

OREGON HEALTH & SCIENCE UNIVERSITY

ORAL HISTORY PROGRAM

a project of OHSU's Historical Collections & Archives

an interview with:

Susan Tolle, M.D.

interview conducted on: February 24, 2017

by: Lesley Hallick, Ph.D.



Narrator: Susan Tolle
Interviewer: Lesley Hallick
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Transcribed by: Teresa Bergen

Lesley Hallick: Hi, how are you, Susan?

Susan Tolle: I am so glad to see you. I think of the many adventures we have had.

Hallick: This is going to be fun. A trip down memory lane.

Tolle: Yes.

Hallick: For the record, my name is Dr. Lesley Hallick, and I'm interviewing Dr. Susan Tolle for the OHSU Oral History Program. It's February 24, 2017, and we're in the studio on the first floor of the BICC building at OHSU.

So, there so many questions that we could ask. But I'd like you to start with a little story of your personal history. And it's a fascinating one. And if I cut you off, I apologize, because there's just so much professional material to cover. But you're a rare breed of long-time Oregonians. So why don't you share a little of that with us?

Tolle: Well, thank you. I do think that fourth generation Oregonians are a bit more scarce here than they once were. I was born at Tillamook General Hospital, where my mother worked as a microbiologist. And my father was a fisheries biologist at the coast.

I was raised around Portland and ultimately went to Lewis and Clark. I found it a great experience, and they also had the very best statistics at the time for the odds of getting into medical school.

Hallick: And my understanding is you graduated in record time. Want to say a little about that?

Tolle: Well, I did have younger siblings following behind me. And if you took more hours at the time, there were no additional charges. So I was able to graduate in just under three years by taking a minimum of twenty-one hours.

Hallick: Every term?

Tolle: Correct.

Hallick: And you applied to medical school, I assume?

Tolle: And I did apply to medical school and was accepted a number of places, but chose OHSU for many reasons. And I certainly rejoice at having been here and been a part of what has changed remarkably over time.

Hallick: You started out saying your parents were both scientists, and you were a natural science major at Lewis and Clark, I believe. What was your process like in thinking about science versus medicine versus, I don't know, creative writing, say...

Tolle: Well, creative writing wouldn't have been a talent, so that was pretty easy. But science just seemed so natural. There seemed to be so many wonderful questions to ask. At the time, women were not particularly encouraged in medicine. Neither in more, distant members of the family did not think it was a good idea. And at the time, the percent women at OHSU was much, much smaller. In fact, there were only four women in the senior class the year I enrolled.

Hallick: Wow. And tell us a little bit about what it was like to be a medical student and one of only four women in your class, and your thinking process in terms of your areas of interest in medicine.

Tolle: Yes. There were four women in the senior class. My class had seventeen. So we were at the beginning of expanding. But we made up a little over 10 percent of the class. For example, in my lab section, at the end of the alphabet, I would have been the only person in the lab section. I did not have a woman attending on any of my clinical rotations. And in internal medicine, of all the residents we had, one was a woman.

Hallick: You ended up in internal medicine. Can you tell us a little bit about how that took place?

Tolle: Well, I didn't seem to find a desire to be focused in a tight area. I liked too many things. I wanted long-term relationships, and that was extremely important to me and still is. And it's certainly a pleasure in general internal medicine and geriatrics here to have patients that I've cared for for decades, and sometimes several generations in their families. So I love that aspect and that called to me.

I also loved the challenge of things being different and your days were always different, both in the Ethics Center and in general internal medicine. I like a challenge. I like things to change. I like to be part of cutting edge. But I love relationships and I really value them, whether it's with colleagues in our more rural communities in Oregon, or whether it's patients or whether it's long-time faculty here.

Hallick: What about the puzzle of diagnosis? Was that a draw as an internist?

Tolle: It's a draw. And it's a draw not as much as being the diagnostician as trying to be the best listener that I can be, and really trying to teach communication skills. And our program in compassionate communication we hope will emphasize that even further. Because as medicine has become much more technological, we have sometimes lost a little bit as we turn our back to the patient and type on the computer. And that whole sense of really listening, deeply listening, creating a space that a patient feels safe and honored when they may have something that they're not the most proud of, that they don't want to talk about or that is hard to admit, whether it's anxiety and fears about things, whether it's a symptom that they're worried what it might mean and find it scary to actually share with you. But that, that called to me more than anything.

Hallick: The art of patient history taking and that sort of—

Tolle: And connectedness and active listening, and a sense that people felt respected and heard such that they would trust you and share. That called to me greatly. I mean, all of us love to make a great diagnosis. But I find so often, if you really enhance your skills at active listening, and people feel safe and can trust you, and do trust you, which helps if it's over time and the relationship has built, your odds of making the diagnosis correctly go up.

Hallick: There's questions that come to mind, but they're probably better for later in terms of how things have changed over time. But let's come back to that. Would you talk a little bit about your residency choice, and how you made it, and a little bit about your residency in San Diego?

Tolle: Yes. I did not know what I wanted to do beyond general internal medicine. At the time, I pursued residency training, I wanted an excellent program and I wanted to keep my options open. But I was thinking that I would return to the northern Oregon coast and be in practice in general internal medicine at that time. And no one from OHSU at that time had gone to San Diego in internal medicine. People seemed primarily to come the other direction. They tend to come from California here, and from across the country here. And most graduates, particularly then, did not go to southern California. That was not a pattern of traffic flow. But it just seemed a truly outstanding program. And at the time, call was every third night. So whenever you weren't on call, you could count on the weather being wonderful, which was an advantage for those opportunities when you could go be like all your fellow interns kind of faced out on the beach sleeping. But it was a really wonderful intellectual environment. And I learned to scuba dive in caves and surf and sail and a few other things in the time when I was not working at the hospital.

Hallick: And you were there for four years?

Tolle: I was there for four years. So I did do a chief residency. I remember the one-page job description we had. Big page and lots of white. And then there's one line in the middle of it, and you were supposed to sign it, and it said, "Your job is exempt from the Fair Practices Act."

Hallick: No guarantee of eighty-hour week in those days.

Tolle: No. And you can and sometimes did work more than hundred at the hospital. But it was a different pace. Patients stayed in the hospital longer. The acuity wasn't as high. We kept people who weren't as sick longer. And we slept a little bit during some of the time we were there. So I wouldn't want to compare and say oh, I worked so much harder than what people work today. The way people work and the acuity level, I think a lot of things have changed. But I did see the inside of the walls of the hospital a lot.

Hallick: And at the end of that time, you made a choice to take your next step. Would you talk about that, how you chose to come back to OHSU?

Tolle: Well, being chief resident offered some opportunities to teach. And I'd never given a lot of thought to that. And it was really fun to do interactive teaching with the other house staff. And to be challenged. Because obviously you learn when you're going to teach, because people can tell if you haven't studied your topic. So I want to take one short break.

Hallick: Okay.

Tolle: We'll take one little pause. [Pause]. Returning to the chief resident, it was such a great experience to begin teaching, to learn about teaching, to find how you would convey ideas, share ideas, what engaged people most. And unexpectedly, Curt Holzgang and Don Girard suggested I come look at Curt Holzgang's position when he was leaving.

Hallick: And he was chief of internal medicine...

Tolle: He had been the primary leader in the outpatient clinic area when I was a student. I had really liked him, admired him. He connects so wonderfully with patients. And they said, "You can always go into practice, but you can't go the other way. So come and take a look at the position." And I had such a great time meeting the group and seeing what some of the teaching opportunities would be. And at the time, we didn't have hospitalists. So we were inpatient, we were outpatient, we were teaching around the state and flying on little airplanes to rural communities. When I say little, I mean five seats. Landing in Baker City. That kind of teaching, which was so fun. And so I just said, "I'll give it a try." And I'm still here.

Hallick: And until that time, you hadn't considered a faculty position, career?

Tolle: Had not considered it. And didn't look anywhere else. It was like, this is a wonderful place to be. It's with wonderful people. And I went with, and you can always go and practice at the coast later, if you want to. And later just never came.

Hallick: It sounds like you had a bit of a fix in your practice of small rural communities, though.

Tolle: I did. I really, well, I was born in Bay City, which is a town of 300, just north of Tillamook. And there is something about rural communities and taking care of your own and caring about your neighbor, but also knowing your neighbor. And maybe knowing a lot about your neighbor and your neighbor's family. But you knew people as people in the context of their lives in a way that is different in an urban area. And bringing that back into practice of really knowing people in the context of their lives has served me well. It really means a lot to me about the programs we have and will continue to develop.

Hallick: Sounds consistent with your passion for relationships as well.

Tolle: Exactly.

Hallick: Why don't you tell us a little bit about how you ended up doing scholarship and research in end of life, or maybe it started in a different place. How did you go from teaching to scholarship and research in your faculty appointment?

Tolle: I had a very abrupt introduction to being an attending here. One month after I joined the faculty, I had my first attending service. It was humbling in a lot of ways. Every single medical student that year that I taught was older than I was. Which was humbling because of my very

straight path through education and the fact that many students take at least four years for college. Anyway, so there was a lot about, you know, trying to look older and be the attending and study very hard at night and work very hard. So it was an intense rotation.

But the very first day, a patient was admitted in the middle of the night. She was in her late twenties. She had right upper quadrant pain. Nobody knew why. And she'd been discharged, seen and released from another hospital in the area. At five in the morning, she was found dead. No one knew why. I hadn't met her yet. You assume the service at midnight.

And so I came in to meet with her husband and the team. And I was concerned about many aspects of how we managed end of life care. Handing him a bag of pink plastic belongings. Being told at the time with legal, we don't know what happened, don't share information. Having the intern leave medicine, she was so worried that she had made a mistake, and permanently left medicine.

Fortunately I had just been a chief resident and could step in and be a house officer at the same time for the month. But there were so many things about it that didn't follow up with the family, the connectedness piece. Didn't adequately support the house staff. There wasn't a wellness program. In the middle of this, it did turn into a ten-day court trial, which we won unanimously once they found that she had a benign tumor in her liver that had bled into it and ruptured, and she had died in minutes. There was nothing that could have been done. And we were found not guilty.

But that's not an easy way to enter academic medicine, and certainly not most people's story. But it led me to be interested in the interface of law and ethics and medicine and end of life. And to feel at the time that almost anything I did would make it better than what happened that day.

Hallick: Sounds like communication with the family was a major component of that.

Tolle: It just felt completely wrong to not speak with them, and to not continue a dialogue. And then to see them in court instead. And so, you know, I have never been, even had an attempt at a suit or subpoena since. But to have that be your very first day attending, it's a rough welcome to OHSU. But it made me think, what are the experiences of other families?

And the first person I did research with was John Benson.

Hallick: Oh, wow.

Tolle: Who had been my attending—

Hallick: I forgot that.

Tolle: —at the VA, on GI, and then had gone on to direct the American Board of Internal Medicine.

Hallick: So this must have been during the '80s.

Tolle: It was.

Hallick: Before the Ethics Center existed. So, could you talk a little bit about your faculty roles here from say, '81, when you arrived, to '89, when you started the Ethics Center? The relationship with Benson is fascinating. You taught in the dental school. Can you talk a little bit about that sort of varied role?

Tolle: Well, I did love teaching. And I loved teaching across the disciplines. And part of the communication that I was always drawn to recognized that we were a bit siloed and that having good communication across the disciplines was helpful. And having time for teaching was something I was drawn to.

So when the dental school had a half time position to teach medicine to the dental students, I took it. And I really enjoyed colleagues there as well. I ended up writing sixty articles about dentistry and ethics with Gary Chiodo. And because there was a real scholarship piece, building that bridge that was rewarding and interesting and, at the time, empty. And we began to explore more and more ethical issues. That just spoke to me in so many ways.

So it was seven years into being on the faculty here, and two babies later, that I competed for a Pew Kaiser Mid-Career Award—I kept saying, I'm not mid—at the University of Chicago. And went back for a year's fellowship in clinical medical ethics.

Hallick: And if I could back you up just a little bit, you mentioned your resource project with Dr. Benson.

Tolle: Absolutely.

Hallick: Which in a way was a sort of forecast of some of the things that came later after this fellowship. Can you talk a little bit about that research project with Dr. Benson?

Tolle: That project is obviously how I got the fellowship, by publishing several scholarly projects about end of life care, it made me competitive for a wonderful opportunity. In working with Dr. Benson, what we did was contact families one year after death and ask them what we did well, and where we could improve. With in-person interviews and obviously had some structured questions, some open-ended questions. And things looked very different then. Patients were in the hospital longer. There were more expected deaths in the hospital on our ward service.

Hallick: No DNRs.

Tolle: We were just beginning to figure that out. And there were far less deaths in intensive care, and there were far less intensive care beds. So things looked very different. We didn't have a helicopter pad. We weren't a Level 1 Trauma Center. Things look very different now as far as the composition of who died in our hospitals.

And the percent of people who died in the hospital all across the country, including here, while we were lower than average then we are now, was much higher than it is now. The sense of dying in home hospice, of planning, of making choices not to pursue treatment, was much less thought out, and much less carefully orchestrated, than it is now.

And so, I learned so much from these families. And we began to do various kinds of surveys. But that was the first major publication was the experience of those families a year after death in University Hospital. And we learned many things about systems and other things that

could be optimized. And we learned that people complained much more often about their loved one received too much care than that their loved one received too little care.

Hallick: Right. Fairly new concept at the time.

Tolle: Fairly new concept at the time. And that was the beginning. And the anguish that they felt. And sometimes the burden they felt if they did choose to stop, feeling that the whole system wasn't well-gearred for that, and they had to fight so hard.

Hallick: They were to blame somehow.

Tolle: And that they sometimes were made to feel like “murderers,” which is a term that they would use about how they felt about themselves in advocating for stopping treatment in a system that wasn't well-gearred to initiate help and support that conversation. And so you really felt as if you were fighting hard to stop treatment, and felt it was all on your shoulders, for some of the families. And understanding that, and understanding that that wasn't improving for many, the length of life, but certainly the quality of life near the end was just one of those—you got this interesting data and it called you to the next study. And it began to lead me to work with national colleagues who had some similar interests. But it was a very small group of people at the time.

But that original study with John Benson helping teach me to write, which has never been a strong suit, was pivotal in changing my career. And I don't think there's a thing I have done to advance in my career that he hasn't written a letter of support. Whether it's every step in promotion, whether it was going to the University of Chicago, whether it was the residency in San Diego. He must have quite a file on every one of the steps in my process. But certainly to call him a mentor and a friend would be ever so appropriate.

Hallick: One of the things I remember in '89 when I started as provost and you were starting the Center, was another conflict that arose. And my question is whether this happened, occurred to you during the Benson interviews or whether it came later, was the conflict that sometimes occurs between staff and these end of life circumstances.

Tolle: Absolutely. And that had already become increasingly obvious. Because the family interviews sometimes identified mixed messages from staff. That a specialist in one organ system might come in and say, “The kidneys are looking a little better today.” And meanwhile, every other organ system is failing. And they're on a ventilator and the settings are going up and the cognitive function is down, and they have a GI bleed now. And they clearly have multi-organ system failure. But the creatinine was 0.1 better today. And so sometimes the messaging was a problem, rather than the actual conflict. But gave families a ray of hope of better outcome than the total picture should have ever given them. And made more of a roller coaster ride of better, worse, better, worse, than could have been shared with them had there been a more comprehensive look at the whole person.

So I was worried about those mixed messages first, besides team conflict. Team conflict sometimes was across disciplines, with nursing feeling that the patient and family may have wanted to quit sooner than the medical team wanted to quit. And feeling not heard. Sometimes talking to family about maybe you want to ask these questions, maybe you want to think about stopping treatment. But not always having forums to have those conversations. There wasn't an

ethics consult service, there wasn't a palliative care team. There wasn't good training in how to have goals of care conversations. Sometimes the conversations were just simply avoided, and basically the nurses were often saying, "This conversation needs to happen. And the family needs to know how bad things are." And they see their joy and hope when one specialist says, "This is slightly better today," knowing everything else and hearing all the other conversations that in the big picture, that's not where things are going. And just wanting much better communication. And that was more common than actual conflict.

Though there were times there were conflicts, and the conflicts could be family, team, or team within team. But we had very little way to work them out. And mostly everything just sort of kept going. Which is what the family interviews said about some of the cases. "We just went on too long. Way too long. Wish we had known how bad this was."

And granted, we don't always know. And there are people who survive that we are truly amazed, against all odds, that they have survived. And there are times when patients look quite poor and in great distress, maybe because they're at the absolute nadir of their chemotherapy. But the bone marrow's going to engraft and their going to get better. And the team actually has different science and facts about the fact that there really still is a chance. And can we all get on the same page so we're actually operating with the same facts? Because good ethics relies on good facts. Or you're just going to go somewhere that makes no sense at all.

Hallick: This sort of takes us back to the work in the dental school. One of the hallmarks of the Ethics Center was the inter-professional approach. And that now is kind of all the vogue, but it was fairly unusual at that point. I'd like to hear more about your fellowship in Chicago as it then impacted what you did next, and whether it played a role in your professional approach.

Tolle: Well, many of us who worked to establish the Ethics Center – Mike Garland, Virginia Tilden, Gary Chiodo, and I were the founding four—representing nursing, dentistry, philosophy and medicine—now look back and say we did interprofessional before interprofessional was cool. And it's true. And at the time, national colleagues would come and consult, and would say, "You will never be able to bridge across silos the way you want to." That the silos are too strong and that people will not get promoted within their departments when they're playing across different units. And that their work will not be respected. Which is why I was always deeply grateful to you and to Peter Kohler, for allowing the Center for Ethics to report to the provost office instead of one of the schools. Because it did allow recognition of work more broadly. And it facilitated the fact that every one of the original leaders was able to advance to full professor doing this work that so many across the country said you could not academically advance.

Hallick: Well I remember those conversations very well. And I will confess to have been quite dubious at the time—

Tolle: Yes.

Hallick: —as to whether that was the best thing for the Center. There's a little bit of a, no one is looking out for you phenomenon that can occur in interdisciplinary programs. You were quite persuasive that you could overcome that.

Tolle: And I had you! You know, for twenty years, we stuck together and tried to make sense out of promotions across units in schools, and joint appointments, and just general advocacy for the right thing that built things like the ethics consult service early on, and really helped advance some of the things that built some bridges. And by working, of course, in the dental school myself, and having an equal time in both camps, it really did help. And you can imagine that people like Virginia Tilden would be a pretty skilled advocate for a nursing voice. And obviously Gary Chiodo for a dentistry perspective. And of course his bringing in public health dentistry and patients and the connectedness of population health that I was trying to figure out before that was also quite such a thing that it has become. And systems change at a population level was also not as robust in those days.

Hallick: Right.

Tolle: So what happened was, before I went to Chicago, when I had been accepted for the year-long fellowship at the University of Chicago with Mark Siegler and Chris Cassel and lots of people that have become leaders in connection with us in various ways, we began to write what would a center look like when I returned? And we began to work together to write both the model and the grant funding that would allow us to open our doors when I returned.

So the expectation of my fellowship year was that there would be ten peer-reviewed publications during the one-year fellowship and two grants.

Hallick: Tall order.

Tolle: And they came every three weeks. Mark Siegler would come and stand over us with a clipboard, and go, “What do you have to add to the Center’s CV?” I’m like, “Mark, you were here three weeks ago.” But he was under a good deal of pressure—this was a brand new program—from Pew and Kaiser to produce. And so he was pushing very hard.

In the end, at the end of the year, I had nine publications and three grants. I shifted one grant. I needed money more than I needed publications at the time. And so we did have funds from the Meyer Memorial Trust to open the Ethics Center’s doors on July 1, 1989, the day I returned from Chicago.

Hallick: And the day I started as provost. So, I remember it well.

Tolle: Yes.

Hallick: So you know, those early years were an interesting challenge of cobbling together resources. Not only to fund the activities of the Center, but to fund your very salary.

Tolle: Correct.

Hallick: Could you talk a little bit about that whole process, and what tensions it might have created, and how you spent your time? And how the Center developed.

Tolle: Well, you told me at the time that I had more lines of salary than any other faculty member at OHSU. A little piece from various different grants, salary from the dental school,

salary from general medicine, little bit of clinical salary. And that was how it was in the beginning, was just a lot of hard work and hustling. Because while OHSU formally endorsed the Center for Ethics and Health Care having the title “Center for Ethics and Health Care,” and granted us an oversized closet for a space, that was about twenty feet by fifteen feet, there was no allocation of funds that was promised. And we were encouraged to continue securing funds through private philanthropy.

And the Meyer Memorial Trust pushed that very hard, because it was match money. It was half a million dollars, but you got fifty thousand every time you raised fifty thousand.

And so I first got here, and to get the first fifty thousand, I had to raise fifty thousand. With saying I have a vision, but without much to show. And that, I would encourage people to set up to get at least a little upfront money so that you could show a few things, and get out of blocks, that was very hard work. Thank goodness for people like Cornie Stevens, who began to chair our fundraising activities with the community, and introduced many of her friends to us. She makes all kinds of jokes that her friends go running when they see her coming, because she had made so many appeals; many of whom still give to this day.

Hallick: You’ve established several endowments that have supported both you as director and many of the individuals who contributed so much to the Center. Those stem back to Cornie’s original support and this army of donor volunteers that have supported you. When I am asked about fundraising, I usually cite you as an example of the tea party lady—

Tolle: Yes.

Hallick: —who can create donors out of social events better than anyone I’ve ever known. Could you talk a little bit about those endowments and their importance to the Center? And then we’ll talk about what has been accomplished by the Center?

Tolle: It is true that we built a network, working closely with Cornie Stevens and a number of other people in the Marquam Hill Society, wanting to see the Center grow, but never having what you might call a major stockholder. There has never been anyone who contributed more than 50 percent of the assets of the Ethics Center. We have seven people who have given over half a million dollars. And we have forty-five who have our Center for Ethics logo pins and have contributed fifty thousand or more.

Hallick: So it’s a quintessential grassroots movement, really.

Tolle: It completely is. And many fundraisers cringe when they hear how we do this. When they hear that the Miles J. Edwards chair had no majority donor and that 322 people contributed to that chair. And that it took five years. It’s not a fundraiser’s dream to do it that way. But you have a lot of community support, and you represent the people. And it’s the connectedness and this broad voice of supporting a range of activities. It’s not that our donors want only this area to be focused on. And that has been helpful as well in having a breadth of issues that people care about.

In the beginning, most of our donors were very focused on improving end of life care. And the majority had had a difficult experience in their families and wanted things to be better for others.

Hallick: You started to touch on the content of these discussions. And I think that's where we want to go next. You don't raise an army of donors like that without a cause that resonates. Could you talk—or causes, as you pointed out. Could you talk a little bit about sort of the epic events – Death with Dignity Act, the origination of the POLST – that helped shape the Center, and why those issues are so important? And maybe along the way, what the major milestones for the Center have been.

Tolle: The Center for Ethics benefited from being in Oregon. Especially if you wanted to focus on end of life care. Oregon Health Decisions helped have Oregon be the second state to have an advanced directive and to really push forward for community meetings and community voice and things like the Oregon Health Plan and the community meetings process and priority lists and this whole broad voice and hearing all voices and creating a place for voices. And working with the legislature about when you draw the line, what does that mean? And how is it different to draw a line about procedures, rather than drawing a line about income and you're out of the lifeboat because your income is 157 dollars a month too high. Rather, your medical conditions, treatment options are so ineffective that they will not be listed.

And that thinking is a very different thinking, and Oregon was the beginning of that. This was an area that so resonated with Mike Garland and with a number of other people who really cared about doing the right thing, the just thing. Focused on the common good. Those kinds of discussions.

Hallick: So the origins of the Oregon Health Plan really helped move this.

Tolle: Helped us reach out into communities. Helped us be a part of a dialogue that moved beyond end of life care to how you make difficult decisions initially at end of life and then more broadly. And to begin to engage in that dialogue. Of course, Oregon got enormous attention during the three-year period of voting, discussion, spotlight on Oregon's Death with Dignity Act. The vote passed in '94 after funding five to one in opposition. That's not what's happening in other states now. There's a lot more funding in the coffers for organizations advocating for Death with Dignity. But at that time, there weren't. And the opposition was very strong. Lots of outside money. But it showcased and educated about what is hospice. Huge articles about what is hospice, what are the alternatives. Because while much of the money did not create tremendous good in you're wrong, she said this, he said that discussion, there were significant investments in educating the public about what is an advanced directive, what are your choices and options, what is hospice. That was a time where, and we're doing more research, and we're better understanding and developing the POLST program, which we began to develop in '91.

Hallick: Tell us what POLST stands for.

Tolle: Physician Orders for Life-Sustaining Treatment. And that is different from an advance directive where you write your philosophy about what you want, and you appoint a surrogate. But a POLST form takes that philosophical document and says, I mean tonight If I am "found down" [and unresponsive] I do or do not want to go to intensive care. I do or do not want to be on a breathing machine. I do or do not want to go back to the hospital. And emergency medical personnel can actually honor it. Because it's medical orders. An advance directive they cannot

honor because it's not medical orders. I have one. I go to a meeting off campus, I hit the bridge abutment and I'm life-flighted in here, please do not look at my advance directive. I want you to do everything. Let's see if I can continue to do this work I value so much. And so, an advance directive is hard. Did you mean now? Did you mean in the future? It's a philosophical statement. But it is not a roadmap for medical personnel until it's turned into orders at the right time.

So we were learning, over and over, in my early days as an attending here, that if you had a very busy call night, you were going to have somebody admitted from a nursing home with advanced dementia and pneumonia. And they were going to get intubated and be in the intensive care unit. And the family was going to come in and go, what on earth are you doing? And we were going to go, well, we had no records. We don't have access to the nursing home notes. The orders can't be followed that the nursing home doctor wrote because they don't have privileges here, and they are not recognized by the EMTs as having authority through their online medical control.

So while that worked while you were in the nursing home, it doesn't work anywhere else. And beginning at a systems level to fix all of those pieces that meant no matter what health system – not all health systems play nice with each other—and recognize someone writing an order who doesn't have admitting privileges at their facility, either a competing facility or a nursing home, and get that to work, meant lots of regulations that had to be written, lots of, you know, step by step taking down the roadblocks so that you could have your wishes honored through portable orders across all setting of care. Which happens now.

Hallick: You're describing an incredibly complicated problem, across a complex set of systems that deliver healthcare. So it's a great example of some of the challenges today in this country. Can you talk about the Center's role in assisting to find solutions and kind of how those solutions work with the POLST now?

Tolle: The Center for Ethics, through private philanthropy, created the POLST program and served as its administrative home, and still does, for the Oregon POLST program. For thirteen years, we were also the administrative home for the national POLST effort. And funded the staff and the operations. And on January 20th, last month, national POLST became its own independent organization, and is spending more time with federal efforts, things about transferring across states, and reciprocity across states, in the way we've just talked about reciprocity across facilities and—

Hallick: Within a state.

Tolle: —within a state. So that has given me the opportunity to actually take on new research projects, because I'm not doing as much fundraising to support the national POLST office as I have for thirteen years.

Hallick: So let's go back thirteen years, or about that, where you identified this problem of people coming into the hospital who probably didn't want to be there. How did the Center, first of all, even explain this complicated problem to a potential donor? And who became interested in helping you kind of overcome those to create a system where people could direct the kinds of care they wanted, or didn't want?

Tolle: Yes. And again, often it was people who had had a bad experience in their family, who had had a loved one on intensive care that would have preferred more of a focus on comfort, and where communication was less than ideal. And often where they didn't really understand the prognosis, and would have made different decisions had they known.

The donors really resonated with the fact that it could be better. And many resonated with stories that we began to tell. Sometimes we would make a movie that told a particular story that helped explain whether it was for the legislature or whether it was for patients and families to have conversations.

One of them is called "POLST: When Advanced Directives are Not Enough." And it is the story of Max, who collapsed because of an aortic valve that was closing. And he had an advance directive. He did not have POLST form. He had a very bad heart disease and had elected not to have the valve fixed. And his wife is there waving the advance directive and trying to get the EMTs to stop doing CPR. And they don't stop because they don't have medical orders. And she talks about how much he would have hated it. They continued to do CPR into a hospital, where it was simply called for failure of effectiveness. And he died. But she felt that this is not how the last chapter should have been. She would have preferred to have been holding his hand. It was in a public place. So there was a lot of sense of indignity that was distressing to the wife as well.

And we were able to take that video and help the Oregon legislature make a decision to fund the Oregon POLST registry.

Hallick: Nice. Do I remember correctly that in one of your videos, or one of the scenarios, your mother was an actor?

Tolle: My mother, my mother is one of the founders in the Center for Ethics, and is a champion. Her greatest contribution to POLST was contributing lots of other people to do interviews and act, by going throughout Mary's Woods and talking to her friends and neighbors about why they would want to be in our movies, or talk to the *New York Times*, or the *Wall Street Journal*, or otherwise be featured. So it's particularly dangerous to live across the hall from my mother, where two different people had major starring roles. One was Sister Frances Wink, who helped make one of our most recent educational videos about faith traditions and the role of POLST and respecting wishes to stop life-sustaining treatment. And another was her beloved friend, Helen Hobbs, who ended up in the largest newspaper in Japan with her picture, with Erik Fromme, and you know, helped also in some of the movies.

But my mother was very courageous in being filmed all afternoon and talking Mary's Woods into letting us block their driveways and other things for a whole half day with firetrucks and ambulances and load her in and out of the ambulance until we had just the right scene. And she reenacted, actually, a medical event that had happened. She had gotten heatstroke working too long in a garden, and had collapsed away from her POLST form. So she reenacted that for the benefit of the POLST program. And was facedown on a lawn that had recently been fertilized. Some people treat their mothers better than I did.

And she goes, "I'll never be able to get up."

I'm like, "See all these EMTs?" They would roll her on a backboard and load her in and out of the ambulance all afternoon.

But she convinced the Mary's Wood leadership to let us film on the grounds and be the first to submit all the POLST forms that people had there by going and asking them if they would

like to be part of the early registry, and getting it up and running. So she was very much a champion throughout the whole process. And came to many of our social events, and would bring a bus from Mary's Woods of three tables to come to our annual luncheons. And she, like so many others, just really cheered us on and encouraged others to participate.

Hallick: It's a real, "it takes a village" kind of story.

Tolle: Yes. And of course, because she worked here in microbiology, pediatric microbiology, OHSU was something she cared so much about anyway. And then to get behind this program, and make friends with so many of the other friends of the Center.

Hallick: What a wonderful story. One of the other aspects of this Center's role, I think, and correct me if I'm wrong, was the sort of advent of palliative care.

Tolle: Yes.

Hallick: And end of life or other aspects of care. Can you talk a little bit about that? My recollection of conversations with you where there was a resistance to give too much pain relief because it lowered, the belief at the time, that it lowered respiration. Can you talk a little bit about the advent of palliative care, and the Center's role in all that?

Tolle: Well certainly Miles Edwards was an incredible advocate for palliative care and ethics at the end of his life. He had been a pulmonary and critical care doctor in an era when way too many people were intubated. And when they didn't give any medication for comfort when they took you off of a ventilator, if there was a decision to stop it. Which leads to a sense of profound distress, a sense of suffocation, and is really quite cruel. But there was such a sense that you might hasten death if you used any narcotics. And you don't have to use very much to dull that sense of shortness of breath and give a sense of wellbeing, even if your oxygen levels aren't real good. And so there was a study. It involved five people and the mythology about the morphine. And it was not well done. And Miles did a study of people where a little bit of morphine was given and proved that they live longer than the apnea tests would have suggested they would live, because they weren't terrified.

For those of us who've ever scuba dived, if you're frightened, you can watch your oxygen gauge go down in a cave. If you calm down, the rate of drop, your total oxygen needs, if you stop struggling, if you chill, if you breathe more slowly, if you're not terrified, if you're not in distress, if you're not gasping and struggling, you will use less oxygen. You will actually live longer.

And he published a piece about this. It was the last thing he wrote. He was so proud of this piece. But he carried such a burden of all of the people for whom he had stopped a ventilator with no sedation at all. And he became such an advocate of creating palliative care here. And he would go and stand outside the door of administration every day, and say, "Remember the palliative care team. We need palliative care here." This was during the most intense times of the debates about Death with Dignity. And the OHSU did fund the palliative care team one week after the vote. And every program in every health system within Portland, within weeks began to move forward with having a palliative care team. There was a real sense, we don't do a good enough job at end of life, and that should not be a reason that people are choosing Death with

Dignity. And some institutions did not want to be known for Death with Dignity. And the Catholic health systems were among the first to begin building robust palliative care teams.

And the Center for Ethics never took a stand for or against, to this day, whether other states should do this, whether it's a good thing or a bad thing. We have said, even to this date, only about a thousand people have utilized Death with Dignity in twenty years. It's about three people in a thousand who die. So we have focused our energy primarily on the other 997 who die, because everybody benefits from knowing your prognosis better, from better communication, from better symptom management.

Hallick: And from palliative care.

Tolle: And from palliative care near the end of your life. And why, you have a hard time getting palliative care if you didn't know your prognosis and if people are completely oriented toward cure. There's a lot of advocacy now for saying can you have palliative care and curative treatment for a serious, potentially life-limiting illness as a concept. But the original Medicare/hospice benefit in '84 clearly said you had to choose. And you wanted hospice and you enroll in hospice and you'd revoke the traditional curative treatments. And that legacy still lives on, to a degree. And the funding mechanisms for doing both are not well-orchestrated.

Hallick: One of the contributions, major contributions of the Center, I believe, has been taking the kinds of things you've just described and bringing them into the medical school curriculum.

Tolle: Absolutely.

Hallick: Can you talk a little bit about the educational aspects of the Center as it relates to the things you've been discussing?

Tolle: Well, education is incredibly important. And we have wanted it essentially everywhere that has to do with healthcare. We have wanted it in rural communities and partnering with those rural communities and people in practice. We put more effort early on to practicing professionals. Because if you go and you teach medical students, nursing students, dental students, pharmacy students, and those that they admire do not think it is valuable, it's probably not the best investment of your time and energy until you fix some of that infrastructure. So we did it in that direction. So transforming the medical curriculum was not the first part of our agenda. Strategically, our agenda was changing the culture at OHSU as a whole, changing the systems, changing systems and culture statewide, reaching out to partners all over the state. Our medical students do rural health rotations when we have partnered with those professionals about POLST, about advance care planning, about goals of care conversations, about transfers across settings of care. That helps students have a better experience there as well.

Hallick: So before you talk about the students, then, it sounds like I should have asked how you describe the incredible network of conferences and continuing education that you orchestrated over the last decades in these various settings.

Tolle: That is true that it's first. That we really started transforming practicing professionals' practices before we ever went to student and education as a major focus. And we began with the

first endowment the Center for Ethics had, in 1989, which was our statewide Kinsman Ethics Conferences that we continue to this day. We move them around the state. The next one will be in April, and it will be in Salem. But we move to Medford, to Bend, to Eugene, to Portland, sometimes Vancouver. And have rotated the conference site, encouraging ethics committee leaders at smaller hospitals and in other settings to be coming together and bringing a keynote speaker. But mostly sharing with one another how we can advance systems and change.

And that's really the group that helped us figure out why POLST was needed and what it would take to make it work. And how while I described a patient with advanced dementia and pneumonia, which is the usual cause of death for advanced dementia, being intubated, who never would have wanted that, it was happening in every hospital. It was not unique to us. And that's what we learned at the conferences in the early '90s was, this was everyone's experience, and no one had a solution. And if we were going to have a solution, we would not be able to look outside Oregon for it. We would need to build it. Because it did not exist.

Hallick: So can you give a couple of examples of the topics? I know they've evolved from year to year, of these Kinsman Conferences that brought out these discussions?

Tolle: Well, we gradually changed the statewide conferences to be other than end of life care. Because we were going around doing regional conferences, multiple places per year that were more focused on end of life. And we wanted the Ethics Center not to be purely end of life. Mike Garland once said, "End of life care is the cat that ate the Ethics Center." And he, of course, wanted us to do many more things related to social justice—

Hallick: Equity, yeah.

Tolle: —resource allocation, a lot of other areas. And kept seeing this focus get so large. So we gradually changed our ethics statewide conference to be other than end of life bringing everyone together. And then had more palliative care, communication skills, end of life, ethics-related regional conferences that have continued to this day.

Hallick: Because the need is there, obviously, to have those discussions.

Tolle: Yes. And things keep changing. We have new tools. We have new ways. We need to teach people how to use the electronic registry, go right to the patient header and it says, "E-POLST yes or no." And in looking right at that, you instantly can see what the patient's orders are. And OHSU is in the process of innovation and within the next month we're going to be able, while I'm in my own patient's record and it says "e-POLST no," it will convert to "e-POLST yes" and read the entire statewide POLST registry and feed it back to me, so I will see a form completed at Legacy two weeks ago. And we're partnering, for example, the next conference I'm doing is in mid-March, is with Sam Health to develop this system for their five hospitals and their ninety clinics. And so we go and say here's a system change that works. We want to help you do it, too, and we'll give you the educational tools, we'll give you data that show why it makes a difference. So that's been fun to do.

And we go to Enterprise, and we go to Burns, and we go to Tillamook. And the next one that's a regional conference will be in Florence this summer.

Hallick: So I'm dying to ask you about the differences between an urban environment and a small one. But I'm going to hold back, because I'd first like to ask you to compare Oregon with the rest of the country in terms of this sort of thing. Where are we nationally in implementing things like POLST?

Tolle: Well, we have led all of the major innovations. It was developed in Oregon. And the Oregon POLST website gives a history that says how every step of the development took place, who was involved, what different problems got solved at different times, what years we allowed advanced practice nurses to sign. And then a study that shows how incredibly beneficial that has been by a medical student here as her capstone project. And a couple of weeks ago, national POLST has endorsed advanced practice nurses signing in all states.

And so all of that has evolved, obviously, starting here. We have some advantages as a state. We had more of a community meetings process and a lot of work with the Oregon Health Plan and some other things that had voices in education. We had a public that was more sophisticated. And we have always been on the lower end of death in hospital and the higher end of hospice use than other states.

But we have gotten far better. And it's such a remarkable thing in the last few months to look at national fee for service Medicare data and look at the entire country as a 20 percent sample. And look at Oregon and look at Washington, a comparable state that has a skilled POLST program, has demographics that are a bit like us in a number of ways, and yet see how far behind they are. How much less often people die at home, which most people say they want. How much less often in hospice. How much more often are in the intensive care unit in the final thirty days of life. And even if you get admitted in Oregon in the last thirty days, how much more likely you are to still go back home.

All of that takes the entire history and puts it together in an entire package that says it's much more than just the POLST form. It is all of the regulatory change, systems change, education change, public education, educational materials, outreach, that you do over and over again – and media – that makes such a difference in empowering the public, educating healthcare professionals and now increasingly also educating the next generation, which we are actively doing, but did not do in the earliest years. We spent much more time educating people in practice and working on the systems problems.

Hallick: So to try and understand where the national scene is right now and what's left to be done, what percent of states have a POLST-like process? How effective are they? Can you give us a sense of the national?

Tolle: Yes. Everything started here. And in 2004, we began to convene, "we" the Center for Ethics, convene six states that were getting started copying us in the POLST program. After the first publication we put out that followed eight nursing homes with POLST and comfort measures only, and measured at a year how many of those people ended up dying in the hospital. It was 5 percent. No one had seen anything like it. And while we can't prove cause and effect, we can prove a very strong association with a remarkably low rate of death in people who said specifically, "I do not wish to return to the hospital." And thus death in the hospital was unwanted. Terminal hospitalization may have been necessary, because their comfort may not have been able to be managed, or they wouldn't stop seizing. I'm not saying you can be certain that and you will never die in the hospital. About five percent of the time, I don't have the skills

to keep you at home. Things took a turn that we just can't manage. But the goal is to avoid that "terminal admission" as it's referred to in the hospital, meaning you don't leave alive. And we had shown an association between the POLST and where people died to a degree that other states began to pick it up.

So we started meeting regularly with this group of six, and monthly exchanging information, working together. And getting lots of calls from other states that wanted to help. So that was the beginning of the national POLST Paradigm Task Force, which we chaired for thirteen years and administratively supported here in Oregon.

And Oregon continued to just keep innovating, keep adding something new. We still are. And keep doing research, and asking where do we need to have an educational program? What tool does somebody need on their computer, in a rural community, as the hospice nurse goes out to enroll a patient and family? And there's a four and half minute video in English and Spanish that's called, "Understanding POLST." And you watch that with your family, and it's at a fifth grade language, and it meets the needs of people who are sick and maybe scared and struggling to process things. They may be frail and their hearing may be down a bit, and their vision may be down a bit. And it goes at a pace and it's geared to the fact this is heavy content, but it's got the visuals. It shows you what a permanent feeding tube looks like. It gives you a sense visually of what you're signing up for or not signing up for. And it helps improve the language used by the healthcare professional who is trying to do the education about this.

So these tools, getting them now into a system so that maybe the social worker watched with the patient and family before they had a further conversation with the physician in primary care who's so busy.

In one of our rural communities, finding ways to save time, get information where it's needed, improve efficiency. And the next movie that we're making, the filming starts on fourth of next month.

Hallick: So the continued innovation and development of new and better tools to help people implement is your focus still at the Center.

Tolle: Absolutely.

Hallick: So how many states have some version, maybe an early one?

Tolle: Forty-seven states have POLST in development or are actually implementing. Twenty-one of those are endorsed, which means they've solved their legal problems, they have a form that fits the model, they are part of a bigger coalition, sharing information. They may not have very much money, and their state may look like Swiss cheese, with the whole northern region that doesn't have anybody using it yet. There isn't a reason that it's blocked, though. There is not a legal problem. There is just that they haven't been able to get the education and rollout out to that region.

Now in Oregon, we are the most penetrated. Every single hospital uses it for some of their residents and knows what to do with it when they see one. Every single long-term care facility uses it for some of their residents. We know because they order the forms. And we know because they submit to the registry. Every single hospice program uses it for some of their patients, often most. And most are appropriate.

And our biggest challenge now has been to convince people a little is good, a lot may not be better. And that many people are too healthy to have a POLST form. And that every single person who goes into rehab after a knee replacement does not need a POLST form for the two weeks that they're there. And so we're working with the hospital association – actually, I did a talk this week – to try to change the transfer orders so you have code status, which they need – do you want to be resuscitated – yes, that's fine. But you may not need the longer conversation. That may be the wrong time, wrong setting, wrong person to have it with. It isn't your longstanding primary care doctor. And you're just plain too healthy.

But one of the prices of our success is that you can find the POLST document now years later. So you created it for this two-week stay, but it lives on in the registry.

Hallick: So it may not be appropriately answered for—

Tolle: And the depth and thoughtful conversation looks like it happened, and may dissuade conversations from happening that should be happening with a change in health. And we have learned that if you mark “full treatment” on a POLST, you are more likely to die in the hospital than if you have no POLST at all. So we want to be careful where we put them and what we do with them.

So Oregon has—

Hallick: Is there a system to update them?

Tolle: There is a system to update them, but it shouldn't be based on time. It should be based on health status. Because we can have done a review and someone can have a big stroke the next week. And it needs review now, not on a three-month regular—

Hallick: Right.

Tolle: And trying to incorporate that into primary care just as you might have alerts to review for it's time for your mammogram, it's time for your bone density, you haven't had a shingles shot. Can we trigger reviews that perhaps pull out people who have gotten sicker? You've had three admissions to the hospital. Are we doing a review? Those kind of things, technologically we can do now, and would be a next leadership opportunity for the Center for Ethics.

Hallick: You mentioned that now there's a national nonprofit that's been created to take over some of the federal and national implementation. Are you still working with that group to help facilitate what sounds like very different levels of development in different states?

Tolle: Yes. First of all, of course, our materials go everywhere, and our movies are widely used and widely watched. So that continues. And we just export. But I chair the National POLST Research Committee, and help with the cutting edge of research across the country.

Hallick: And so let's come back to the education question, now that we've had a little bit more context with the providers. Could you describe a little bit what kind of education you consider best practices? And cut across several professions, so you can see how that plays out in different healthcare provider educational sectors?

Tolle: Well the first thing is, our conferences around the state almost never have a majority discipline. So when we're in Tillamook, we would have nurses, social workers, physicians, chaplains, physical therapists, a few administrators. We would have people from long-term care. We would have people from acute care. We would have outpatient, we would have inpatient. And so it helps that community solve some of its communication and systems problems, because you literally bring people together who may not see each other much. And then we also tend to provide them data from their exact region. Here is how often you all are submitting to the registry. Here's how often patients in your area are dying in the ICU and compare it to other hospitals of similar size. And they find that very interesting and engaging.

And if you show fifteen pieces of data, you usually have one where there's some improvement that could be made. And so they often gear up. And afterwards, it's not unusual to have a group that keep working on a problem. Many of them do not know how to use some of the educational tools that would save them so much time. And designing ways to get it plugged into their systems behind their closed circuit TVs, whatever works for them as an educational time saver to reach out farther to patients and families, is obviously incredibly well-received.

Hallick: So with that as backdrop, talk about while they're still in school.

Tolle: So once we have really geared up, though education never ends. These things require boosters. Technology changes. When we wrote the first POLST form, there was no such thing as CPAP/BYPAP. There were not ventricular assist devices. There are some things you have to incorporate. And forms need to change, so education needs to change.

So you still have ongoing educational needs. I didn't want to say we would switch from community to student education. But we have added a lot more. We for a year have been teaching a course called Living With a Life-Threatening Illness. The students usually rate it as the most impactful course in medical school. They meet in their first year for ten sessions. And they go six times to the home of a person they call their patient-teacher. Someone who has Lou Gehrig's. Someone with advanced cancer. A few of the patient-teachers die during the course of the class. They become very attached. But they see the world so differently. They go into the home and they see that only a crank hospital bed has been ordered, and the wife has carpal tunnel. And they see why things may not work well for a patient and family. Sometimes they go to a physician visit with the patients. And they have been talking with the patient about what they're most afraid of. And they watch them not say it at the visit. And they just see the world so differently forever once they've had this. First they get so connected to the patient and family. They have to write a goodbye letter. Because while they would like not to say goodbye, they get busy with the rest of their lives and they may not follow-up. And if they've told the patient and family they will, that's not good. And we're not supervising them anymore, and that's not good.

Hallick: So that's like their final?

Tolle: That is the only required writing project is this goodbye letter. And they hate it.

Hallick: I'm sure. It must be very painful.

Tolle: They find every excuse in the world not to do it. But they're going to change rotations. They're going to be at the VA one time and somewhere else. They're going to say goodbye to people they come to know. And I tell you, they find every way to make it, "Goodbye, except..." But it's a very powerful experience for them.

Many of the patients' families read those at the memorial service.

Hallick: Oh, wow.

Tolle: They're very powerful. Because there's a sense, even though my family member couldn't leave home anymore, they were changing the direction of education of someone in the next generation. Their life mattered. What they were doing mattered. The students often say, "The patient has hardly any energy and I'm taking what little they have this afternoon." And they have to understand this is called dignity therapy. When people know that they are making a contribution to the planet, making it a better place, and knowing that you are truly impacting the listening skills of a medical student early in their career and through their whole career. It's pretty powerful stuff. Pretty powerful stuff.

Hallick: I'm going to ask you to think about the next generation of Ethics Center leadership.

Tolle: Absolutely.

Hallick: What are the things they'll have to confront?

Tolle: Well, and we're very much at this stage of looking deeply. We've written a new strategic plan. We're actively recruiting. We have never had one of our endowed chairs leave before. So everyone is the inaugural. I am the Cornelia Hayes Stevens Endowed Chair. Lynn Jansen is the Madeline Brill Nelson Chair in Ethics Education. David Barnard is the Miles J. Edwards Chair in Professionalism and Comfort Care, but Dr. Barnard is retiring. So we are starting a recruitment for someone who will not be the inaugural chair. And thinking very actively about succession planning for that while we're actively raising our fourth endowed chair, which is for the Program in Compassionate Communication, which will be about communication beyond end of life. The end of life piece will remain with the Edwards Chair. But lots of other things happen. Disclosure of medical errors, all the things that happened in that first case we talked about. So many things that need trust and caring and how do you integrate the computer and the moment when somebody's talking about feeling suicidal and you put the computer to the side and you really listen and you connect. And how do we bring a world of technology and the connectedness that we envision a long-standing primary care relationship to have, and the best of both.

So it's very exciting to be building that. We are 800,000 toward the three and a half million we need. But you're on your way. And the first half is always harder than the second half. And planning what will that person do, and how will all of this synergize. And partnering much more with what I hope will be robust on this campus of a program in end of life research where lots of different units partner with each other. Look at big data. Look at systems change. There's a public health piece. There's a piece under emergency medicine and John McConnell's group. There are a lot of different ways to have us synergize and become even bigger leaders at the level we are now capable of in end of life care and make that even more than it has been.

And so I just see some amazing opportunities for growth and for obviously the next generation that replaced the inaugural endowed chairs. And how do we have an environment that is strong and lives on? And the Center for Ethics still is 97 percent funded by private philanthropy and a small contribution from the School of Medicine for the substantial teaching we now do in the School of Medicine.

Our next big dream for the School of Medicine, and we've been given permission to pilot test, is to create an assessment of mastery in communication skills as a graduation requirement through the simulation lab.

Hallick: In general communication skills or specifically on—

Tolle: The communication skills will relate to ethics and professionalism. So that would be the topic, thematic area. An example would be something like disclosing a medical error. How honest are you? How trustworthy are you? How defensive are you? How full of disclosure do you have? How often do you blame the nurse? How much jargon do you use? So we care about the bigger context of your ability to communicate. The theme area we would be testing is professionalism and ethics.

Hallick: So in the past, students learned that by just example, if they learned it. Right? So now it's being articulated in terms of what the competency really includes? Is that—

Tolle: Exactly. And there will be a minimum. And there will be remediation and assistance if this is not a competency you can meet. It will be incredibly well-standardized. Because we need it, it shouldn't matter that you're in introvert or an extravert. You should be able to pass this. But there are certain things about listening skills and communication skills and respect that we should be able—because all that's going to be videotaped – to show that you did not meet that expectation. And then it may lead to bumping up some educational interventions earlier on, if there are areas where people are struggling. And we have permission to pilot test in 2017, and make it a graduation requirement in 2018. Which is just an exciting time.

And of course, it will raise the stock of communication skills knowing it's a graduation requirement. If a student is struggling early on, there will be much less tendency to just pass them along only to have them not pass in their fourth year. And much more of a sense of remediation.

We have helped ourselves greatly by the way we accept medical students now. Because we do test communication skills as part of the MMI. And there are seven stations, and they have little quick vignettes that they do. And if they really flounder in communication skills, they aren't going to get accepted because we have such a large pool.

But I do want to emphasize that we are also teaching in the School of Dentistry. We still have five case-based sessions for the seniors every year where we teach with a dental faculty member and someone from the Ethics Center. We are newly doing some case-based presentations in April with the School of Pharmacy. We have always partnered and shared with the School of Nursing. But our most robust teaching is still in the School of Medicine. And of course they contribute a small contribution to paying for teaching time, which the other schools do not do.

Hallick: This is sort of offline, but we have a dozen health professions at Pacific [University]. They're all midlevel providers. The core theme for all of them, virtually, is social equity and delivery of inter-professional care to the underserved. So I'm curious, because the approach that you would have to take for some of these issues is quite different if you're in a vineyard with undocumented workers, for example—

Tolle: Exactly.

Hallick: —than it might be in a health system. Do you extend the kinds of things that you're doing to other cultures—

Tolle: Yep.

Hallick: —to other environments where the amount of healthcare available is very different, and provided by different sorts of people?

Tolle: That brings up our next movie. Movie number twelve will be with a family whose first language is Spanish. And the script is being written by a group out of Hood River. Their programs are called Clear Language. The script will be fifth grade language, culturally adjusted to narrate over the story of this family. And it will be how do you think about having a surrogate? How do you complete an advanced directive? When do you complete a POLST and how does it benefit your family? And how do you say yes to some things and no to others? And actually have an ability to do that. Saying the word “cancer” out loud, which is culturally sensitive. And actually saying no to authority is also culturally sensitive.

Now I do not have these skills. So we are hiring by contract a team of four that does include a community health worker in Hood River. So we're all the way to that, and we're deeply grateful to the family that has agreed to be filmed and share this continuity story that we will, of course, put up on YouTube. It will not be Oregon-specific, so we anticipate broad use in Texas and California and a lot of other places about just how do you have these conversations? It moves us back from where we've been, which is how do you complete the form, and says is it the right time? What do you think about in advance?

Historically, we have focused on healthcare professionals. In the past year, we have created a community insight committee. And we have begun to say no one is really bridging the piece that we need bridged. We're going to have to step into this ring. And we are partnering with the AARP, who is chairing that committee with us. And we will have focus groups at, for the first time, as part of our conferences as we go around the state, we'll block out the end of the day and meet with the community. Review our materials, ask what else is needed, are there stories that are not being told, what's not understandable, and continue to upgrade.

So that's broadened our horizon to actually become part of community education in a way I had never thought would be the Center's purview. But it's just not done well enough by anyone. And we're very serious about taking it back, making it better, and beginning to serve audiences that are underserved and hard to reach because of the communication gaps and education level.

Hallick: When you talk about going beyond end of life ethical issues, you find that things like diabetes, for example, are a huge cultural issue. And you might find a group like Adelante Mujeres a very useful partner.

Tolle: Yes.

Hallick: Because they create these sort of, I mean, it's a huge sort of farm to table effort and micro businesses by Latino women and their daughters. But it has a huge educational component, but it also has a huge health education component.

Tolle: Absolutely.

Hallick: And so there's a whole communication style that's really, doesn't challenge the culture, per se.

Tolle: Exactly.

Hallick: But it brings sort of health issues to the fore. So there's a lot of things that can be done around chronic disease that have a lot of the same ethical questions.

Tolle: Exactly. And it sort of loops us back to our very beginning. Because one of the people we're working with on this new film script is Tina Castanares.

Hallick: Oh, wow.

Tolle: Was on the original Oregon Health Plan, deciding the rankings. And is out north of Hood River. And has helped us link with all the people that can do the things I would not be able to do. So I just feel like you listen, you serve, you listen again. You take things back. You develop more skills. And as we create this chair for the Program in Compassionate Communication, led by someone other than me who is even more passionate about other things than end of life care, we're going to get some more balance. Mike Garland's dreams will come true in the Ethics Center as we add greater depth. It's not as if we've done nothing in the other areas. But clearly at a national level, we are most known for our work in end of life care.

Hallick: One of the things that we found is that, we have this interdisciplinary diabetes clinic. It was actually started by an optometrist. And we have students in dental hygiene, students in a variety of things. And pharmacy students and so on. But one of the things that was proven most helpful from a cultural point of view is to have an occupational therapist in the mix.

Tolle: Yes.

Hallick: Because they can talk to people in a way that they are more willing to admit that they didn't take their meds.

Tolle: Yes!

Hallick: Or that sort of thing. And you might consider, people don't tend to think of what an OT does. But they can facilitate interdisciplinary conversations that are culturally sensitive in a way that's quite helpful.

Tolle: Yes.

Hallick: Something to think about.

Tolle: So I just see the Center growing and being more sensitive to that. And being more skilled in both health literacy and across cultural issues and cross-discipline issues. And really, what does it take to help a person manage chronic disease, diabetes being a perfect example, but there are plenty of others. And also the growing ability to manage a frail elder at home in a complex network that empowers and assists but is also got the infrastructure that is not neglect.

Hallick: So, we're sort of out of time here. We are out of time here. But let me ask you the same question I asked about POLST, about the overall Ethics Center activities. How do you set this in the national context? Are these growing in other states? Are you providing an overall leadership role? What's the next generation of ethics centers look like?

Tolle: Yes. Our ethics center looks different probably from any other ethics center in the country. And I'm reminded every year when I go back to the annual fellows meeting at the University of Chicago that many people are doing incredibly valuable, scholarly work about ethics and what's right and what's the appropriate decision to make about many wonderful topics. And it's very fun to listen. But we are so much more applied than anywhere else. How, okay, it's great that you have a right and you have had for decades to refuse life-sustaining treatment. So how come it doesn't work? You know, how do we make this system change to effectuate your right. Is that palliative care? Is it ethics? Is it communication skills? Is it geriatrics? Well, it's all of them.

And that's the whole thing of why we are so different. Because I don't care that you are not a card-carrying ethicist. You're a part of what it's going to take to solve this ethical problem at a systems level and collaborate. So we're very friendly with geriatrics. We're very friendly with palliative care. We're very friendly with primary care and champion across a lot—primary care is not just physicians. You know, it's everybody who makes primary care happen. And empowering them with the lessons in geriatrics, the lessons in palliative care, the lessons in ethics, the data, to make it work in rural communities, in big cities, in health systems, in a way that brings all of us closer together at a time when things are kind of unclear about exactly how healthcare systems will function in the next chapter.

Hallick: Sounds like you think some of them are a bit ivory tower-ish.

Tolle: Well, not everybody plays nice with others. And you certainly see it in other states that are trying to roll out POLST programs. And if our system in Boston, for example, isn't running it, then we won't play. Has been a bit of the problem across the country. We have the huge advantage of having the only academic health center. And the leadership was never questioned. But many other states face real problems in how you can have enough leadership to get everybody at the same table and row in the same direction.

Hallick: I'll ask this last question, and you can feel free to have it deleted if you don't want it on record. But one of the things we never really talked a lot about in public is the very large cost impact of some of these processes and savings, frankly, that accrued Medicare and things like that. Can you say anything more about that in terms of what's known, what's not known, how that's played out?

Tolle: Well certainly if a person does not wish to die in the hospital, and they avoid a terminal admission, it is likely there is a cost savings. However, if the person is marking full treatment and is more likely to die in the hospital without a POLST form, there's likely not one bit of cost savings for that individual. So I'm always concerned when people run data about POLST. They take all POLST and put them together and they try to make a fiscal calculation that there is some sort of saving because you have a form. And I want you to divide up your categories and to honor the fact that if you want more, you get more. Now the one thing about POLST is that near the end of life, the vast majority of people set limits. And so in an appropriately offered population, the majority of people are going to do what is so characteristic of our state. Make a plan, put the plan in place. Have the infrastructure that the plan can actually work. Because, for example, you can say I don't want to go back to the hospital. You get more short of breath. There's nobody to call. There is no plan you don't have hospice. You don't have any backup meds at home. You can't breathe. You're gasping. Guess where you go? The emergency department. So it's much more than saying no. You actually put a plan in place.

And the plan isn't free. There was an analysis done by Dartmouth Atlas colleagues last year. And looking at cost by state and end of life care, and states that have the lowest spending in the final six months of life were states like South Dakota. That is because they're not paying for hospice and palliative care. They're paying for nothing at the end of life. So if you get no care at all, it will be the cheapest. That, you know, if you don't go to the hospital, and you don't get hospice and nobody comes and you buy no medications for pain and suffering, and you just stay at your house, that will be the cheapest.

So if you carry the argument to that extreme, you end up in a very dark place. And I've been extremely concerned about the primitive nature of looking at cost savings and end of life, especially linked to POLST. When the issues are much more complex, and the argument isn't a goal of nothing. It's the right amount of care. And believe it or not, sick people cost more than healthy people. So it is logical that there would be some increased cost for most in their final months of life. But are we spending them on the things people want in the settings they want? Are you getting what you wanted? Is the quality of care good? Is your suffering reduced and managed? Does your family know what's going on and everybody had time to get on the same page? It won't be free. There will be some cost to putting the plan in place that allowed the alternative to simply refuse all of treatment.

Hallick: Thank you. Anything else that you would like to see covered?

Young: No, you covered everything.

Hallick: Think we touched on—

Tolle: A lot of stuff.