going to be with them 150 miles from now. That if the going gets tough that you're not going to sort of stop coming and seeing them, or stop caring for them, or stop appreciating them. Some of what you're doing is in fact making a pledge of non-abandonment, and sometimes that's helpful. Some of what I can do for some of these patients is to give them things to read because more information is helpful for them. Trying to figure out what helps them cope the most in the moment and then seeing if I can provide that for them.

Dr. Quill:

Think about the young man that I presented earlier. He wanted a commitment that if his suffering got horrible at the end that I was going to help him to die. He didn't need a prescription in hand. He needed a commitment in hand. And he really wanted that commitment, and I gave it to him. I was committing to helping him in any way that I could at that point. I said I'll be as creative as I can. We don't know what's going to be happening. The odd thing about the current environment is that we've created an environment where when doctors are faced with that dilemma they often say don't ask me that question, I don't want to deal with that. I'm afraid to deal with that; it feels too dangerous legally. But doctors do help patients to die. We do help patients because all of our patients die if we care for them long enough. We try to ease it as best we can. What he wanted was a commitment to help him find a way out that would work for him if he got into a bad situation. If I were a doctor who was adamantly opposed to aid-in dying, I could still say to him I will do my best to help you find a way out. It might be sedation, it might be stopping eating and drinking, I don't know what it's going to be. We don't have to get into the specifics. He would need to know what I can't do as well as what I can do.

Dr. Arnold:

It's the commitment and the being willing to sort of witness with him the future that in my experience is more important than the details of exactly what you'll do or what you won't do.

Dr. Quill:

But, if you make that commitment ...

Dr. Arnold:

You've got to keep it.

Dr. Quill:

You've got to keep it. If you make that commitment and you don't keep it, that's the worst. That's being a bad person. It's worse than being a bad doctor. It's being a bad person. It doesn't mean you do things you can't live with, because you don't do things you can't live with. If that ends up being the pivotal thing, then they need to find another doctor. If you can't live with it, then you can't live with it and you don't do things you can't live with.

Dr. Reitemeier:

Well, thank you very much. Are there any other questions for our two panelists?

Audience:

That last point, I think that was really good. I think you were saying that it's more important to say, if a doctor can't do one thing they should tell that patient. I'm going to do everything I can, but really I can't do this one thing. So it's more important to say what they can't do.

Dr. Arnold:

I think it's important to say it. I don't think it's important to lead with it. I think that in the end, when all the talk is done, if there are things that I just can't do, I need to stress mostly what I can do and then I need to acknowledge that there are some places that I as a person — not that there is anything wrong with their request, but I as a person can't do.

Dr. Reitemeier:

Thank you very much for a most stimulating evening. Please join me in thanking our two speakers, Dr. Quill and Dr. Arnold.



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