

HISTORY OF MEDICINE IN OREGON PROJECT

ORAL HISTORY INTERVIEW

with

Erin Hoover Barnett

Interview conducted March 2, 2011

by

Jim Kronenberg

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Interviewee: Erin Barnett
Interviewer: Jim Kronenberg
Date: March 2, 2011
Transcribed by: Teresa Bergen

[Begin Track One.]

Kronenberg: This interview with Erin Hoover Barnett took place on Wednesday, March 2, 2011, at the Oregon Medical Association in Portland, as part of the History of Medicine in Oregon Project of the Oregon Medical Education Foundation. The interviewer is Jim Kronenberg and this is tape one of one.

Erin, I'd like to start just mainly for the record, why don't you give me sort of a brief bio. Where were you born, where were you raised, your education. That sort of thing.

Barnett: Sure. I'm happy to. Thank you. So I was born in Wisconsin and I grew up in Wisconsin and also Ohio. my dad was a political science professor, so we followed him to college to university, etcetera, as he had teaching positions, faculty positions. Back to Wisconsin for high school and then Minnesota for college. I went to Carlton College. I also majored in political science. I would say that social justice issues started to become a little bit of my interest in college. Paul Wellstone, who became senator and then was killed in his second term during a tragic plane accident, was one of my sort of heroes in college.

Then I moved down to Chicago, a few years there. Started as a journalist. I worked in community weekly newspapers in Chicago in the suburbs.

And then moved out to Portland in 1990. Arrived just as Ballot Measure 5 had just passed and the funding for the schools was about to change drastically. Got involved in writing for the Oregonian right away as a freelancer, and then as a contract writer. I covered the schools. Then I got on our crime team, covering police. That was right during a lot of the gang violence in Portland. That helped me get hired at the paper because I worked very hard to do tough work on the crime team as a cub reporter. And then I went on to cover other beats, including health in the late '90s, which then led me to cover physician-assisted suicide. And went on from there to do a number of other things before leaving the paper in 2008. And I'm now a communications manager for Portland Public Schools.

Kronenberg: You were, at least in my experience, you were obviously the lead reporter on the physician-assisted suicide story for a very long time. And I suspect you didn't do too much else, given the coverage that the issue had at the time. Was this an exclusive duty, in fact? Or did you cover other stories?

Barnett: So I actually, as beats go, did not have that beat that long, partly because it was so intense. I became the lead reporter pretty much the day after the law was finally allowed to go into effect. And that was in November of 1997. And then I remained as a lead reporter for the next, basically two-and-a-half year. I think it was 2000 when my colleague Don Colburn took over as our lead reporter. So during that time, I covered

assisted suicide, but I also wrote about end of life care. So I did quite a bit on hospice and pain management and various policy aspects related to pain management and the law itself. Some debates in the legislature that happened after the law took effect. But pretty much everything was related to end of life care. I think I morphed in 2000 into covering aging. So I made sort of an expansion of that beat, then, afterwards.

Kronenberg: We recently interviewed Dr. Patrick Dunn, who I'm sure you know quite well. And we looked at physician-assisted suicide not just in terms of that issue, but related issues and developments. The advent of comfort teams, and the role of the durable power of attorney in hospice and so on. When I got into the medical business in the late '60s, I think it was probably ten years before I even heard the term "hospice." And it's really changed a lot. Can you talk a little bit about, in terms of your writing about policy, your review of how things have developed, and to what degree the Death with Dignity Act was a driver for those developments?

Barnett: Sure. Now I think that's probably one of the most fascinating. And perhaps I think you could say that most people would agree, regardless of their view on that specific issue, positive developments was what happened with pain control and comfort care and just a recognition of what happens at end of life, what the emotional/physical/spiritual needs are of individuals as they're dying. It's a topic that Americans and many societies are, of course, famous for not wanting to talk about. And in Oregon, there's no question that we became a place where you could talk about death, and you could talk about what you wanted. And I think that as the debate played out, again, really regardless of where you stood on the specific issue of assisted suicide, I think it allowed for families to have conversations around the dinner table. And when they were dealing with a loved one who was ill, being able to have those conversations about what do you want, how are you feeling, you know, what would make you more comfortable. And also feeling an ability, maybe feeling galvanized to advocate for a loved one who wasn't getting the comfort measures that they needed. Realizing that we actually as individuals, not only are there medications or comfort measures that can be given, but we actually deserve to have them. We actually might even have a right to have them. And I think those, that sort of ability to advocate for a loved one, I think, was probably helped in families who were comfortable advocating for each other. And you know, I mean, policy-wise, one of the biggest pieces I remember was when JCAHO, the accrediting agency for hospitals, for, if I understand correctly, Medicare and Medicaid, I believe, came out with a policy that basically put your accreditation on the line if you were not giving adequate comfort care and pain management. And that led, if I again remember all of my facts correctly, to things like the little happy face chart that you would look at when you went into the hospital and say where you were on the pain scale. I certainly know that we are now in a situation where maybe the pendulum has swung too far and there are some deep concerns now about overabundance of pain medication again. People struggling with addiction, diversion, etcetera. But clearly there was a need for this discussion about the ability and the rights of patients to not die in pain, suffer, etcetera. I wanted to briefly share that I did an interview with Dr. Cicely Saunders, who was the widely viewed as the sort of founder of hospice, of the movement, in Britain. And she was a fascinating woman. And was so gratified to know that in Oregon we were really

exploring and expanding the use of hospice. I really believe hospice is now something that most people assume they will do. I may be wrong, but certainly it's become much more accepted. You know, as you said, you hadn't even heard of it ten years after you were involved with medicine. And now I think it's something everyone's aware of. And I really believe that a lot of that is related to kind of the shot across the bow that this debate about legalizing the ability to take your own life really caused people to wake up and say we've got to do better by people at the end of life. The other piece that should be mentioned, and I assume Dr. Dunn did this, was the POLST form, the Physician's Orders for Life-Sustaining Treatment that Dr. Susan Tolle and the Oregon Center for Ethics and Healthcare created was a master stroke. And it's now gone to many states across the country. And I can remember just a couple of years ago with my father-in-law, who was 87, transported off to the emergency room when he shouldn't have been, from his care facility. He was very frail. And my being with him and my mother-in-law, who is now 90. And the doctor and nurse were able to bring out the POLST and say, "I don't think that you have one of these. Let's talk about this." And it led to this conversation that helped Ethel, my mother-in-law, to grapple with the fact that Clarence was probably near the end of his life. It helped me to understand that that was where he was, so we could take steps as a family. And the most important thing is it kept him from having to run back and forth to the ER every time he had a little thing from his care facility. It allowed him to die in his bed in his room surrounded by his things and people who cared about him. And that's a gift to families. So that clearly came out of the debate about assisted suicide, the POLST.

Kronenberg: I recently had a personal experience with hospice. And I can say it was enormously helpful and gratifying. As long as my wife and I live and are able, we'll provide financial support for that particular hospice, because it was such a positive experience at such a terrible time. As not only a reporter who covered these issues for a long time, but also as a citizen of the state for something over 20 years, how have you seen the hospice movement evolve, in terms of how it's perceived? Not only by the medical profession, which has certainly changed, but by the public in general?

Barnett: I do think, and I don't feel like I'm a great gauge of this, but I definitely think that people, the word "hospice" is a word that people understand now. And they may, the only danger is some people have the misconception that hospice will involve someone coming to your home 24 hours a day to be at the bedside. And that's obviously not the model. It's more of a check-in, make sure you have what you need, help you understand what's coming, get the equipment into the house. And you need to be able to provide the care in some way or another. But I think that most people certainly know what, have a sense of what hospice means. Now clearly all of this, the ability to bring in hospice, to have end of life conversations, is a very personal one. And there are many families, of course, for whom they really still very much struggle. I mean, in order to talk about hospice, you have to be able to face the fact that you're dying. In order to talk about the Death with Dignity Act, you have to be able to face the fact that you're dying. And that, I think, remains one of the most difficult things for human beings to do. There's a reason for that, you know, we're hardwired to live. So as much as you might know about hospice, which I do believe more and more people do, and it's become more accepted,

there's also that hurdle to get over in an individual family's experience of being able to take that step and own the fact that the loved one is going to die. That's hard.

Kronenberg: As a reporter and I know personally a very curious person, what was the most interesting part of this whole story to you?

Barnett: You know, I remember when the law took effect. I mean, a couple of thoughts about that. I went up to the hill and I interviewed Dr. Goodwin and Dr. Toffler, who had offices right down the hall from each other at OHSU. And really, I think, I mean, obviously diametrically opposed on the issue. And both very strong leaders on each side with their own very deeply held passions about what was right and what was wrong. And Dr. Toffler said something I'll never forget. He said, "You know, it's a different world today. November 7, 1997." I'm not sure if I have the date right. And it was because in his world, and I really believe, fundamentally, for all of us, the fact that we now had the state, through our voters, the state sanctioning the ability for someone to take their own lives, was a huge paradigm shift. And you know, obviously, some people viewed it as a victory for sort of patient's rights and this type of thing.

But I'm certain that for many doctors, it was a very, it could be perceived as a very difficult thing to accept. Because if you believe that a physician should do no harm, and your definition of that includes therefore not helping someone end their life, that was a pretty profound change. And so I think I was very much aware, and I'm thankful to Dr. Toffler for really helping articulate what a dramatic moment that was. And from the perspective of a doctor, a physician, someone who feels like they're trying to do right by patients. But also for us as a society, this was a very big step.

So that, sort of the weight of it, I think, was impressed upon me at that moment. But as I started to cover it in my job, and certainly the way I perceive my job, was that I needed to walk with people through their experience, using this law. And that's obviously a very personal thing to do. It's somewhat presumptuous that anyone would even allow me to be in their life in that way, though a number of courageous people were willing to do that because they felt strongly enough that they wanted to share the experience. And you know, finding what you really realize when you get close to people who are facing that decision is one, first of all, just the incredible power of wanting to live. The will to live. And to adapt to, even as you lose some of your abilities, and your illness makes things harder for you, the ability to adapt because you so don't want to leave your loved ones, and want to carry on, is stunning.

I just as one example, and I'll talk a little more about this case later, but Patrick Metheny, who was only, I believe, 42, when he was diagnosed with Lou Gehrig's Disease, and just a really entertaining guy, just fiercely independent, a carpenter, very good with his hands, very ingenuous, very resourceful, very funny, you know, whiskey drinking, you know, kind of wild guy. And just a fantastic person. And he kept drawing these lines in the sand, as he would describe them, in saying, you know, "At this point, life won't be worth living when I can no longer dress myself," or this type of thing. And then he would get to that point. And then he would realize that he could accept help to do some of these things, or he would be really resourceful. Like he was a smoker, and he created a contraption that would hold his cigarettes. I'm trying to remember that correctly. He had all these ingenious ways of getting past, you know, his increasing

frailty. And that was pretty remarkable. I mean, he was someone who was just sort of, nope, after this, I'm done. But then he would adapt. And I think people realize that it's actually one of the sort of terrible beauties, if you will, or the grace that we find when we're nearing the end, that we do often hold onto life in quite beautiful and powerful ways. So I found that fascinating. I mean it's very sort of heartening about the human condition in covering this issue.

Kronenberg: Was that your most challenging assignment?

Barnett: I think it definitely was. And the reason was, sort of on a personal level, I just really, I admired Patrick. He was just a neat person. So obviously to spend time over time with someone who you really like who's dying is never a nice experience. But I think that in terms of sort of journalistically and personally, it was very challenging. Because, so Patrick had a wonderful travel trailer that he had parked on his parents' property. And he lived just south of Coos Bay. His family was very much in sort of Ken Kesey territory. They had a home in the woods. They were a wonderful, very solid family. Very, very much loved Patrick. Very willing to do anything that they could to support him, and also caught in that bind that families have of here they love this man, and he is also fiercely independent, and wants to do things his way. And so they would, you know, they took turns doing what they could. His parents were there. He had a wonderful sister and a neat brother who came and spent long periods because he lived out of town. He had a young son, 13, I believe, and an ex-wife. And they all came into his life.

And I think that the challenging piece with Patrick is that under the law, you have to be able to take the medicine under your own power. And the medicine being, as we know, something that you ingest. It's not an injection. It's something you drink or swallow. And Patrick, who's very intelligent, was very aware of how challenging that is for someone with a neurological disease that compromises their ability to move their body, etcetera. So he had the medicine for a long time. It sat next to the pickles and the strawberry jam if I remember correctly in his little travel trailer refrigerator. And ultimately, he had this vision that he would do a sort of living memorial type gathering where people would come and share and they'd laugh and joke together. And then he would go off and do this thing.

But he also realized that he wanted to live as long as he could. So he was increasingly not ready to take this final act. And when he finally did decide to, he was really at that moment of facing having to go into an assisted living which I think his family might have been very happy for him to do that. They could have been with him longer. For him, it wasn't what he wanted. So he ultimately made sort of a very quick decision that the moment had come. He had an extended family member with him at that time. His family was taking shifts with him at that point. At this point, an extended family member was with him. And when he made the decision that this is the time for me to take this medicine. And he had some difficulty taking the medicine.

And so I reported this. Because as a reporter, I felt like the most important thing I could do is be as true to the story as possible. I mean, I felt like my role, and I think Patrick very much felt my role was to explain what is this experience like. And to be as accurate as I can. And I took that role very seriously.

The reaction to the story was, on two pieces that was, I think, noteworthy and interesting. Supporters of the law, people who were very actively supporting the law were very angry with me that perhaps I should have just not said anything about how it went or didn't go, but just that you know, he died. And he did. He succeeded in his desire. He did die. That that's all that needed to be said. And I felt very strongly as a journalist that my job was to give the information that I had. And that it wouldn't have been right for me to basically not disclose information that I was given, that that was not what I, what the public was asking me to do as a journalist.

But the piece that was the most difficult for me, and to this day is something that I just, I have to just be with, is that that story was very painful for his family. And it also led to them receiving some very mean-spirited phone calls from people who had their own perceptions of what happened. And these are attacks this family did not deserve, but they got because of something I did. And that was, I, to this day, feel terrible about that. It's not something I'm proud of. It's something that I, again, I have to just sit with. I have to own it. Something I did was hurtful to a family that did not deserve it. And I think it's a reporter's obligation to take responsibility if they have caused pain. To think very carefully about what they do and recognize the impact it's going to have on people when they do it. I think it's a very high obligation for any reporter, and anyone involved, a doctor, anyone else involved in a situation like this.

Kronenberg: You've already partially responded to this question, but I'm going to ask in a little different way. I think I know the answer, because I certainly experienced it in my role. But were you ever accused of bias or a spin in reporting by one or both sides?

Barnett: Yeah. I mean, I think the issue of bias is interesting. I mean, clearly in the campaign, it's appropriate to really be looking at whether there is bias. Because that's a point at which readers and voters are trying to make a decision about something. And so ideally the coverage is as dispassionate as possible, and is just the facts. I think the truth is that with this issue, it was such a, it's such a huge paradigm shift. The idea of, again, the state sanctioning a way for people to take their own lives, and that doctors would prescribe this medicine to do this, was such a huge paradigm shift that there was almost like a feeling that not only did we need a really strong debate, but that it could be a very pointed debate. And I would say that our coverage in the *Oregonian* at that time was pretty pointed. I mean, we used phrases in our headlines like "Death doctors" and that type of thing. If I recall correctly, I should look it back up, but there's no question that there's very pointed coverage. But again, it wasn't just voting on more money for schools or something like that. This was a huge societal shift that we were voting on, so there needed to be a strong debate.

I was not the lead reporter at that time. When I became the lead reporter, the law had taken effect. So I think the issue of bias changes then. I mean, it wasn't so much for me to be reporting on you know, all the bad things about this law in sort of that manner, because it was legal now. So I think it was a different objective. And my view of my objective had more to do with, as I said, explaining to people how this law played out at the bedside so people could understand how it played out what it was like, how was this public policy actually working. And to be as honest as I possibly could. And not

sugarcoat things. And also, but also not, you know, write them in a way that was critical or criticizing of individual's actions.

So I mean, sure, there were times when, I'm sure, sort of to the extent you had sides, which you did, people questioning where I was coming from. I think after the Patrick Metheny story, supporters of assisted suicide were unhappy with me and questioning of my, where was I coming from that I wouldn't have sugarcoated what had happened. I mean, they felt like I wasn't being compassionate, and obviously that bothered me. But, you know, at the same time, people who were not supporting of the law at times also weren't clear where I was coming from. And I guess I ultimately felt good about my relationship with Greg Hamilton, Dr. Toffler, others, Kenneth Stevens, because I felt that they continued to play a very important role. Which was to continue to push and say how's it going, is it really like it's supposed to be. I mean, that role does need to be played. I think it needs to be played in a respectful manner that's not about criticizing individuals or families. But Kenneth Stevens just did an op-ed in the last few weeks when the report came out for this year about assisted suicide. And I felt that he raised some important points, that are we not tracking as closely as we used to be with this law and who's doing it. Are we not quite caring as much if we get complete records. These are questions that do need to continue to be asked and answered. And I think that the physicians who are continuing to stay close to this and watch it are playing a valuable watchdog role that is needed.

Kronenberg: You and other reporters observed and reported on what can only be characterized as an acrimonious and sometimes divisive debate for a very, very long time. As a matter of fact, I can make a case that it still continues and probably always will. Frankly, sometimes people on both sides got pretty obnoxious. I'm not saying that you did, because I was never aware of it, but did you ever wish that you could editorialize in your reporting, set one side or the other straight?

Barnett: I don't remember feeling that way about this issue. There's other issues where I felt, probably issues having to do with race and other topics, where I wish that I could call people out more. I mean, again, I felt like as a reporter when there were topics of disagreement or the need to bring out two sides, or more than two sides to an issue, in this topic, it was to allow each side to give their best case. And when things were nasty, and I might need to actually try to think of some specific examples, I think our approach at the *Oregonian*, if something got particularly nasty, is we wouldn't even necessarily give it the weight, you know? I think you can make decisions, you know, selectively, deciding what's going to go in and what isn't. If something is just completely obnoxious, it may not need to see print. So I think there might have been some of that selectiveness. But I never had a feeling of, you know, needing to call someone out.

Kronenberg: The *Oregonian*, and, for that matter, state, national, and even international media covered this story relentlessly over a very long period of time, in my experience, being from the dark side. Why was it such a big story, and why did it have such legs?

Barnett: I think again it was such a paradigm shift for medicine, for society. It also, in Oregon, spoke to sort of that independent view of that we have of ourselves, pioneering

view of ourselves, that we would be sort of on the cutting edge or early years of this debate and moving all end of life care forward. But the ability to actually take this final decision into our own hands kind of played into our whole independent narrative in the state. So I think that was part of why, it was sort of part of, in some ways, Oregon's branding, if you will, that gave it a lot of legs. But I mean, again, nationally, it didn't just encompass the few people who might want to take their own lives when they were terminally ill. It had to do with everything. It was a shot across the bow to medicine about how you don't care for people at the end of life. I mean, it was patients saying they were going to take control because thank you very much, Doc, but you're not doing it for me.

And that was not, obviously, what any physician wants to hear, nor is it what many believe they're trying to do. They obviously feel that they're trying to do right by their patients, and learn that they weren't. So it touched so many areas. You know, policy, Medicare, Medicaid, you know, all of these. There were pain management, accreditation, all of these issues were really wrapped into one issue. And that's why I think it was so blasting.

And yet also interestingly, so few states have really followed. It has not spread across the country. And I think other sort of political forces, obviously, it sort of took over that things really shifted in terms of sort of the national focus that this isn't the kind of thing that I think will have legs again for some time. It's hard to know. But it didn't catch on like a lot of people thought it would.

Kronenberg: In talking with Dr. Dunn about this issue, I asked him if since in my experience with physicians, as technology and the ability to save and preserve life became more and more sophisticated, there was a tendency among physicians in the position to provide that kind of care, to become more and more aggressive in terms of their use of the technology and life-saving techniques in spite of what the patient might need. Because that's, after all, how they were trained. And it's always been my perception as someone who has followed the medical profession very closely for a long time that there indeed was a paradigm shift when [glitch] began here and the law actually passed, and then passed again and was then [glitch] covered this story. Do you agree that physicians, at least here in Oregon, have a different perspective about all this? And I don't mean that they've learned from it, but they see their role differently in dealing with end of life patients?

Barnett: You know, I mean, I'm sure that Dr. Dunn and yourself probably have a clearer view of that. My sense would be that physicians have changed. I do know, I've gone through the death of both of my parents, just in the last few years, both from aggressive cancers, both way too young, in their sixties. And this was in Washington. But I was very struck by the ability of the doctors to, really from the get go, be able to have some of those conversations and help us have the conversations about not just quantity of life but quality of life. So it does seem to me that that, the ability to talk about quality and quantity together is more acceptable now. And the recognition that patients have choices, and that it's not just whatever the doctor decides the course is. I think people are less likely to accept that it's just whatever the doctor says I can do, that's what I do. There's more a sense of well what is it that I want, what are my values? And I think that has entered the consciousness for medicine and for patients, you know, over time.

Kronenberg: You're only 17 years after it passed, and your opinion, as a keen observer of this whole phenomena, what has been the effect of the Death with Dignity Act in Oregon? Good and bad? For healthcare and for the public?

Barnett: It's hard for me to think of a lot of negatives. Because ultimately, so few people every year use the law. So in terms of, and you know, as individuals using the law, it doesn't necessarily affect my life that somebody else made this decision to close their life in this way. I think that, I would find it very interesting to talk with doctors who continue to feel very strongly in opposition to this practice. Because they may have some insights about shifts that have happened that do seem negative. I pretty much see the positives in terms of, just again, with pain control and with patient advocacy and empowerment. I think those things have been quite positive.

I would say, again, that I think it is important to continue to track. I mean, I think you could easily, it seems like you could almost get to a place where this is so accepted that people really aren't watching. And I think it would be important not to get to that place. Because it is something that there needs to be, you know, there needs to be some hoops that you go through. There needs to be some watching, some care and caution involved, so that there is a clear process. And people really do have to, through the process of waiting two weeks, etcetera, really think about what they're doing. That it is not just a rash decision. Not so much only for that individual, but also because of their families.

I mean, I think something I learned in covering it is that it's the family that's left. And they have to wrestle with how they felt about the path that their loved one took, and their own feelings of loss and even abandonment in some cases, if a loved one decides to do this. And obviously it cuts short the period that they're alive. And that can be hard on a family. So I think we do have to continue to track and watch and take this very seriously. And you know, be sure that we never get to a place where it's just something that sort of oh, everybody's doing it. It should never get to a place of where it's sort of a relaxed environment around this practice.

Kronenberg: Thank you very much. This interview with Erin Hoover Barnett took place on Wednesday, March 2, 2011, at the Oregon Medical Association in Portland as part of the History of Medicine in Oregon Project of the Oregon Medical Education Foundation. The interviewer was Jim Kronenberg, and this is the end of tape one.

[End Interview.]