HISTORY OF MEDICINE IN OREGON PROJECT

ORAL HISTORY INTERVIEW

with

Patrick Dunn

Interview conducted March 2, 2011

by

Jim Kronenberg

Oregon Health & Science University, Historical Collections & Archives, Collection 2004-005

Interviewee: Patrick Dunn
Interviewer: Jim Kronenberg
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[Begin Interview.]

Kronenberg: This interview with Patrick M. Dunn, MD, took place on Wednesday, March 2, 2011, at the Oregon Medical Education Foundation in Portland as part of the History in Medicine in Oregon Project of the Oregon Medical Education Foundation. The interviewer is Jim Kronenberg. And this tape is one of one. Dr. Dunn, let's start with kind of a bio. Where did you come from? How did you get to Oregon and Portland?

Dunn: Sure. I'm a native Oregonian. I was actually born in Portland, in NW Portland. And I've really lived here all of my life. As far as my educational background, undergraduate at Linfield College, and then went to medical school at the Oregon Health and Science University. Graduated from there, and my internship and residency were actually done at Good Samaritan Hospital, that then later became part of the Legacy Health System. And I stayed on as a clinical educator over a number of years. Really the bulk of my career was at Legacy and Good Samaritan Hospital as an internist caring for patients, as well as teaching residents how to be good internists, hopefully.

And then toward the latter part of that aspect of my career, I became an administrator, you know, and helped to found and direct the Legacy clinics for about six years. And then after that, or actually during that time, was also my interest in clinical ethics and particularly end-of-life care.

Kronenberg: And that brings me to my next question. And that is, just how did your professional and personal interest in end-of-life issues and medical care come about? How did it evolve?

Dunn: Right. I started my internship in 1979, and kind of the early '80s was my training. And during that time of my training, I had a little practice of my own, and had patients of my own. And caring for those of other attending physicians in the hospital, where patients were admitted and cared for, primarily for end-of-life care in an intensive care setting. And many of them had wishes according to either themselves or their families that they didn't want that kind of care. Most of the patients at that time were dying in the hospital. Probably 70 percent of patients were dying in hospital. Maybe 30 percent outside the hospital at that time. And here we had this development of a number of technological advances in medicine that were keeping people alive toward the end of their lives that necessitated care in a hospital or even an intensive care unit. And it really was not allowing their wishes to be honored, to possibly have a lower technical type of care at the end of their lives, and to be at home with family, and to die in familiar surroundings.

So I think it was through those earlier experiences that I had with my own patients, and with patients of my attending colleagues, that it seemed like there was some work to be done to try to improve care at the end-of-life.

Kronenberg: You mentioned that at that time, just as an aside, that something on the order of these patients who were at the end of their lives, died outside the hospital. Where, where did they die most frequently?

Dunn: Well, really, at that time, again, it was more rare that they would die outside the hospital. It would occur, really, in long term care facilities and at home. But there really weren't the support systems that we know today that would help patients die in those types of settings. Hospice, palliative care, comfort care teams. Those are things that really came as part of the cultural evolution of end-of-life care in Oregon over the ensuing years.

Kronenberg: It's fair to say that the passage of Oregon's Death with Dignity Act nearly 17 years ago was big news here and elsewhere. As a practicing physician, how did you see it affecting your colleagues? And how have things changed in this regard over the years?

Dunn: Well, the Oregon Death with Dignity Act was a very sentinel event here in Oregon, and, I think, was recognized nationally and internationally, as a very significant event in the care of patients. And it was really the people of Oregon who indicated that they wanted more control over their own lives at the end of their lives. And whether that be care in the hospital, care at home. But they wanted to have more of a say in how they were cared for during those tough times.

So I think the vote, I think it was November 8, 1994, was the initial vote, that passage of the Oregon Death with Dignity Act, 51 to 49 percent, that really put that issue in front of my fellow colleagues and myself as a practicing physician that we needed to do a better job in caring for patients at end-of-life, improving pain control, decreasing suffering in general, helping families contend with the burdens of caring for a loved one at the end-of-life, development of palliative care and hospice services, appropriate use of medical morphine that had been underused prior to that time. And I think with the Oregon Medical Board that very firmly came forward, indicating that it was appropriate in those circumstances to use an adequate amount of morphine and other opioids to help patients at the end-of-life.

So I think that when the Oregon Death with Dignity Act passed, that we were really on the verge of Oregon Physicians really helping to develop the tools that would help patients and their families when end-of-life care needs arose. And this became a lightning rod, I think, not only for discussion about what those tools might be, but also became the very timely stimulus for all of us to have those very important discussions. So that regardless of how an individual clinician felt personally about the Oregon Death with Dignity Act, and the fact that there was a law that was going to allow a patient to ingest a legally prescribed medication to end their lives if they met certain criteria, that regardless of your personal values, you had to deal with it. Because if you had a patient that was possibly asking for the provisions under the act, you had to either indicate that you were going to participate, you were not going to participate. So how were you going to handle that?

And it wasn't only clinicians. I mean, it was also all healthcare organizations that were dealing with the same thing. Whether it be a hospital setting, a long-term care facility, hospice organizations, and various professional organizations, including the Oregon Medical Association, you know, what policies will you have in place? You know, will you allow your constituents to participate in this new law? Of course, there were some legal changes that occurred, and challenges, really, from 1994. And it wasn't, indeed, passed again or reaffirmed, I guess, by Oregonians in a second vote in 1997. It was a reaffirming vote at 60 to 40 percent in favor of continuing the law.

So that I think it was really a wake-up call to my physician colleagues to redouble efforts at improving end-of-life care from where it had been.

Kronenberg: As you have, I've worked in and with the medical community for a very long time. And I'd like you to comment a bit on, on a phenomena that I was very conscious of in the '70s and '80s and even the '90s. And that was that many physicians felt that their primary goal with patients who were in extremis was keep them alive as long as they possibly could. It was not just a medical challenge, it was an intellectual challenge. Would you agree with that?

Dunn: I think that there was a culture at the time early on in my training, so we're talking late '70s, early '80s, that it really was the goal, you know, of physicians, to keep patients alive. There was an appropriate view of the sanctity of life as being extremely important. However, during that same time, there was a rise of patient autonomy. And not only the vote about the Oregon Death with Dignity Act, but I think an expression by patients in general that they wanted to have more say about their own care. And it wasn't necessarily to continue burdensome treatments at the end of their lives. That instead that they wanted to be at home, knowing that they were going to die within a short period of time. That they wanted to be comfortable. And that the primary goal wasn't necessarily to continue their lives at any cost and any intensity of treatment. But instead, to have appropriate relief of their suffering. Not only pain control, but other aspects of their suffering, whether it be psychological or spiritual suffering. And to bring those types of care aspects, you know, to the bedside to help patients.

So I think that there was this shift from the early '80s of, as you were saying, keeping patients alive for as long as possible, using the technologies that were advanced. And instead, a rise of patient autonomy indicating that you know, perhaps that our goal should be to try to help minimize suffering and not necessarily use all of these technologies, because the burden became greater than the benefit to them.

Kronenberg: So it's fair to say that debate on the issue resulted in a certain amount of consciousness-raising in the medical community about how physicians and other caregivers dealt with end-of-life issues. And I think it's also fair to say that there was a certain amount of uncertainty on the part of many physicians. You were and continue to be involved in professional efforts to assistant physicians deal most effectively with care prior to the patient's death. An early example was a community task force on end-of-life issues. Tell me about it, how it developed, and what its effects have been.

Dunn: Sure. The Task Force to Improve the Care of Terminally Ill Oregonians was initiated in January of 1995. So this was a couple of months after the passage of the Oregon Death with Dignity Act. And our first meeting occurred in that January. The group was composed of representatives from a wide array of healthcare organizations. It included physician organizations, nursing organizations, pharmacy, social services, hospice and palliative care, the legal community, and also healthcare organizations that had very disparate values with regard to the Oregon Death with Dignity Act. Oregon Health and Science University on the one hand, that being a state institution, of course, needed to respect and follow the law. And on the other end were the Catholic health system, Providence health system, that also was a member of the task force. Obviously was not in favor of the Oregon Death with Dignity Act.

However, the group was able to come together with that as a stimulus, with an overall goal to help improve the care at end-of-life. And not necessarily just address the issues associated with the Oregon Death with Dignity Act. That was the stimulus. But it wasn’t the overall mission. The mission instead was to certainly develop standards with regards to the Oregon Death with Dignity Act, regardless of personal or organizational values regarding the act. But second, also, to help with education, relationship development across organizations, and act as a clearinghouse of information in all ways to try to improve end-of-life care. And that was going to be better for patients, families, colleagues and organizations. So that was the original stimulus.

And then the group, believe it or not, continued to meet on either a monthly or quarterly basis for a 15-year period of time. And we had developed a number of products from that effort. One was the guidebook that dealt specifically with the Oregon Death with Dignity Act, which is available online. The last revision was done in 2008. And we’re not anticipating additional revisions, having felt that we’ve done the work there. And a second was developing a compendium of resources for end-of-life care by county in the state. Hospice resources, palliative care, social service agencies that would be of help to patients’ families and to clinicians. And I think that probably what the most important accomplishment, really, of that group, was really building the relationships, at least on end-of-life care, across organizations and relationships I think that really continue today, so that if issues arise, there can be collaboration on addressing those issues, sound policy development, collaboration on educational efforts, with the overall goal, again, to enhance end-of-life care in Oregon.

Kronenberg: There are a number of services and activities that, at least to my knowledge, before the Death with Dignity Act either didn’t exist at all or in kind of embryonic form as to what they are. And I’d like to talk about some of those with you and get your perspective. First of all, one that fascinates me are comfort teams, so-called comfort team. What are comfort teams? How did they develop? And what has been their effect on the quality of care for terminally ill patients?

Dunn: Right. Well it may help to start back with the history about the hospice movement in general. Hospice came about in England with Dame Cicely Saunders in

1967. Made it across the Atlantic with Kubler-Ross in 1969, with the development of teams of healthcare professionals that would work together to try to minimize the suffering of patients and families at the end-of-life. And the hospice movement, I think, really became embodied in legislation and a policy through Medicare in the mid ‘70s. And then became kind of the law of the land where at least in the last six months of life that there would be comfort care services that would be provided for patients at that time.

Now the challenge was is that it is very difficult to estimate you know, when somebody might have a six months prognosis. And there also was a lot of pain and suffering that occurred prior to the last six months of life. So patients many times would be admitted to the hospital or to other care facilities and would have these unmet needs of relief for pain and relief of suffering and yet may not qualify for hospice. And so there was this unmet need for a palliative care type of service. And so in the mid ‘90s, at least here in Oregon, there was the development of comfort care teams in those early adopting hospitals. Oregon Health & Science University led the way with Legacy Health System, Providence, a number of others had developed similar services. Providence, I believe, actually had a support care type of service that may have even predated that.

But the goal of those teams was to, again, take a multi-disciplinary team approach to assess what a patient’s needs were on not only a physical or medical basis, purely, but also their emotional, social and spiritual needs, understanding that much of the suffering comes from those other aspects of their person. And to bring those resources to bear that would help to minimize the suffering that patients would have and the burdens on families.

And so, comfort care teams, starting in the mid ‘90s, have really evolved to become the standard of care, not only in Oregon, but also across the country. And, I think, have done a tremendous service in helping to blur the boundary of that six-month terminal prognosis that hospice requires by law, and the financial ramifications that go along with that. And allow the provision of needed services prior to a hospice enrollment.

Kronenberg: Is it fair to say that hospital-based comfort teams really originated here in Oregon?

Dunn: That’s a good question. I’m not sure if I know the answer to that. There was a significant interest in comfort care teams in a number of centers for excellence of end-of-life care across the country. And one of those, certainly, was Oregon Health & Science University. Others also in other parts of the country, particularly New York.

Kronenberg: In terms of talking about hospice, which is because of a recent personal experience that was enormously positive with regard to hospice, they may have existed, but these services were virtually unheard of by the public and, I think, by many physicians, until PAS debate in Oregon. And now they’re recognized as valuable assets in end-of-life care, not only by physicians and other caregivers, but certainly by the general public. And even health insurers. How has hospice changed the environment of end-of-life care in your experience?

Dunn: Well, hospice is an absolutely tremendous resource. And you mention your own personal experience. I’ve had my own personal experiences with family with hospice. And I think what hospice brings is a sense of comfort and hope, even at the end-of-life, for the patient and the family, that otherwise really can't be provided by a physician who's very busy in an office or hospital setting, or nurses that are practicing in other settings. So it's this designated team – physicians, nurses, social workers, occupational and other therapists, and spiritual caregivers – that really come together with one goal in mind. And that is to ensure that the patient is as comfortable as possible, and that any suffering that they have is addressed. I think they go also beyond the patient and kind of treat the family as patient as well, understanding that there's a tremendous dynamic that occurs for families at the time of dying. There are a lot of issues that may have been buried within families over a number of years that bubble to the surface at the time of a person's dying. And the team is exceedingly skilled at eliciting those underlying issues and dealing with them in a very compassionate manner.

Kronenberg: Even before the physician-assisted suicide debate began in Oregon, a number of efforts were underway locally to aid and assist people in having more say in how they were treated in their last days. This issue of autonomy. Let's talk about some of these. One which most people these days are familiar with are living wills. How did they develop, and what has been their role?

Dunn: Living wills developed really as a consequence of this rise of patient autonomy. There were tremendous technological advances that began in the late '50s and early '60s. A couple of them, actually, fairly close to here in Oregon. Just north in Seattle was the development of hemo-dialysis for end stage renal patients. Seattle and Spokane. And then also the development of defibrillator, for patients who had gone into cardiac arrest. That was just one of myriad treatments and advances that occurred over the '60s and '70s. Enough so that patients were being cared for beyond the times that they would have wanted, and that the burdens of their treatments were outstripping the benefits that they were perceiving.

And so with patients wanting to express a greater voice, whether it be through legislation or through the court system, that living wills came into being, particularly after the Karen Ann Quinlan case in 1976, that would allow patients to express their own values about how they would want to be treated when they came to the end of their lives if they were unable to make decisions at that point and express their own opinions at that moment. So I really conveyed kind of a lasting expression of values that could be transferred to somebody that that individual trusted to make decisions for them.

The initial living will in Oregon was in 1978. And that was later amended in 1983 with a power of attorney statute again allowing somebody to make decisions for a loved one that had been designated in advance to make decisions for that individual.

And then by 1989, both the living will and power of attorney statutes in Oregon were put together into a single statute. And then our current advanced directive statute came into being in 1993. And it's actually quite progressive. It indicates four different clinical states that a patient might find themselves in, and can designate what it is that they would want with regards to end-of-life treatment, including tube feedings. And then also includes this power of attorney portion. That is, naming somebody to be their decision maker if they were unable to make decisions for their healthcare. And that's our current law here in Oregon and I think has been very helpful in, again, this expression of patient autonomy, patients wanting to take control of their healthcare decisions as much as possible.

So you might say that we would be done, that advanced directives have solved the problem. The problem with advanced directives is that they unfortunately had not been well adopted. You'd think that they would have been, but they had not been well adopted by patients. And that even now, only about 26 percent of patients have completed advanced directives. Adults, you know, who are eligible by law to complete one. And even those who are very close to death, hospice patients, as an example, this is national data, but only about 50 percent of patients at the end-of-life have completed an advanced directive.

So the challenge is that when we come to end-of-life that there is a tool for patients to be able to express their autonomy and their values with an advanced directive. However, it may not have been completed. And if it was completed, it may not be available at the time of need. So that it may have been completed, but it's in a file cabinet somewhere, or it may be in a doctor's office that's not accessible at nighttime, or in a hospital record, for example, that may take a day to get efficiently.

And so because of the lack of availability or completion of advanced directives, and also because it was an expression of patient values that still had to be interpreted into medical orders, we, in Oregon, decided to consider a new way by which we might be able to honor patients' wishes at the end-of-life. And that's with the physician orders for life-sustaining treatment, or POLST project.

That project developed purely out of patient need. We had an ethics network here in Oregon with different regions, and the Health Ethics Network of Northern Oregon met and presented patient after patient in the late 1980s that were admitted to the hospital, then to an intensive care unit, contrary to their wishes. Whether they were orally expressed wishes or that they had already completed advanced directives that were then later found, and here's the patient on multiple life-sustaining treatments in an ICU setting, and that that was contrary to their wishes. And it was purely because, it wasn't available, it was either not completed an advanced directive or it wasn't available at the time or it wasn't interpretable at the time, because it wasn't in the form of medical orders.

And so we had the idea of developing a standardized form that would take an expression of patients' values, whether that be orally or an advanced directive and embody that in medical orders that were consistent with emergency medical services protocol. So when EMS might respond to a crisis situation at a home setting or an institutional setting with a patient, that they would immediately know that this is what the patient's wishes were with regards to resuscitation, other emergency services issues, such as endotracheal intubation or use of various medications for arrhythmias is another example. Tube feedings, and even antibiotics.

And so this form, then, became an idea to ritualize a discussion between a physician and later a physician's assistant and nurse practitioner to have a discussion with the patient or their surrogate, and to make sure that their values were embodied on their POLST form that then would be kept where they resided. If it was at home, it would be kept on the refrigerator. And if it was in a long term care setting, it would be the first document in their medical record there so that it would be again completed, immediately found, and accessible, and would be already pre-interpreted for EMS to immediately respond to.

Kronenberg: Can we talk a little bit more on the issue of accessibility to the POLST form. The mechanics of it. I understand what you are saying, but for the purpose of this discussion, it might be good to expand on it a little bit.

Dunn: Well, okay. I'm trying to figure out what you want, exactly, Jim. Do you mean about accessibility—

Kronenberg: Let's hold.

Simek: Take a little pause.

Kronenberg: What I'm driving at is, you know, you put it [unclear] the refrigerator. And—[inaudible] Oh, okay. What I'm driving at is, you describe the process. What I'd like to get down on the tape is exactly how this process works.

Dunn: Oh. So maybe walking a patient through the process?

Kronenberg: Right. Exactly.

Dunn: Okay.

Kronenberg: So the doctor has a stack of forms in his office, and it's his policy to have this discussion with all new patients. And presumably, then, that goes into his chart. How, from a sort of a logistical standpoint, how does it get to the patient's refrigerator, to the hospital of choice, or [unclear] choice and so on, and how is it accessed.

Dunn: Okay. Okay. Well, let me see if I can provide an example. When I was practicing, it would be very common that a patient would come into my office who was very healthy. And we, they were coming in for, say, a preventive health exam and a physical exam. At that time we would include as part of that discussion, not only immunizations and cancer screening, but we also would talk about end-of-life care preferences. And I'd make sure and you know, caution folks that I wasn't trying to tell them something that I wasn't otherwise being direct about. That they were very healthy, but it would be good for them to consider completing an advanced directive.

So all adults in Oregon, 18 years and older, are encouraged to complete an advanced directive. So that's really for all individuals, even those who are of excellent health. I've completed my own advanced directive for my own healthcare purposes, as an example.

Now the POLST form is different from an advanced directive. It complements an advanced directive. However it's targeted, really, for those individuals who really you would not be surprised if they died within the next year.

So again, coming back to my office setting, if a patient came in and I felt that I wouldn't be surprised if they died in the next year then I would, hopefully sensitively communicate that with the patient and possibly family members if they had come in with them to the office setting. And have the discussion about medical treatments that could be used for them and to understand those values. And then for me to record those on a POLST form. And to make sure that the patient understands that the purpose of the POLST form is to take those values that they're expressing and put them in a form that would be understandable at a moment of need. And that this was for them. And that this was a document that would go with them to wherever it was that they were living. So if they were living at home, this would go home with them. It's a brightly colored pink form, so it can't be missed by EMS. And kept generally on the side of a refrigerator like with a magnet, not on the front. A lot of times people don't want to look at their pink POLST form staring them in the face as they're going to get their ice cream for that evening. But side of the refrigerator. And EMS knows to look in that location.

And so if there was a moment that there was a need, and EMS were called, so 911 is called, EMS arrives. And they would immediately look on the side of the refrigerator and if they see the POLST form, they then would use the POLST form to guide their actions. And the treatments that they would provide to the patient being consistent with the patient's wishes.

At the same time, they also would be contacting their medical control. And if there's any problems or concerns that they might have, or if their only challenges at the moment EMS comes to a scene where they start to use the POLST form for orders, but there might be a family member who is considering you know, I want more done with that, EMS will always provide a higher level of care, higher level of treatment, if there is a discrepancy or concern at the scene, that then will later be sorted out once the patient's transported to an emergency setting, for example.

The form, then, I used in an emergency setting or in the hospital to formulate further treatment that might occur there. If the patient is treated in a long term care facility, it's possible that the patient would not require transport, and that they could possibly be cared for in the setting that they currently are. Or if they're a hospice patient and they really prefer to be at home, and EMS happened to be called for comfort reasons, then comfort would be provided in the home setting. And they would work with hospice to try to keep the patient in that setting if possible. However if comfort cannot be provided in whatever setting, whether it be home or long term care facility, then the patient for sure would be transferred to the emergency setting and a hospital where comfort services could be provided.

Kronenberg: That's very helpful. You probably should be given a chance, because you certainly deserve it, to describe for us your role in all this, which has been if not, if not pivotal, then certainly very important. What have you done? What have you been doing, in terms of this continuing?

Dunn: Well, first of all, I would just say it's been a personal and professional privilege to be able to not only work with the patients that I have over years and to teach the residents that I have over years, but also to endeavor to address significant quality issues in care at the end-of-life, and to help facilitate a number of projects with colleagues that I feel really have made a difference over time. And I feel the Task Force to Improve the Care of Terminally Ill Oregonians is one that I think did make a difference with regard to developing standards for the Oregon Death with Dignity Act. And then beyond that, as I mentioned, to ensure that its mission of enhancing end-of-life care throughout the state would occur. And I think that that is ongoing and has a life of its own.

And what predated that, really, was this POLST project. And it was the same task force multiple organizational representation. And, again, I had the privilege of helping to facilitate that group that continues to meet on a quarterly basis and now has a state run, state-provided registry, supported registry, that also is helping to make sure, you know, that patients' wishes are honored. So I guess my role, I feel, has been one of facilitation and helping to coordinate and bringing colleagues together and organizations together with the convening help of the Center for Ethics and Health Care at OHSU to address some of the most challenging issues that I think that we've had, at least in end-of-life care, over the last couple of decades.

Kronenberg: So your experience with this whole issue of end-of-life care has really been a career-long one. And you've been in the position through your own interests to have a great deal of input and influence in this process. A lot of things have been done, but I'm sure, you agree, continuing. That will continue in the future. Can you spend a minute talking about what else you think can be done in terms of improving the quality of care, medical care, as well as supporting care and the like at the end-of-life?

Dunn: Well, we've come a long way. And yet there, I believe, is still a ways to go. And that the end-of-life care is a continuum kind of quality improvement process. As an example, the POST, Oregon POLST Task Force continues to meet quarterly. And they end up using input from physician and other healthcare professional colleagues to improve the form itself over time. And the means by which the information on the form will be accessed.

When we first started that process back in the late 1980s, electronic medical records were not even something to be considered. And here we are, of course, that that's the standard of care. So the POLST project is moving to that, where forms can be completed in an office setting. Just as I mentioned I would be in my office, the orders would be recorded within the electronic medical record directly. Patient's signature provided at that moment. And then the information transmitted electronically to the Oregon POLST Registry, which now exists.

And so information then can be accessed also through the registry, potentially in the future, electronically. The improvement there is not only efficiencies, you know, that is decreasing the amount of time and effort that it takes to get that important and very sensitive information in the right place and available at the right time. But it also decreases the risk of errors that might occur in transcribing orders onto a piece of paper, onto a piece of paper, into an electronic database, for example, for the Oregon POLST Registry. So that is an example of one quality improvement that continues to occur with just the Oregon POLST Task Force and the ongoing effort.

I think beyond that, that we still have a ways to go with regards to using the tools that now have been developed. Comfort care teams require greater financial support. I'm hoping that with healthcare reform that there isn't necessarily this hard and fast barrier of six months prognosis for patients to access appropriate palliative care services and needing to require for hospice only.

Also I think that although Oregon physicians and healthcare professionals have really pushed to try to make hospice services available for their patients, sometimes it still comes too late, and not enough to benefit from this wonderful multidisciplinary team that’s available. So I think that we need to keep that on the forefront of our mind and to make sure that we’re providing the services necessary for patients and their families, you know, given the tools that really now exist and have been developed over the last 20 years.

[End Interview.]