

Palliative Care: Communication and the Patient Experience

Resources - Video 4

Kerry Bowman:

I'm Kerry Bowman from the Joint Centre for Bioethics, and I also work in the Toronto teaching hospitals, and I've spent a lot of time working on end-of-life situations. We have to really ask ourselves, you know, are we avoiding this situation, are we frightened by the situation, because we really, really have an obligation. People can easily think, well, you know, end of life is only for a core group of palliative care and specialized people. That's part of - and those people are wonderful, but that's part of the problem, is people feel "I'm not qualified to do it; therefore I'm not going to do it", and therefore no-one does it and in fact you have people isolated at the end of life. So they're not situations to be avoided.

A very important consideration in end of life, you know, within any medical setting and particularly hospitals, we work in teams, and communication is really, really important. So although the physicians may make the ultimate medical decisions, we're working in teams. And it's not rare in those teams that a family or a patient may turn to someone in allied health - that could be, you know, a rehab person, it could be a social worker, it could be a dietician, it could be anyone. And maybe they know that person better; maybe they're more comfortable with that person. So it's important we not just assume that these conversations are only ever going to occur between physicians and their patients. I have seen many times where patients or their families find - for whatever reason - they're actually more comfortable with someone else on the team.

So, you know, although that person may not be a decision-maker, that person really can and should have a respectful conversation. And you know the most important thing is to listen to what the family is saying; offer them support; tell them how the system works. You don't have to give advice; it's not about giving advice. How do things work. What are their values; what are their wishes. Anyone on the team can and should be able to do that. We as healthcare workers can make medical recommendations, but really only the patient or their family can decide what value they put on those recommendations. And, you know, the - ideas like - concepts like quality of life are very interesting to concepts, but only a person can decide that for themselves. When you look at another human being's life, and say "that's not an acceptable quality of life", that's a BIG judgement. Because we're not

all the same, and we live with different cultural and religious values. And we need to acknowledge that.

You know, another thing that comes up with end-of-life for a lot of healthcare workers in Canada - and to be honest with you increasingly so - is the question of euthanasia. And we have to be very clear on this for now, because I want to be very clear: right now, under Canadian law, if we did any action that would hasten a patient's death, that would be considered euthanasia and that would be a criminal charge, and a serious one, under homicide. But that too is being challenged in the Supreme Court of Canada, so that may change with time [and did, in June 2016]. But it's very important that if patients come to us with those kind of requests that we don't over-react. And we need to gently tell people exactly where the laws are at, and what rights and options they have, without becoming too judgemental of those types of things, because there's more and more of that in the media. But what a patient can do - or their family - is say "I no longer want this treatment", even if that treatment's keeping them alive, like a breathing machine. They can say: "I don't consent to this; I don't want it." Anyone can refuse treatment. So they can then come off life support machines. Where the difference is, is if a patient says, "I want you..." - the medical person - "...to give me an overdose of something that will end my life." That's radically different from a legal point of view, and that, in fact, would constitute a homicide. There's a big difference between these two things; it's extremely important we understand the difference at this point. But also, you know, we need to support our patients, and we need to have conversations with them, even if these conversations are difficult.

The role of the family is to tell us what they believe their loved one would want, based on conversations and values. But that can't be different than what the patient would want. So it's not that the family decides; it really isn't. We're using the family as a way of them expressing the patient's wish. And if you do know, somehow, that the family is saying something significantly different than what the patient has told you when they were capable, then you've - you've really got to work on that. You can't accept that as it is. So it's always the patients' wishes, and, if the patients can't speak for themselves or can't communicate in any way, then in fact we're asking the families. But we have an obligation to explain to families what it is we're asking, and why we're asking. Cause if we don't do that, we're not being fair at all.

It has never been more important to communicate clearly and respectfully in end-of-life than it is right now. It's - it's important on an ethical level, but it's also important, you know, on a procedural level because we're in a state of

transition. So our communication skills are something we all need to really, really work on in this area.