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Compassion and Choices: The Rights of the Terminally Ill

EXPANDING AND PROTECTING THE RIGHTS OF THE TERMINALLY ILL

Hosted By: Susan Dolan

Guest: Barbara Coombs Lee. Ms. Lee is an attorney, nurse, a physician's assistant and the President of Compassion & Choices, an organization dedicated to expanding and protecting the rights of the terminally ill. Ms. Lee welcome to the Clinicians Round Table.

SUSAN DOLAN:

Ms. Lee, welcome to the clinicians round table.

BARBARA COOMBS LEE:

Thank you. It is wonderful to be with you.

SUSAN DOLAN:

Tell us about Compassion & Choices and how it began?

BARBARA COOMBS LEE:

It began after an initiative, <_____> was taking the initiative in Washington State failed and the advocates for that were some of the most active people on behalf of AIDS patients in the state and at that time it was the height of the AIDS epidemic. There were a lot of people who were looking forward to a really desperate, difficult, very painful end-of-life experiences. They had witnessed their partners undergo the same and there were a lot of violent suicides among those people, people jumping from bridges and things and we as advocates, so that’s a shame, that’s wrong. That shouldn't be seen as the only alternative for peaceful dying and they decided that they would become sources of information and steadfast nonjudgmental witnesses as people made their path to peaceful dying (1:30). So they researched how people could have a peaceful death. They stayed with people as they made these choices and even sat at the bedside, so they were always very transparent and open about the eligibility criteria about the guidelines and safeguards and about what these volunteers did, but that is how they began and really in service to people who were searching for a means of peaceful dying, and then over the years we branched into various funds of advocacy, legislation, and litigation and now we are about 4.5 million dollar organization that is national.

SUSAN DOLAN:

Where are you located?

BARBARA COOMBS LEE:

We have two home offices, one in Portland, Oregon, and one in Denver, Colorado, and then we have about 60 local groups affiliated organizations and chapters and we have volunteers essentially in every state of the union.

SUSAN DOLAN:

What led to your interest in quality end-of-life care?

BARBARA COOMBS LEE:

Well as you mentioned in your introduction I was a clinician for many years. I was a nurse, a nurse practitioner, physician assistant. I worked in Intensive Care, I worked in Public Health. I worked in just about every setting of medical care and I saw some, what I would regard as a very good life affirming death and I saw some very desperate agonized deaths and I determined that I would like to do everything in my life to optimize people's opportunity in order to have peaceful deaths. Then I went to law school (3:00) and I did some work with the Oregon legislature and I saw how laws are made. You know, there is the old adage; there are two things you don't want to see being made and those are sausages and laws and that's fairly true. It’s a difficult process that doesn't always have a good outcome and I didn’t think that the law making process was working very well for dying people. So I kind of put the two parts of my training together, the clinical part and the legal part and decided to see what I could do to improve things.

SUSAN DOLAN:

Give us an update on state legislation regarding end-of-life care.

BARBARA COOMBS LEE:

I can say that there is a pending bill in the State of California that I think is a ground breaking bill and that is what we call the terminally ill patients right to know law, and what that would say is that when a terminally ill person begins a conversation with their doctor about end-of-life options, says "hey doc, what's in store for me. I know that my time is limited, my illness is terminal. Are there some choices that we need to make?, what are those choices?" In response to that, physicians need to deliver a candid and a comprehensive discussion about end-of-life choices. For some physicians, it's a little bit of a common reaction I guess, if you are not comfortable talking about these things, it is easy to say "well, let's cross that bridge when we come to it" or "don’t worry about that, leave that to me."(4:30) This bill empowers patients to say well "I really want to have this conversation and if you and I can't have this conversation, could you tell me where I could have this conversation, and a physician then must refer the patient to some agency in the community and there are many, many who do this kind of end-of-life case management who will talk with the patient about what choices that I had.

SUSAN DOLAN:

Ms. Lee how did you respond to those who say lawmakers shouldn't meddle in physician-patient relationships?

BARBARA COOMBS LEE:

I think that lawmakers should not meddle in physician-patient relationships insofar as those relationships are intimate and personal and idiosyncratic to the situation, but I think it's right and proper for lawmaker to create broad categories and benchmarks and say these are the standards of good care. This is what patients do deserve and sometimes lawmakers just have to intervene and provide those benchmarks when the medical profession itself is not and a good example is informed consent. That’s a principle and a set of laws that I think that those are good principles that when patients are making medical decisions they need consent and their consent needs to be informed. Now that document of informed consent didn’t come from the medical profession, it came from person in the courts and then clarified by legislatures (6:00). Now, that doesn't mean that legislatures should get into the intricacies of what all of the options are that are discussed, when that informed consent takes place, etc., but at least the lawmakers say this is what the standard is for patient information and patient consent when a medical procedure is contemplated.

SUSAN DOLAN:

Ms. Lee what do you believe are the biggest misconceptions doctors have about end-of-life care.

BARBARA COOMBS LEE:

Of course, this is <_____> and I would profess this by saying that the medical community physicians have made enormous strides in the last 15 to 18 years in discovering the problems in end-of-life care and in addressing them. Physicians know more about hospice. They refer patients to hospice more now than they used to. They understand more about pain and symptom management. They are more generous with opioid analgesics and more willing to let that patient direct their pain care than they ever had before. I think the one thing that many (7:30) physicians do not realize still though is how much patients appreciate frankness about their terminal illness and their prognosis and being included in the decision making process. Many people enter the last phase of their lives, last few weeks or months of their lives fully intending to exercise the same kind of responsibilities and personhood in that last phase that they have in their lives. That’s the essence of the quality of their lives and so they don’t want to turn over all the choices and turn over all their control to their caregivers. They want to be co-decision makers. That doesn't cast any aspersions on their relationship, their respect for the doctor's learning, and the doctor's advice, but it does say something about what it means for them to be a person and a participant in their own dying. I think that that’s a big area where palliative care physicians really all physicians who deal with dying patients and hospices and palliative care programs; I think that’s an area that could evolve substantially to great improvement in the next few years.

SUSAN DOLAN:

You mentioned patient directed pain medications. Tell us more about the efforts of Compassion & Choices in that regard.

BARBARA COOMBS LEE:

Many years ago we were instrumental (9:00) in passing a Pain Patient’s Bill of Rights in the State of California and that has become a model act and that essentially says that a patient in pain has the right to any and all current medical modalities to treat their pain and that essentially means that the proper dose of pain medication is that dose that relieves the patient's pain, and when a patient is dying they are likely to experience rapidly escalating need for pain medications. I fear that the patient may be turning into an addict is not a valid fear. A fear that the pain medication itself may cause the shortening of the patient's life when the patient is nearing the end of the life that is not an appropriate reason to cut back on pain medication. Essentially what the patient needs in order to alleviate the agonies of dying, that’s the appropriate dose of medication. So that’s what that bill did. It really kind of established that it's the patient's right to be relieved of pain in any and all modalities to do that. Those are the proper modalities. Another bill that Compassion & Choices was behind and has become a model bill is one that understands that physicians who might have been trained at that time when pain and palliative care were not prevalent or not part of the training, they may need some additional medical education (10:30) in order to maintain currency and in order to have just the skills and the knowledge to deliver good end-of-life care to the patient and so it's a condition of licensure and renewal of licensure in the state of California that the physicians be current and have attended some course work in pain and palliative care. It met some resistance, but in the end the California Medical Association supported that bill and a feedback that we have gotten has been very, very good from physicians who essentially didn’t know how far pain and palliative care had advanced and didn’t know about the techniques that they could be using to relieve the patient's suffering.

SUSAN DOLAN:

How do you respond to patient's family, healthcare professionals that do say that morphine is killing the patient?

BARBARA COOMBS LEE:

You know new evidence is that it is extremely unusual for even very, very high doses of morphine and other opiates to actually impact on the time of death. The truth is that the patient's tolerance of these medications rises so quickly that really the opiates are only relieving the suffering and not causing death, but even in cases where the level of pain medication is raised and the patient's death follows soon after, I think it is absolutely appropriate to say that it is the underlying disease that caused the death of the patient. The patient is dying of cancer and the suffering and pain associated with (12:00) that called for the best that medical has to offer and the best that medical care and medical science has to offer is the relief of suffering when death is imminent.

SUSAN DOLAN:

Ms. Lee thank you so much for joining us to discuss Compassion & Choices.