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Can Unfounded Hope Harm Patients?

IS THERE SOMETHING WRONG WITH BEING AGGRESSIVELY OPTIMISTIC?

Welcome to the Clinician's Round Table. I am Dr. Leslie Lundt, your host and with me today is Dr. Lawrence Schneiderman, professor emeritus in the department of Family and Preventive Medicine and adjunct professor in the Department of Medicine at the University of California, San Diego. He has had a distinguished career in medicine and ethics. He is the founding co-chair of the UCFP Medical Center Ethics Committee and he has been an invited visiting scholar and visiting professor at institutions across the United States and abroad. Dr. Schneiderman is the recipient of the Pellegrino Medal in medical ethics.

Dr. LESLIE LUNDT:

Welcome to ReachMD.

Dr. LAWRENCE SCHNEIDERMAN:

Thank you for inviting me, pleasure to be here.

Dr. LESLIE LUNDT:

Dr. Schneiderman, in your recent book "Embracing Our Mortality," you devoted entire chapter to the question, what could be wrong with hope? Tell us about that.

Dr. LAWRENCE SCHNEIDERMAN:

Well, what could be wrong with hope is if it is not realistic, it does not help the person, it might even harm the person. A good example is when I had a patient with metastatic breast cancer. She was actually a friend who came to me and asked what should she do because an oncologist had been recommending ablative chemotherapy and bone marrow transplantation and as far as I knew, at that time, this is before the randomized control trials were done which showed that it was of no benefit. I told her that in my opinion there was no good evidence to support such a traumatic procedure. That was not good enough. The oncologist gave her hope and so he said, we should do it because this is a kind of procedure that will give you hope and it turned out to be a very disastrous tour for her. She suffered a lot and in fact later when it showed that there was no benefit she was quite characteristic in that she did not live any much longer than she

would have with what was then considered conventional chemotherapy.

Dr. LESLIE LUNDT:

Has not hope been shown to be a positive factor in patient's recovery though?

Dr. LAWRENCE SCHNEIDERMAN:

In fact, no.

Dr. LESLIE LUNDT:

No.

Dr. LAWRENCE SCHNEIDERMAN:

In fact, that whenever people make this claim and I examined it in good randomized double volume control trials where they really try to see does an optimist attitude does instillation of hope, really prolong life, or help the patient? The answer always turns out to be no and these are cited in my book. For example, there is a famous study called support study of over 1000 patients who are terminally ill. What they did was they compared the outcomes of patients whose prognosis was worse than their own estimation of the prognosis. In other words, these were patients who when asked how long do you think you will live, how well do you think you will do, they were far more positive and hopeful than the physicians who had what was obviously a more realistic estimation. It turned out that these patients did not live any longer and all they did was suffer more because they underwent procedures like ventilation, attempted CPR with all the traumas associated with that and without any evidence that their lives were prolonged.

Dr. LESLIE LUNDT:

What does the research tell us about physician behavior with regard to hope?

Dr. LAWRENCE SCHNEIDERMAN:

Well, it is very variable. Physicians as it turns out have a hard time dealing with giving bad news. There are a variety of reasons. One of those that I suggest is physicians really think that they are exceptions to the rule that they take such good care of patients that their patients will do better and also there is a problem if a physician tells the patient, "you know what, you have got a bad disease and your median survival is only 3 months." This may be reporting the best studies, but if the patient lives 6 months or a year after all which we would expect with the distribution, just random distribution, the patient is more likely to say "Oh, that dumb doc, he told me I was going to be dead by now, look at how long I am leaving." Doctors hate to hear that and I think that that may be one of the factors.

Dr. LESLIE LUNDT:

Now, I am thinking that as you are speaking that is this different from culture to culture, so I would guess that in the United States, we are much more aggressive about these sorts of hopeless treatments than they are in other parts of the world. Is that true?

Dr. LAWRENCE SCHNEIDERMAN:

Ya, that is true, that in fact in Europe, they just think we are bizarre. There was a famous case that I think that doctors must have heard about the Terri Schiavo case, where this was a young woman who was permanently unconscious and was kept alive for over 15 years and the family, the parents as did the husband. The parents were hoping for a miracle and were insisting that Terri Schiavo be continued on a feeding tube. In Europe, this is a famous case as an illustration of those crazy Americans, how could they do something that stupid to continue medical treatment for someone who was so beyond the chance of survival. There were some cultures and they are in this country, the Native American culture and some religious traditions that also believe that if you give the patient bad news, it is bad for the patient. This has never been tested, but it is truly a cultural phenomenon.

Dr. LESLIE LUNDT:

Is there more attention now being put on these issues with all the discussion about cost containment. Clearly, these things must cost an enormous amount of money and put added burden on her healthcare system. Well, there is no question that one of the issues we are going to have to face is the rationing of healthcare. What I like to distinguish between telling the patient and deciding on a treatment based on its medical indications, if the treatment is futile for example if there is no realistic chance the patient will benefit than that treatment should not be offered, whether it is cheap or expensive. This will then give us a new line on those treatments, which could be beneficial which we have to decide how to distribute them. For example, heart transplant. Clearly, if someone is in end-stage congestive heart failure, receiving new heart could benefit that patient considerably. The problem is we do not have enough hearts to go in all the people who need them and so we will in the future have to deal more realistically with the notion of rationing. Right now, it is the R word. Politicians are still saying the absurd thing "Oh, we cannot have rationing in our country, that would be bad or we cannot do this because that would be rationing." In fact, we are rationing irrationally now and we just have to hope that some day we will come to our senses and be able to make a better distribution of our healthcare resources.

If you are just joining us, you are listening to the clinicians' roundtable on ReachMD XM 157, the channel for medical professionals. I am Dr. Leslie Lundt, your host, and with me today is Dr. Lawrence Schneiderman, author of the Embracing Our Mortality. We are discussing what is wrong with hope.

Dr. LESLIE LUNDT:

Dr. Schneiderman, just promoting the belief and hope force us into really what is an uncannable position as physicians.

Dr. LAWRENCE SCHNEIDERMAN:

Well, and let me just say that physicians can be honest as well as giving the patients a good realistic sense of hope. Remember, when we talk about the average lifespan in a patient, say who is being treated for cancer. What we are talking about is the median survival. In other words, we are saying that with this treatment, this disease, at this stage, the person in the middle of them and not what we call the average, but in fact is the middle person will survive 3 months. That means that half of them will survive fewer months and half will survive more. You can tell the patient "you know, you may well be in the long tail of the curve, that is good." The other point to make is when you tell a patient that you have cancer, you know that is the big deal nowadays, do you tell the patient she or he has cancer and nowadays we are supposed to say yes, but that is not the whole truth. You have cancer, here is what we can do for you, here is what we will do so that you can be reassured that no matter what happens, we will stick with you and if pain is a big problem, this is what I tell

patients, I guarantee, I use that word, that we will treat the pain to your satisfaction and we can control it. It may in certain extreme cases require that we give you such high doses of pain medicine that you are sedated, but if that is what you want, do not be afraid. Under those circumstances, patients usually are willing to say "Okay, I will give a try to the treatment that you recommend, knowing you would not abandon me.

Dr. LESLIE LUNDT:

In your book, you mentioned 3 types of what you call patient narratives. Tell us about those.

Dr. LAWRENCE SCHNEIDERMAN:

Ya, this was something by David Icsci. He kind of came up with 3 categories, which I thought were you know very insightful. Patients can respond in what he called a linear restitution narrative. In other words, here comes the disease. I had great plans for my life, I am going to continue those plans no matter what and I am going to expect a miracle. People like this when they hear they have cancer and they may not live long enough to see their son graduate from college, which of course is a very sad experience. They will run around all the quacks in the world, looking for that miracle and they really just will not accept the fact that they are mortal, that is what he calls a linear restitution. I am going to continue no matter what it does to other people and will not do anything to me. The second one is what he calls a linear chaotic. This is sort of the opposite, but it is also the same. In other words, when the disease comes, these people feel windy, they get very angry, they go to pieces. They say "how could this happen to me, I will not understand and the world is a cruel, terrible place." It is nature. We live and we die and that is why I call it embracing our mortality and this is what the third group, what he calls the polyphonic. These are people who are constantly experiencing what is good about the life that they have and can take pleasure in the simplest things. I had a patient, actually a woman, who had chronic fatigue syndrome and the interesting thing is I discovered this in a patient with not cancer, but with a chronic condition of mysterious origins. She was hopeless when she came to me. She had this enormous chart because she had seen every specialist you could imagine all of whom could come up with nothing to help her and I just decided to tell her, look you have a condition that is fatiguing you. If you had cancer, what would you do with this fatigue, would you just sort of crump out and stay in bed? No, would not you try to make the most of every moment of your life. Get out there and push yourself. Well, you are lucky in one respect. You do not have a disease that is going to kill you. So, why do not you just go ahead and do the best you can. Well, week after week after week, you get pushing yourself, experiencing what she was able to, not concentrating on her limits but on her possibilities and this helped her enormously. She was able to recover and I think that this is what we try to help out patients discover at the end of life. It is not that you are limited completely as you have got things around you the air, the smell of you know the leaves, your children, voices, friends. All those things are very important and we can appreciate much more as Samuel Johnson said if we know we are going to die and be hanged in a week, we concentrate our mind considerably and I think that is what we can do.

Dr. LESLIE LUNDT:

Well, thank you so much for being on our show today.

Dr. LAWRENCE SCHNEIDERMAN:

My pleasure to be here. Thanks for inviting me.

We have been discussing Embracing Our Mortality with our guest today, Dr. Lawrence Schneiderman. I am Dr. Leslie Lundt. You have been listening to the clinicians' roundtable on ReachMD XM 157, the channel for medical professionals. If you have comments or

suggestions, please call us at 888 MD XM 157.

Thank you for listening.

This is Dr. Alan Hemming, professor of surgery and chief of transplantation and hepatobiliary surgery at the University of Florida in Gainesville. You are listening to the first national radio channel created specifically for medical professionals, ReachMD XM 157.