

Speaker 1: As part of the University of Michigan's Bicentennial Celebration, the U of M library brought StoryCorps to campus to capture personal stories of the people who make up the university's rich history. The University of Michigan is world-renowned for its breakthroughs in pediatric medicine, but sometimes children are so sick that the possibility of living a normal life is unlikely. And that's when the Pediatric Palliative Care Team steps in. U of M Medical student Trisha Paul was blown away by the team's work, so she invited her professor and mentor, Dr. Ken Pituch, to sit down and talk about how he handles such difficult circumstances, as well as the groundbreaking research he's doing to ease the burden on families facing these arduous decisions. Dr. Pituch began the conversation by describing the role his Palliative Care Team plays in a child's care.

Dr. Ken Pituch: We're the anti-suffering squad. Our job is to minimize the pain, the misery, the turmoil that's associated with undergoing treatments for a disease while other specialists are still working on trying to make you as good as you can be, physically.

Our job is to try and help all of those things around the edges, and sometimes it's in the middle. Sometimes it's helping with symptoms that nobody else has quite figured out how to take care of. Could be pain, digestive problems, constipation, itching, nausea. But often it's the other things that make it really difficult to deal with a serious illness, the social disruption that it causes, the strain on relationships, the spiritual uncertainty that people have. Somebody on the team that can help them face answers to the question, "Why me? Was it my fault?" So, Palliative Care Teams have evolved in almost every large hospital, both adult and pediatric, around the United States, with team members that include physicians, nurses, social workers, spiritual care providers, sometimes psychologists, child life specialists. Everybody who can have something to add.

Trisha Paul: I think it's great to see how those services have now become available to children as well. What is something that you are passionate about in your job?

Dr. Ken Pituch: One of them is really focused on the things that we do in the hospital and that's to help everyone get better at conversations that we have to have with patients and their families when they're facing a major decision about what do we do next for someone who we know is not going to get better. Nowadays, we have technology that can keep people alive for a long time. The problem in the hospital that we're facing is that parents are asked when children are not likely or even within any realm of the possible to get better to the point where they can walk out of the hospital or be able to walk and talk and eat and play and smile that parents are still faced with these really, really tough decisions. What we're finding in our research is that when these decisions come up, we're not very good at presenting the options and the decision in ways that make for a decision that can be accepted without great, great pain and sometimes great, great regret of whether or not the decision was made appropriately or not.

That's one of my passions and one of the research projects that we're working on, and one of the curricular endeavors that we've embarked on, to try and find out what is the best way to have these conversations with parents who may be facing

these tough, tough decisions. You've had a lot of conversations with young people who've had cancer.

Trisha Paul: Mm-hmm (affirmative).

Dr. Ken Pituch: Any particular story that you can remember that was about communication and how it helped somebody face an awful diagnosis and a grim prognosis?

Trisha Paul: I think for me the two examples that come to mind is one teenager I talked to who, after I spoke with him for about an hour about his cancer and what it means to him, he told me about how he didn't think he had ever really spoken about his cancer this much. To see that there was a patient going through this experience and not having the opportunity to talk about it was, I think, disappointing to me. As I've progressed throughout my medical education, I've seen how the medical system really swallows up patients, especially teenagers and pediatric patients.

I think on the flip side of things, one of the kids I spoke with who was in remission, after talking to him, even though he was six months out from his cancer treatment, our conversation really enabled him to cope better with the experience that he had had. He really opened up after that with his parents. His mom expressed to me later how grateful she was that that conversation had enabled him to move past some of his experiences more productively.

Dr. Ken Pituch: Yeah, I've seen the same kind of things happen. You asked me about passions and I told you about my first one, which was this communication piece. But the other involves all of those kids and it probably is two-thirds of all the kids that we get asked to see in the hospital are not going to be dead within a year or two, but they're never going to be better. Many of whom spend more than two weeks a year and some who spend four months out of a year in the hospital. The way support has developed for these kids, their specialists are often just focused on their own area of specialty and there's nobody who feels competent in holding it all together and figuring out for this child that has a neurologist, a gastroenterologist, an ear nose and throat doctor, a pediatric surgeon, a physical medicine specialist, that the average number of medications that these kids on are nine or more with a total number of doses of medicine administered in the 20s or 30s. Full time job for a mom, and the mom will say sometimes, "You know, I'm a mom. I'm not a nurse. This is hard." And it really is.

So, what we're trying to develop here in Michigan like they've done in a handful of other states is to come up with a better program, so that there are folks who can learn how to look at all sides of this problem, figure out who are all the players involved in their care. Can we streamline their number of appointments, their numbers of medications, and be available so that the mom knows who to call when their kid starts to cough or vomit or have worsening seizures, so we can keep them out of the emergency room and out of the hospital.

In places where they've done this, like California and Wisconsin, they not only increase the satisfaction of the families that are involved in these programs, but they save the insurance companies, sometimes it's state Medicaid, they save over \$1,000 per patient enrolled in these programs per month. So if we enroll 100 kids in a program like this, we hope to be able to demonstrate to our payers that this would be something worth investing in.

Trisha Paul: I feel as though the services you described really fill a void in medicine, where amidst all the other sub-specialists, I think that palliative care really helps to maintain a parent's perspective and a child's perspective and their goals and make sure all that's happening from a medical standpoint really aligns with what's best for the patient and the family as a unit.

Dr. Ken Pituch: Our hope is palliative care, as we know that there is so much disease out there, that palliative care specialists will never be able to do all of the conversations, communications, symptom assessment management. What we need to do is make sure that every physician and nurse who works with seriously ill patients has enough background to be able to do probably 80% of the communication and the symptom assessment that we do, and that we can really split our time between dealing with those patients who really need extra expertise in this area and spend the rest of our time involved in the educational efforts to help everybody else get good at it.

Trisha Paul: I think as an English major, the communication aspect and how palliative care is able to engage in those difficult conversations that often go unhad in other areas of medicine, that's something I've really appreciated. I think that I'm excited about looking forward and thinking about how palliative care education for everyone is really something that I think is becoming more and more established across the country. I think it would really help to move medicine forward in great ways.

Speaker 1: That was Dr. Ken Pituch and medical student Trisha Paul discussing the groundbreaking work of U of M's Pediatric Palliative Care Team. These interviews were recorded by StoryCorps, www.storycorps.org. For more from the series, just visit arts.umich.edu/storycorps.