

UW School of Law

Transcript: Death with Dignity

Greg Hicks:

...Expertise in bioethics, genetics and the law, global health, health and human rights, medical malpractice, and public health law.

And immediately to Pat's left is Elaine Starks, a PhD, MPH Assistant Professor of the Department of Bioethics and Humanities at the School of Medicine. She received her Master of Public Health and Health Policy Administration from Cal Berkeley, and a PhD in Health Services Research from the University of Washington.

And her research includes issues related to end-of-life for patients, their family members, clinicians, and health systems as a whole as they try to engage these troublesome issues and difficult issues.

Terry Price, to Elaine's left, is an adjunct faculty member at the University of Washington Law School, one of our own, a member of the class of '01. Terry has his BA from the University of Pennsylvania and a Masters of Social Work and Clinical Social Work from Smith College.

He has extensive practice experience as a clinician, he was a clinical social worker at Children's Hospital and Regional Medical Center here in Seattle where he worked with children and teens with cancer, and also in an infant intensive care unit.

Terry's most recent work has been as a counsel at the House Democratic Caucus in the Washington State House of Representatives. And he may utter his own disclaimer but I'll do it for him: For those who are in those public positions, Terry wishes it to be clear that although he works for the legislature, the views that he will express this morning, the comments that he will offer are his own and are not to be attributed to the legislature.

And finally our leader of our panel, our moderator, is Tom McCormick. He has a doctorate in ministry and is a real pioneer and leading figure in health ethics here at the University of Washington School of Medicine.

He developed the program in biomedical ethics and is responsible for the ethics component of the required portion of the curriculum for the medical students at the UW Medical School. He

has been part of the faculty of the medical school for over 30 years and has just stepped down as the director of counseling at the School of Medicine.

I can't imagine someone with deeper, richer experience and the practical application of ethical issues in clinical settings, and Tom will bet the moderator of our panel. And again, we couldn't do better than Pat, Elaine, Terry and Tom.

And so I think we're in for an especially searching exploration of Washington's new statute and its implications. So again, welcome one and all, thanks for coming out early. The coffee is strong, eyes are open, and we're going to have a great morning.

[laughter]

Thank you for being here.

[applause]

Dr. Thomas R. McCormick:

Thank you very much for that generous introduction, and let me add my welcome as we're here to think though together and have a conversation about Washington's new law.

Just to set the context for this: I suppose, historically, one can point to the mid 70s and cases like Quinlan, Cruzan, and Bouvia where issues of patients' rights to withhold care or to withdraw unwanted medical technology, really began to claim the nation's attention.

And here in the state of Washington, cases like that of Bertha Collier, the use of ventilator of Joe Hamlin at Harborview, a mentally retarded individual who never had the capacity to state how he would want to be treated at the end of life. Or the case of Barbara Grant regarding the use of a feeding tube. Many of these cases were pioneering cases and precedent setting cases in our own state.

So the American public and the citizens of Washington have a history of concern centered around the notion of patients' rights, and centered around our increasing enthusiasm for the principle of autonomy, the right of individuals to choose how they wish to be treated.

We've obviously had legislative steps to help guarantee those rights through Washington's Natural Death Act and its revisions. Leading us to Initiative 1,000, that for the first time in our state, makes it possible for a patient to come to an agreement with his or her physician to receive assistance in having a medication that the patient could hold in their hand and to take, self administered, when the time is right.

This panel of experts with us this morning are going to provide a context to understand the current law, and they're going to explore with us some of the history of the Oregon situation, and some of the ethical issues that lie at the heart of this particular piece of legislation.

We're not here really to debate the nature of the law, so much as to put the law out there for us to look at, and to think together about the kind of issues that it raises. So as our speakers are introducing their own particular topics, I hope you'll be making a note of questions you'd like to bring to us in the question and answer session following their discussion.

I would like to begin by calling on Pat Cussler to talk to us a little bit about the law itself so that we can be grounded in the reality of what that means.

Pat Cussler:

OK, well I get the easy job in the sense that I get to summarize the current law. As most of you have probably been following, we had Initiative 1,000 that was on the ballot in November last year. We had a pretty dramatic turnout here in Washington and the initiative prevailed with 57.8% of the votes.

This was not, of course, our first foray into the area of 'death with dignity'. Terry will speak in a few minutes and give us a little bit of the history of how we got to be one of the first states to look at this issue, and to implement a law.

But essentially this movement towards the idea of 'death with dignity' has been present for a number of years here in Washington. And the idea here is that terminally ill, competent adult patients who are predicted to die within a six month period, will be able to be able to repress and self administer medication to hasten their death and forego additional suffering.

So if we take a look at the law which won't become effective until March 5th, and indeed the first patient who actually exercised this right requested this last weekend, we see that the law has a lot of requirements with respect to who's eligible.

First of all, patients who are eligible have to be Washington State residents, they have to be competent, they have to be terminally ill, and the terminally ill definition is an incurable, irreversible disease expected to cause death within six months. This fits in directly with what terminally ill means under Medicare for instance.

They have to be over 18 and they have to be able to voluntarily express their wishes to hasten their own death. There is a complex method of ascertaining that, indeed, the patient is fully informed and is not only consenting, but seeking this opportunity to hasten their death.

So there are requirements in the law that deal with guaranteeing that the patient has been fully informed by their physician about their condition, about their opportunities for other sorts of hospice and palliative care, and pain control treatment.

And then beyond that there are additional protections that deal with witnesses that have to be present, additional physician confirmation, two oral requests, a written request, parameters with respect to the fact that at least one witness can't be someone who is a relative by blood or entitled to any portion of the estate, or the owner/operator of a healthcare facility.

So, essentially you have a fair number of protections built in, in terms of which patients are actually eligible to elect this opportunity.

With respect to the physicians, physicians who would be engaging and working with patients, I think it's in their debt to write the prescriptions, are typically physicians who have primary responsibility with the care of the patient. And they would be responsible for providing informed consent, making sure the patient is fully informed, clearly delineating for the patient what all the other palliative opportunities are, and working with the patient throughout the process.

Now obviously, not all physicians are willing to engage in this activity. So there are provisions for opt-out in the law, not only by physicians but by institutions. We've already seen in the early days of implementation that there's a number of major institutions that have opted out from participating, as well as physicians.

And so as we go down "why, " I think that one of the issues is going to be, where the discussion is, is going to be the issue of whether or not this is truly something that is accessible to patients who really want this. It may well be that in a given community, all of the physicians or institutions will have opted out.

There are some protections built in for physicians in the sense that physicians are providers who participate in the 'death with dignity' provisions are not susceptible to criminal or civil liabilities for aiding and abetting suicide. And they're not susceptible to loss of license or these sorts of things, which might have been an issue if indeed this were an illegal act, which it no longer is.

There are complex reporting requirements that allow Washington state to kind of keep a running tally of what's going on with this law, so that we can study this law all the time. And we have of course modeled. The law is heavily modeled after the Oregon law, which has been in place now for a number of years. So that's sort of the provisions, a brief overview of the law. And I think that our other speakers, one of our other speakers, is going to talk a little bit about some of these legal cases and other states that have implemented 'death with dignity' acts.

Dr. Thomas:

Yes, thank you, Pat. Staying with the theme of the law for just a minute longer, I want to turn Terry to talk a little bit about the Glucksberg case and some of the antecedents to what we are currently having in terms of this law as that case challenged our law of aiding and abetting suicide. Terry?

Terry Price:

Thank you. Good morning. I want to thank Dean Hicks for the disclaimer, what's an attorney without a disclaimer? And even if I had anything to say about this law, there would be nothing from my day job that would have informed that, because this never went through the legislature. This was an initiative, and under the state constitution, the people reserve for themselves the right to enact laws, independent of the legislature. So, it forms a nice boundary. It's like there's nothing I even could share from my day job that relates to this law.

What I was going to focus on were the two renegade states, here in the Northwest in 1994, because both of them were agitating about these issues at the same time. In 1994 in Oregon, you have the enactment of the Oregon Death with Dignity Act. In Washington, you have the district court challenge to Washington's Natural Death Act about physician-assisted suicide. And that goes up to the Supreme Court with both in 1997 with a Second Circuit case from New York.

The head-on question is whether or not there's a due process right to physician-assisted suicide. And Justice Rehnquist, writing for the majority of the court, already. Justice Rehnquist's is not going to be a very liberal opinion, says that the Constitution protects those rights.

The text he uses is, "are deeply-rooted in the nation's history and traditions, and implicit in the concept of ordered liberty." Under that test, the idea of a due process right for physician-assisted suicide goes down. They reject that idea, that the Constitution does not encompass that.

But that does not stop the agitation. In 1997 after that, there is still concern that in Oregon that has a state law about physician-assisted suicide. And some members of Congress approached then Attorney General Janet Reno to go after that, to examine that and possibly take that law down. And she says no, that she can't do that.

Then comes 2000, change of administration, and in 2001 Attorney General John Ashcroft decides to...is again approached about Oregon and decides to go after it in what eventually becomes *Gonzales versus Oregon* after Alberto Gonzalez succeeds him.

Basically, so we've already shown that there is no due process, right? So what avenue is the Attorney General going to use to approach this? He goes after the law, based on the Controlled

Substances Act. The Schedule II drugs for the Controlled Substances Act are the barbiturates that are being used. If he can show that there is no legitimate medical purpose for using those drugs for physician-assisted suicide...and basically yank the physicians' registration numbers, which would put them out of business, then that would void it, effectively do away with the law.

Surprisingly, he lost at the district court, and he lost at the Ninth Circuit Court of Appeals. The most surprising is that the Supreme Court affirmed the Ninth Circuit, which as far as I can tell was like the first time in 10 or 15 years that the Supreme Court had affirmed the Ninth Circuit.

Terry:

Terry:

Justice Kennedy says, "As the Court has observed Americans are engaged in an earnest and profound debate about the morality, legality and practicality of physician-assisted suicide. This dispute before us is in part the product of the political and moral debate, but its resolution requires inquiry familiar to the courts: interpreting a federal statute to determine whether executive action is authorized or consistent with the enactment.

So yes, it's part of the larger debate. But no, we're not going there. We are focusing solely on statutory interpretation. And all three courts ruled that the Attorney General has overstepped with this rule, thus leaving the Oregon Death with Dignity law intact.

After looking at that I thought, I wonder what kind of state law challenges there have been? Because you would assume that these terms, "capable patient" or we use "competent," "terminal" or even "resident," you have to be a resident. Somebody must have challenged this. I mean all you have to do really is get an apartment in Oregon, and then you can get the drugs and kill yourself. Is that sufficient? Is that what "residence" means?

Interestingly enough, under the state law, the only challenges that I could find were to the measure itself, like the ballot title, and to the repeal to the ballot title. Then there was one other case medical malpractice, where the court said very clearly, this is no way related to the Death with Dignity act. Surprisingly, the gist of the act appears to be relatively left alone, and hopefully we will see that here in Washington.

The last quick questions that I have, have to do with, as you mentioned, the Karen Quinlan, and questions raised in this case from 1983 called Henry Collier, about Bertha Collier, one of the first cases here where we dealt with the right to die.

And the court, in Collier, set out, "What are the state's interests in this area?" Preservation of life is the overwhelming number one, protection of third party, prevention of suicide, and

maintenance of the ethical integrity of the medical profession. So those are the state interests here and preservation of life being paramount.

And the Quinlan case, which is echoed in Collier, said, "As someone is dying the nature of the state's interest recedes, and the nature of their privacy right takes over." So their privacy right outweighs the state's interest in preservation of life, which I think of as kind of the gas and the clutch, as you pull back on one you push down on the other.

So the question is: In 1983, 26 years ago, we said that nature is prevailing, the privacy right is prevailing if you are terminal and you want to refuse treatment. So is that the same then as if you want to do something to hasten your death? Are they legally the same or are they different?

Dr. Thomas

We're going to make a little switch now from purely the legal aspects of the situation to the clinical and the ethical. Dr Elaine Starks has considerable experience in looking through the Oregon experiment or the Oregon situation, and seeing what really happened over about an 11 year period now.

And also in her research she has looked at some of the clinical questions. Why is it that people want to take matters into their own hand? Is this a real change from what's happened historically? How do we frame the ethical questions around this? So Elaine maybe you can share from your experience.

Dr. Elaine Starks:

Sure. I thought that what I would do is just share a little bit about who the people are that have used this law in Oregon. I think there's a lot to learn from our neighbors because I believe we are geographically, and probably culturally very similar in the temperaments of our state, and so there's something to learn from them.

I'm not sure if the law...The first one that was enacted was a different party for the Midwest or the south that you would extrapolate. But I think that the values and the composition of our people are similar enough that we probably have something to learn.

Since the law first went into effect in 1998 there have been 401 people who have used this law. The highest number was last year in 2008 with 60 people taking prescriptions. On average...The very first year there were 16 people, it went up to 27, stayed there for a couple of years in the low 20s, it went up to the high 30s, low 40s and it's been gradually increasing over time.

But in absolute terms this is still very much a rare event. So it's .002% of the deaths that happen. It's roughly 31,000 or 32,000 deaths a year going on in Oregon, so 60 out of those is a very small amount.

So what do we know about these patients? Well, one of the things that's interesting is that when you think about why people do this...In our study, and this has sort of held up over time...The different studies that have been going on through some investigator teams, primarily Linda Ganzini at Oregon Health Sciences University.

She's done some excellent work looking at all kinds of different aspects of the law, from how patients are diffusing it, what families think, hospice providers, social workers, chaplains, physicians. She's nearly interviewed just about everyone who is involved in these cases.

And several things have emerged. The first is sort of what motivates people to do this. We often think that...And the sort of knee-jerk reaction is that people must want to do this because they're in horrible pain and it's about ending pain and suffering.

What's an interesting fact is that 88% of the people who have used this law have been enrolled in hospice. So in the early years what was happening is that it was sort of that thing where people were not sure of what all their options were.

What I like to say here when I'm talking to clinical audiences is that we just had a referendum on the Death With Dignity Act, we did not have a referendum on hospice and palliative care. And there's still a huge gap in knowledge in terms of what those things really are.

So if you can kind of imagine, whenever we're scared we go to these sort of extreme measures to sort of let people know what we're afraid of. And if you walk into a doctor's office and you say, "Hey, I want to use that Death With Dignity Act," you're going to get their attention. They're going to go, "Oh! OK, let's talk. What's up? What's going on?"

Whereas if you just say, "I'm feeling funny and I've got some pain," and you sort of say the things that people who have terminal illnesses say about their experience, you may not catch that attention in quite the same way.

So one of the things that people in Oregon have been talking about is, "We thought that if everybody got on hospice, this was going to take care of everybody." Well, it's now turning out that this is primarily a phenomenon of hospice.

So if it's a phenomenon of hospice, then what is it that hospice isn't doing? How is it that if you take care of peoples' pain and suffering they still want to do this? How come? Well, it turns out

that it's not really about those kinds of suffering issues, it turns out that it's far more about more existential issues about who I am as a person.

And there's an interesting sort of constellation of factors that come together to make this happen. The first is: These are individuals who have been in charge pretty much their whole lives.

When people have dug a little deeper into some of these stories, it has turned out that it's not uncommon for people to have had to assume roles of responsibility very early in life. So either a parent died or there was a divorce. And these are folks who sort of came into positions of responsibility early and took that on, then that became a part of the fabric of who they were as people.

And in one of the studies that Dr. Ganzini did, she asked the physicians who have done the evaluations on these patients to describe them, you know, characterologically what are these folks like?

And these are their descriptors: They are very independent or they value independence, they have very strong personalities, they're used to getting things their own way, they're in control, they're determined, they're very up-front, and they're very inflexible about their requests.

So these are people who would be happy to fire you if you don't really want to do what they want you to do. They might do it very politely, very cordially, sort of like, you know, the TV guy. You know, the one who says...What's his name? The one who fires everybody?

Greg:

Donald Trump

Elaine:

Donald Trump. Thank you.

[laughter]

Kind of like Donald Trump, only they're in your doctor's office. And the other thing that people find that's very disconcerting is that these are also serious planners. So they've had their living will for about 40 years, they've printed their durable power of attorney, and they show up... Well, they look kind of like you guys.

They usually show up in suits or nice clothing, they're not sick looking people in the moment. And what's probably the hardest thing, what we hear always from the physicians is that when

they're used to making these kinds of decisions about life and death, they're used to seeing people in an ICU on a ventilator who can't talk.

And so the idea about ending life is sort of easier because...This is an icky situation, nobody can really talk to them, this doesn't look like life, they're in the ICU, they can't breathe on their own, and so withdrawing treatment feels easier.

When you're looking at someone like Terry who's coming to you very forcefully with this request and has a lot of good energy behind it, it's a very different situation and it's about shifting control.

So it ends up that a lot of what these folks are talking about is that they have what's called primary and secondary levels of control. Primary control being, "I'm in the driver's seat, I drive all the time, I'm in charge of what I'm doing."

As their illness sort of brings their lives closer and smaller, they start to lose their capacity to actually be the driver for all things. Now most of us, we delegate, we get a designated driver. As long as Terry goes where I tell him, I'm OK. But for some people even that move isn't OK, losing that sense of being in charge.

So what ends up happening is this sort of interesting constellation of: Their illness is making their world smaller, that is making them more uncomfortable, and then there's a series of tradeoffs that are going on in terms of their fears about the future.

So this is not...As I say, they show up present while they're all pretty much intact because they're forecasting to the future and they're planners. So they are forecasting to an event that's out there that they want to keep at bay. They have drawn the line and they don't really want to cross it.

And it is very interesting; I'll just read you a quote from our first case who was a woman from Schwinn. She was 66 years old. In April, she was diagnosed with Pancreatic cancer and it is a cancer that progresses very quickly. It becomes very symptomatic very fast and it is not pleasant.

She, within a month, was already losing weight. She couldn't swallow. It is basically a mass that takes over your belly and it is very painful. For her, her issue was not the cancer. This is another interesting paradox of some of these folks. Her issue was she knew that in order to keep her pain under control she was going to have to have increasing doses of morphine. When you escalate the morphine, you lose your cognitive capacity. It makes you very sleepy and you get kind of goofy. If you increase and increase the dose you aren't clear-minded often. You are sort of in lilt.

Her quote was, "I am a very spiritual person and it is very important to me to be conscious, clear-minded and alert at the time of my death. The powerful pain medications were making it difficult

to maintain the state of mind I wanted to have at my death and I knew I would have to increase them."

So her trade-off was not about pain and suffering but rather what it takes to control that pain and suffering. These are the kinds of issues that sort of move out behind or get out in front. And there is one more thing that I will say about this that is also sort of interesting to note.

In addition to all these characterological things and these other things that are going on, the vast majority of patients, like in the early days of hospice are cancer patients. But they also include Lou Gehrig's Disease, HIV AIDS and heart disease as the primary. But 82% of the cases are cancer patients. That makes sense along with some of these other really important reasons and that is the predictability of the illness and where this is going.

So if you know because your physician has laid out what your trajectory of illness is going to be, you can kind of forecast when on that trajectory is going to be the place you don't want to go. This is particularly poignant in the case, for example of Lou Gehrig's Disease where the neurologic signs are literally a roadmap of what you are going to lose next. What ultimately happens is your nervous system shrinks to the core and your diaphragm is also failing and you can't breathe. That is usually how people die.

So if you know that this thing is sort of marching inside of you and moving forward, it is pretty easy to guess when you are going to reach something that you don't think you can manage. These are some more of the drivers and there are things that the best quality of care can dampen down. But the exchange is, as in the case of the woman from Schwinn, your ability to interact and fully be the person that you are.

So it is an interesting example of when one needs to assert one's timing in terms of one's presence as a whole being, is really what is at stake. Not that your pain is intolerable because it is true. Almost all pain can be managed but often if that is truly the case for someone who is in extreme pain; it is at the price of human disguise.

Dr. Thomas:

I want to ask our panel is this primarily a problem for middle-class white people? Are minorities interested in getting assisted death? I am surprised there isn't a popular uprising about the right to health care rather than the right to have health care help you die. I am confused about this. Can you enlighten me?

Elaine:

Well, 98% of the people in Oregon who have used the law are white. So, again, I'm not sure about the middle-class part. It seems that people are for the most part insured. But that includes Medicaid, Medicare and private insurance. The average age is 70 but the range is 25 to 96. Again, that sort of encompasses the different underlying diseases.

Cancer patients can be younger. A lot of the HIV patients were younger. So I don't know that it is a middle-class thing. You could argue that it is a Libertarian right.

Pat:

And you could draw a parallel to the issue of right to health. Of course, that is one of the things we are struggling with right now as we hopefully face some health reform and it is something that we have danced around here in the United States for many, many years, is health care, access to health care.

Is it a privilege or is it a right? Many other nations have, of course proceeded with it as a right, with health care as a right. We have not. But certainly if we think about rights language and we talk about rights to hasten your death and maintain control as Elaine's talked about. We talk about rights to make decisions about having ventilators, having a ventilator pulled or to cease nutrition and nutritional support.

We talk about it in those rights language which is actually, what was at play in the Supreme Court cases that Terry talked about. If we think about it in rights language surely the right to health care is part and partial. One could argue it should come a good deal before this issue of rights at the end of life.

That is another issue we haven't really grveled with in the United States yet and it is certainly on the horizon.

Greg:

Your question just makes me think of death rates for African American males, like 25 to 40 or 20 to 40. You know it is much more violence. So I think that other communities have other more pressing concerns.

Dr. Thomas:

Susan Toll from Oregon Health Sciences claimed that her retrospective view of the Oregon experience is that the very presence of this law allowing patients to ask for a script that will enable them to end their life has speared or goaded their efforts to provide better palliative care and better hospice care for the citizens of Oregon.

There may be some credible evidence of that because last year Oregon was the highest utilizer of morphine per capita of any state in the Union. It appears that Oregon physicians have gotten serious about providing good quality of care at the end of life, maybe hoping that their patient won't ask them for a script.

I am wondering if you think it is going to have an effect on palliative care here in our state?

Elaine:

You could hope so. But that I think that part of the regional effect of the Oregon law is that it kick started palliative care everywhere. So we already are on that upward trend which is a good thing. But I think you are right. There is still room for improvement and I think that the issue that Pat raised earlier about access...The hospitals and hospital systems that are opting out are not uniformly distributed across the state.

So, for example, in Spokane, two of three major hospitals have opted out. Much of the central part of the state has opted out. So there are places where the access questions are kind of a double whammy because already you have to drive long distances in the rural parts of the state to get to medical centers. When you get there, those medical centers are opting out.

So much like the politics of this state, the east and the west are not looking exactly the same. I think we are going to see that. Now the counterpart is that there lots of advocates in the eastern part of the state who are working very hard to make sure that other palliative options are in place.

So I think when you have the opposition to this law it does have a positive effect in terms of making sure that alternatives are put out there and available. So I think we'll see some of that now.

Alice :

I think historically as we look back in time, really dating back to the Washington v Glucksberg and the Harcleorade cases, they really did kick start the idea of palliative care.

Indeed, some of the leading litigants, people who've fostered the litigation, not even Kathryn Tucker actually was working on a parallel track to also bring suites for adequate pain management. So these things walk together so to speak.

I think as we look back, for example, the big Supreme Court opinion in Washington v Glucksberg, it had-was it seven concurrences or was it nine?

[overtalk]

Dr. Thomas:

I don't know...

Alice:

It was...despite the fact that it was a unanimous ruling, it was an extremely splintered opinion. Many of the concurrences talked about the need for states to also focus on palliative care options. And to engage in laboratory activities at the end of life including...what they are talking about is the idea of states being a laboratory for law and new legal innovations where you might have laws that foster better access to pain management care as well as looking at how you might have a legal right to hasten your own death that is not tied, per se, to a constitutional right.

The opinions in the Supreme Court case really talked about states really taking the lead, and finding things and ways to deal with the end of life that were consistent with their own cultural context. We saw a lot of that happen over the innovating of 15 years where we have not only laws like Oregon's and Washington's, but also laws in other states that deal with access to palliative care and pain management, and if not laws, certainly policy that has been promoted by the professional societies.

Dr. Thomas:

Alice, you'd mentioned that physicians have the right to opt out of, or a hospital, or an institution has the right to opt out. Imagine I'm a patient in a small town in [indecipherable 39:53] and my primary care physician isn't participating. One even referred me to someone who is and I happened to do some more groundwork.

I finally find someone in the county seat, and they agreed to write me a prescription. Then the pharmacy won't fill it. So I'm wondering if this legislation by 57% of the people advocated for patients to have the right with the concurrence of their physician. Does the pharmacist have the right to abrogate that whole process? Is this a conscience right we ought to be supporting? What do you think?

Terry:

Well, it smacks of another conscience right for pharmacists that's being litigated right now about the right to not dispense Plan B, the morning after pill. Here I think it's different because there is an absolute statement in the statute that they can opt out, the physician can opt out. But I think these are going on parallel tracks that will inform each other.

The other difference is with Plan B you need it that morning, you know, the next day. Here you have some time. So one could argue that there is a burden, but the burden is not...I mean there's not much of a difference between this week and next week.

Alice:

The other thing that I think is worth noting is that in the case of the pharmacist issue, and as Terry mentioned, we're seeing growing number of pharmacists who are exercising the so called conscience clause idea in a variety of different treatment modalities. I'm an old fashioned doc, I think that's kind of crazy because it doesn't seem to be like they're a provider caring for a patient in the same way that a doctor cares for a patient.

I think the conscience clause idea has more legs. That said, pharmacists are also, in many ways, beleaguered business people. You can use mail-order pharmacy and get these drugs that way and have them delivered to your door.

Pat:

Not with these drugs.

Alice:

With these particular drugs, they're controlled substances.

Pat:

No, it's not even controlled substances, it's this law. So you actually have to pick these up in person. There has to be a physical copy of the prescription, so it can't be a phone-in.

Alice:

That's correct.

Pat:

It has to be a fax, a mail, or a walk-in to the actual pharmacy. And then one of three people can pick it up. It can be the patient, it can be a designated family member, or it can be the physician. What might happen, and this will be very interesting parallels to see about how some of the little abortion docs in parts of the country, physicians can stockpile these meds.

So you don't have to be a pharmacist to dispense them. It may be that we will find pockets of advocates around the state. We haven't heard about this, but a possible alternative, if it really

becomes dire and people are finding that they are the lone provider, they are allowed by law to have these medications as part of their practice. It may be that that's some of the practice that starts and so then you have to start to wonder what's this guerilla movement going on, if that's what it takes.

But your right, these do present some very interesting barriers if people are having to drive miles and miles and miles and miles to A: get the consult and remember this is a process that requires multiple physicians. So you have a primary physician that does a complete evaluation to assess competency, the rationale, and that all the other options have been pursued. The patient goes through that level of assessment, and then they have to do it again with a second opinion consulting physician, essentially repeat the whole process with another person.

It's an interesting paradox because you don't really want to wait until the last two weeks of your life to start this. So you, once again, get into this interesting dynamic. In an ideal situation, the way some people are saying, look, what if people get all these scripts? Because the other pattern in Oregon has been that there have been consistently about a third more scripts written than filled.

So you have a second paradox of if everybody fills these prescriptions and then they don't use them, then you've got a lot of Secanol lying around in someone's houses. And what are you going to do with it? You have to waste it somehow. That's not good for the fish if you're flushing it, and it's not good for the kids if you've got it left in the medicine cabinet. You don't want that many Secanols sitting around.

So in an ideal scenario the physicians are showing up with the medications on the day the person dies. So you fill it that morning or the night before, and you show up with the meds. Well if there's no way to do that, then you're sort of contributing this other layer.

There's an interesting set of stories that we heard in Oregon when the wall law kept coming in and going out. One of the people that we interviewed in our study said that as soon as they gave any house script, they immediately filled it even if it might go stale because they might not use it for a long time, if ever. But they didn't know if the law was still going to be in effect by the time they wanted to use their medication. So there's some other interesting paradoxes when we have these other pressures that try to shut the process down. There's a different level that pops up and creates different dilemmas for us.

Dr. Thomas:

I'm wondering if we've created a new moral duty for physicians in the passing of this bill. Do you think physicians have an ethical duty to be present with their patient when the patient has

carefully covenanted with them to support them in assisted dying? Or does assistance simply mean I write a script? Do you think the doctor should be there when the patient uses it?

Terry:

I'm going to have to say, each physician... You know, your physician has a different relationship with every patient. There are some...I mean, there used to be OB practices where your OB would deliver your baby no matter when you...you know, they would be called and they would go in. You know? Over time too many patients and not enough resources and, sorry, we had a really nice relationship but my partner will just have to deliver your baby.

So...I think physicians, health care workers, need to understand what it is that pulls them toward a particular patient. Is it that they are pulled to that patient because they see something like them in themselves, in which case they want to help that person? In the same way, working in hospitals for many years, you would have to work with staff when they hated a patient. It's like, I don't want to go in that room. It's like, well, you need to get over there, you need to treat the patient.

So if there was a strong relationship between the doctor and the patient, and they had decided that, that seems like a great idea. But just because the doctor feels at a perfunctory level that he or she has to be there, I don't think that's value added.

Alice:

And the laws really decide for the patient to self administer the drugs. In some ways the doctors are let off the hook from being the person who's administering the drugs. One could also argue that that's also a barrier in the sense that many patients may not be capable of self administering at this particular...They can't use the law.

So if you're a Lou Gehrig's patient and you don't have the capacity to lift the drug to your mouth, well then you're kind of out of luck. You can't exercise your ability to use this law because you don't fit the criteria for a patient who is able to self administer.

Terry:

Or you have to do it, as Selene said, you have to do it earlier in the disease process because you want to cover... Because you're a person who likes to be in control and you want to cover your bases.

Pat:

There's another piece to your question, Tom, and that is that in Oregon the number of patients per physician is one. So this is not something that as a clinician you're going to do all the time. There's a couple of docs who've done five, who've participated in five. By and large, this is a unique relationship with a patient. People have different senses of obligation with respect to that.

The study that Linda Ganzini did with physicians about how it was for them in regards to what kind of experience it was. They said it challenged them in ways they didn't know they could be challenged. One being, made them look at how very much they are control freaks. And how much they don't like turning things over to patients, but some responded that this was the ultimate act of patient centered medicine. They recognized that it wasn't about them and they had to give that over to be present with.

Many were challenged, but almost all reported that it was an amazing growth experience, which was understanding the depth of what a human connection can mean.

But not everyone is present because there are some ways in which that final act is just too hard to witness.

Dr. Thomas

Physicians in the state of Washington are finding the new challenge to think through their own ethical perspective on this issue. In the past, if the decision was approached by the patient wanting assistance in dying, as one physician said to me: "I can only say, well, frankly, I can't do it."

I really didn't have to think through my own ethical standards. I think one of the by-products of this law is that physicians within are state are taking a fresh look at the notion that suffering, and the notion of existential suffering and at their own ethical framework for deciding about what to do if they are approached by subjugation.

I'd like to turn now to our audience, and invite your questions if you'd like to direct them to the panel as you've been thinking about this.

Man 1:

I have a question.

Dr. Thomas

Yes?

Man 1:

[inaudible 50:45] self-administered because there's already one in the [inaudible 50:46] County bulletin that suggested that self administered doesn't necessarily mean you have to take it yourself. Or maybe a better way of putting it, [inaudible 50:59] or the self ingesting part is self administered. I was curious about that because this article sort of suggested that this law would be a way to kill somebody because it would also require witnesses when you take the pill. If you could comment on that...

Dr. Thomas

Let me just repeat that question. The law says, you must be self administered, and if you put it in grandpa's scrambled eggs, he's going to eat the eggs, but is that a conspiracy? How do you address that?

Elaine:

It's an interesting case because the law does not require the person who is going to take them to prepare medications. So what we're talking about is Secanol. It's a pile of powder that's about that big. And somebody else, because they're little capsules, is allowed to open them. It's typically mixed in with something like pudding or yogurt or something slippery that's going to go down fast. But there is about a two minute window to get this into your body because it's a fast acting barbiturate and the whole point of it is that people are asleep within about five minutes. So if you don't get it down fast, you're going to get a sub-lethal dose, essentially. So eggs probably would be the right choice.

[laughter]

Man 1:

Ensure.

Elaine:

Ensure? Could work. It's also really nasty. It's incredibly bitter stuff, so it's a bit of a chore to get down. But you are absolutely right that there certainly is a loophole in the law that there is no requirement for anyone to assure to this. You have to be competent to get the prescription, but there's nobody present on the date of this, to make sure that the competency is still there. You have to be competent of both mind and body. So you have to be able to essentially give consent again that you know what you're doing which is partly the reason why some are advocating that

physicians or some other person be present on that day to do that double check. But it's not a part of the law.

But then you also do have to be confident of body. Now there are some people that are saying for the Lou Gehrig's folks, that you can get some kind of thing rigged up. It's just kind of like that and all you have to do is something or other to sort of set the mush in motion. But there is this notion of voluntariness. So it's some very interesting gray zones about can somebody spoon feed somebody? If they can't lift a spoon to their mouths, but they give consent that that is what they want to do. But you're absolutely right, who's watching that? It is not part of the law.

Terry:

However, the flip side is that there's still the criminal code. I mean, there's still manslaughter and there's still murder. So you have a criminal check on one side. But that kind of self administering machine is what brought down Dr. Kevorkian.

Alice:

Didn't, because he quit it every time, until...

Terry:

Well, up until the last one.

Alice:

Right. But he didn't - but they couldn't self administer.

Pat:

I think the law has attempted to try to put as many safeguards as possible in so that essentially it ensures the voluntariness of the actual patient carrying out their own wishes. But you're correct in the sense that these tablets will be...they're likely mixed into something else, and probably the patient isn't the one who did the mixing at that particular point an time. The question is, how do you ensure that it truly is self administered?

I think the key here is the ongoing study of this process and the issue that Helene talked about which is that typically these folks are planners. They are folks who, a small tiny percentage of the potential patient population who actually carefully plan how they're going to access this death of dignity idea.

That of course makes it a little bit...it somewhat diffuses the idea that they could be hoodwinked into getting two doctor's opinions, two witnesses, two written requests, an oral request, a mental health consultation, all of the sorts of hoops that you have to jump through. The idea that that could be sort of fostered by, say, a greedy family member, it seems highly unlikely. There's lots of those sorts of hoops you have to jump through make that less and less likely.

Man 1:

And if there's more that needs to be done, they'll be coming to the legislator.

Dr. Thomas

Let's have another question, yes down here.

Woman 1:

Along the same lines as your question, for those competent terminally ill patients who do not have a swallow reflex and have a feeding tube. Are they allowed, or someone in their family allowed to voluntarily mix it into the solution that goes into the feeding tube is my question.

Elaine:

I think it's sort of an untested question. In theory, the answer would be yes. What's important is that it's self administration and ingestion. So what they mean by that goes in feeding tube would probably be OK. Where it gets a little murky is what if somebody's got a central line and that's the only thing that they've got going in.

We did hear in my study where we had talked to folks that somebody had essentially put together a whole series of syringes where they had been trying to inject the stuff into their line. It turned out to be quite cumbersome because they had to do one with the 2nd opposites, it's a powdered form that they mixed with saline, so it's not really the injectable sort followed by heparin and followed by another one and followed by another one and basically, they said, pretty cumbersome to work it out.

In theory with the feeding tube, you could pour the slurry in there and it would work. I think there's an interesting point here, and that is to sort of back up and remember who these folks are. Chances are they don't have a feeding tube, because they aren't going to go there.

There's an interesting paradox here essentially, Pat alluded to it, by setting the bar high enough that you have to be competent of body and mind. And you're sort of a control freak with a line in the sand about what you're willing to do. You're actually likely to pursue this earlier than you

otherwise might. You're not going to necessarily wait until you are truly at death's door, because you don't want to get there.

Woman 1:

Right, but there are lots of people who are not truly at death's door, and...

Elaine:

And you still have a feeding tube. That is certainly true. There's no specification in the law that you couldn't.

Dr. Thomas:

Another question? Yes.

Woman 2:

Hi, I'm curious about how hospitals that are opting out are interpreting the scope of that opt out. So I'm clear you can't order this from the hospital pharmacy that's probably pretty universal. The nurses can't assess but if the patient has the prescription, he has the medication already or if the doctor comes in with the medication and hasn't gotten it through the hospital or pharmacy. I'm just curious are people just sort of flat out prohibition...how would you actually enforce that.

Do you know? This probably doesn't come up much in Oregon because they are so good at keeping out of the hospital.

Pat:

Well it actually doesn't come up in whole life care anymore in a sense that that most hospice care is not conducted in hospital. And a very small universe of the potential small universe of patients would actually be in hospital when they chose to engage in this process. So I don't...

Alice:

Palliative care actually applies to health systems not just hospitals so it could be outpatient sittings as well but what it essentially means is no part of this business can be conducted on hospital owned property by health system employees.

So you are either in a hospital setting or an outpatient setting which would mean let's say for all evidence they opted out then this discussion is usually happening in an outpatient setting. It's rarely an inpatient. The law says that you can do everything but so that means that in the

outpatient setting you can be assessing the request, you can be asking people why people are interested in this, you could be making referrals to appropriate services of businesses in palliative care but you could not be using any of the health system's property to implement the law.

So you can't be writing prescriptions using that institutions prescription pads, you can't be doing it on the time you are employed by that institution, the pharmacy can't dispense. If you are a physician that has office practice setup and are independent of that health system, you can do that as an independent agent. It cannot be done on hours or property of the health system of which you are employed.

A second piece is that in all of the 401 cases only one has been connected in a hospital. Most hospitals including those who are not opting out, so opting in is sort of a default position, are saying that they don't want to see this happen but not because of the reasons you would think but more because they are constituted as public places and part of the legislation suggests that it does not mandate but it suggests that you not do this in a public place. So hospitals are being constituted that way.

And the final piece is that almost every hospital has policies about how non-hospital based formularies can be administered so they don't allow you to bring in your meds from the outside. So it actually is some interesting policy and logistical questions. Again though I think I can come full circle to say most of these folks don't want to be in the hospital in the first place.

Woman 2:

I was going to say I suppose you can spin a hypothetical where you have a patient at the end of life who by happenstance has been taken to the hospital. They have their prescription at home and they say to their son or daughter or husband, Johnny bring my medicine and they self administer in the hospital. I suppose it could happen in a hospital. The question is whether the hospital would necessarily...

Pat:

It couldn't happen actually. They would prevent that from happening. It would be very surreptitious if it did. It couldn't with the assistance of any of the staff.

Woman 3:

Well when you think about it there's a lot of times I'm alone in the room when the family is there and it's not unreasonable that the family could bring the medicine in and put it into grandpa's pudding at his request and patient could take it all between nurses checks.

Man 2:

[inaudible 1:02:11-1:02:15] aside from feeding tubes, respirators, whatever. Do hospitals opt out follow that course of direction or is it just [inaudible 1:02:35-1:02:40].

Terry:

Well the hospitals have to follow as part of their JACHO accreditation it has to be a substituted decision makers if you're incompetent. In terms of whether this initiative has to have all of these safeguards. That makes me really wonder how many people actually read the whole thing and whether this two parts of it because how many people do you know read the whole initiative when they are signing on to this?

But in terms of hospitals opting out of advance directives...

Pat:

There is a difference between advance directive law and this law. By definition advance directive laws are setting up for circumstances when people lose capacity but decisions still have to be made. The minute you lose capacity you are no longer eligible to use this law.

So the opt out piece at the hospitals I think is different. It's usually on moral grounds rather than on legal grounds.

Elaine:

Your comment does point out the inconsistency there in the sense that in many ways the opportunities for aggressive end of life care in terms of removing nutrition, removing ventilators are more accorded to those who are unconscious in some ways in the sense that terminal care there is a great deal more license in terms of what you can do when the patient is unconscious and one has to ask well we have the Natural Death Act and we have the list of surrogates who are allegedly going to provide substitute a judgment as to what the patient would have wanted if the patient could speak.

But here we have a different level of scrutiny where the patient actually can speak.

Man 2:

But do we trust them?

Woman 4:

Yeah.

Woman 5:

Woman 5:

Hi.

Dr. Thomas

Question over here.

Woman 4:

We have time for one more question.

Woman 5:

Am I correct in assuming that most of the institutions that opt out are Roman Catholic?

Dr. Thomas:

On a religious base?

Woman 5:

The reason I ask is that there are many Roman Catholic hospitals and hospice providers as well and if they opt out where are people going to go to actually use this completely legal procedure?

Pat:

The hospice providers have been dealing with this in Oregon for quite some time and I think the difference is that Hospice providers go to the patient's homes when they are home based Hospice so they don't have jurisdiction over a person's home. And all of the Hospices, including the Catholic ones, take a neutral position because they don't want to set up a scenario where they are abandoning they are patient and not providing care and if it's everything but what the clause says means you can do everything but administer this, or partake in this evaluation.

So if the patient has the medication at home, the Hospice usually wants to know what's going on and what they'll say is call us when she's done. We'll come in after the fact. We might come in before and make sure everything is OK but we will not be present at that moment. We will leave, we will go off site. We will go see somebody else.

So it's kind of an interesting way of silencing and protecting the individuals who are partaking in it.

And there are many people who opt in principle but don't feel comfortable about being present at that moment and it's in part for that reason that there are other organizations like Compassionate Choices that have volunteer case managers who will be willing to be there and who have sort of seen this process and they are trained so they know what to expect.

And a lot of it is just the comfort of having somebody and most people if they do this once it's going to be a rare event. So there's none of the personal histories so these other organizations are in place to sort of bridge that moment when people are trying to do this at the end so they know what they're doing.

Dr. Thomas

We had a very interesting conversation and we're going to turn the program back to Dean Hicks for closing. Thanks for your participation.

[laughs]

Greg:

Just a quick word to thank everyone again for coming out and do let us know about our programs. We're trying to present things to our alumni and that would allow us as a school to reach out and to show you the best that the university and law school has to offer. [inaudible 1:07:56-1:08:09]