

BOISI CENTER INTERVIEWS



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RONALD LACRO M.D. is a pediatric cardiologist with Boston Children's Hospital and the Harvard Medical School. The following interview is an edited version of Dr. Lacro's conversation with Erik Owens, associate director of the Boisi Center, during "Religion, Spirituality, and Compassionate Healthcare" a February 13, 2018 event co-sponsored by the Boisi Center, the Connell School of Nursing, and the Medical Humanities, Health, and Culture Program of the Morrissey College of Arts and Sciences.

FROM BOISI CENTER ASSOCIATE DIRECTOR ERIK OWENS:

I came to know Ron a day or two after my son Nicholas was born at Brigham and Women's Hospital on March 3, 2009. Nick was born with a severe form of early onset Marfan Syndrome that caused rapidly progressing heart, lung, and spinal problems. In his short three and half years on this earth, he endured, with awe-inspiring grace and courage, several life-saving surgeries, dozens of other medical procedures, and the frequent use of ankle braces, spinal braces, supplemental oxygen, and ultimately a bi-pap machine that helped him to breathe. He passed away at our home on the evening of September 30, 2012, a little more than five years ago.

Nick had a strong and joyful spirit, and he loved his doctors, his nurses, his therapists, and all of his other wonderful caregivers, but none more so than Dr. Lacro, who served as his primary caregiver and his medical team leader. So we are bonded together, forever. It is not simply because he cared for my son at a critical time, but because of the way he cared for him, and so many others as well, combining rigorous research-driven medicine with a deep commitment to compassionate care that recognizes the physical as well as the religious and spiritual needs of his young patients and their parents. It was my pleasure to speak with him about his life and work.

OWENS: You were raised Roman Catholic and born on the island of Hawaii, which has a deep tradition of Buddhist culture as well as indigenous Hawaiian spirituality and religious traditions. In what way did these early religious and spiritual traditions make their way into your decision to be a physician, and per-



haps a pediatrician?

LACRO: For those of you who have been to Hawaii, our house was about a half-hour from the active volcano at Volcanoes National Park; it was sort of our backyard. I took everything for granted, back then. But I grew up in Hawaii as one of ten children in a Roman Catholic family out in the country. It was a small town, a little over 1,000 people, so everybody knew everyone else. Both of my parents

worked. The Church was a big part of our lives. We went to church every Sunday. I was an altar boy and a church organist as a high school student.

My parents really emphasized education. They were not college graduates, but it was almost understood that we would all go to college, and most of us did. Most of my older brothers and sisters went to Catholic universities, but I sort of rebelled and went to Northwestern University, near Chicago.

But I think from very early on, I have considered myself – even though I've been in Boston for thirty years – a big-family, small-town Catholic boy. That, I think, really informs a lot of how I approach everything. It's all about family and connections to families, and stories; and it all started in this little town called Naalehu.

OWENS: How did you come to recognize that working with children as a medical professional or specifically as a doctor was your path? What was your moment of commitment when you decided that that's where your life would take you?

LACRO: I didn't really decide to go into medicine until high school. For me the big decision was whether I was going to be a pediatric cardiac surgeon, or a pediatric cardiologist, or a pediatric something. I always knew my work was

going to involve being with children and their families.

Maybe because of my background in a big family, there were always kids younger than me around. So it was natural, and it was just a matter of trying to decide whether I was going to be operating on a little heart, which I considered for quite some time, or taking care of the medical aspects of heart disease, which is what I do now.

OWENS: You had to go through many years of training to receive all of your specialties. How did your formative experience of being trained in all these different places and disciplines shape your vision of how health care ought to be delivered?

LACRO: First I want to mention that I was born, actually, with a heart defect. It was not a major one, I never required surgery, but I was aware of the fact that my heart wasn't completely normal. Here I am, almost sixty years later, taking care of children and families with heart disease. So I think having been to the hospital and undergone procedures, that was a formative experience. Back in those days, little kids were not told things: When they did a catheterization, they just took my arm and put catheters in. I guess my mom knew what was going on, but they never really thought to tell me anything—how long it was going to take, whether I was even going to survive the procedure. It was a very different time. So that informs me, clearly. That has helped me approach families, especially children.

I've had other experiences as well. I think maybe the best pathway to compassionate care is to put yourself in the hospital, or be put in the hospital. This is because even as an adult, as a patient, you see health care in a very different light. I think that, perhaps, even more than any of the educational experiences that I had, really got me to understand what it's like to be a patient facing potentially serious illness in a hospital, whether alone or in the context of a family.

OWENS: How did you learn to talk to young patients and to families? For most of us, it's the scariest thing in the world to have that conversation—especially when sending bad news.

LACRO: I've been fortunate to have been able to observe other fabulous physicians through the years who do it well. I think the best way to learn how to have these

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conversations is to observe others who do it well.

In the best of circumstances, I think having these conversations in some sort of context is helpful. It's much easier if I have a relationship with a patient or a family. You and I worked together for several years, had some very difficult conversations probably from the day we met. I think it's trying to find a way to transmit enough information but not too much, and over time to get to the point where maybe everything can be revealed and understood. I don't think we can do it in a hurry. One of my worries about how medicine is currently practiced is that sometimes the importance of the time is not recognized or compensated.

OWENS: Does one get better at it, or is it always something new and contextual that comes to you in a different way?

LACRO: I think one can always get better at it. Some people have a more natural knack for having conversations. It's about learning stories, it's learning about people, it's learning relationships and

hearing their stories. It's about providing a setting for discussing vulnerability or allowing vulnerability to be accessed. It's much easier to talk about than to do.

OWENS: One of the paradoxes of talking about compassionate care is that nobody wants to provide uncompassionate care, presumably. How do you separate what is compassionate care and what's not?

LACRO: I would hope that every encounter would have at least compassion. Some encounters are clearly not as important as others. A quick visit to urgent care may not require as much of a connection, although I think even in these smaller moments a connection can be important. Whether it's just taking a moment to figure out what someone's interest is, or what's important in their life, it only takes a few seconds. It can change the whole feeling of the conversation. So I think even when I expect an encounter to be brief, I try to make contact somehow. Sometime it may be something physical—one of the biggest lessons I learned was actually from my own physician in a time when I was hospitalized, and physician after physician were coming in to say everything was fine and that I would be going home. My primary care physician came and he sat down. Just the act of sitting down and being present was important. He didn't even have to say anything after that. I think that was the connection that I needed.

OWENS: What is it about pediatrics that offers a different way to be compassionate? Of course, we're talking about children and their families. But does it make compassionate care more achievable when you're dealing with children and in what ways?

LACRO: The reason I can go to work every day is because I can always count on seeing a kid. I think there's something special about taking care of kids. It's usually not something that they did wrong that brought them to the hospital so I think there is that naiveness or innocence that is special. But I think also a kid usually comes with a family. This is

unlike adult medicine where all of your encounters, or most of your interaction, is with that adult patient, generally. You're never only dealing with a patient in a pediatric setting. There's always someone else. There's always family or community. I think that's a great part of why I enjoy the work that I do.

OWENS: In your training and in these conversations do you speak using a language of accompaniment, which is a language sometimes used in theological circles? If so, how does that relate to the expectations that patients or parents put onto you?

LACRO: I see my work as “journeys with.” I've been in practice long enough that I have families where I diagnosed their child with heart disease before they were even born, and now they're graduating from college. For me that's just the amazing thing, to have the journey of having to tell this pregnant couple that their child is going to have this very serious heart defect and require a major operation in the newborn period. With another family, I remember standing at the bedside as the baby was being baptized, and they still see me as honorary godfather. Every year I see her – she's fourteen years old now. So this is an experience of journey and it's the privilege of being able to follow along and join in the trip. Whether it's a good time or a bad time, we're in this together.

OWENS: How do you deal with the religious, spiritual, and multicultural complications that come with working with an entire family on life-or-death issues? Children's Hospital is a very international organization now. They have patients from all over the world. I imagine beyond the languages, there's also values and special religious practices that come into play when you're talking about something as life-threatening and serious as the work that you do. What kinds of encounters have you had and how do you adjust or adapt to dealing with the children and parents in that context?



LACRO: I think first we have to recognize that everybody's different, that for some people it's religion, for some people it's something that's not called religion, but something like religion, and for some people it's something that's definitely not like religion.

There are differences in what patients think and what providers think. This is a bit old now, but one survey I remember shows almost 100% of patients believe in God and find spirituality and religion an important part of their lives. For medical professionals, it's a lot lower than that, and for mental health professionals, it's even lower. For many providers, I don't think it's on the radar; I don't think it's part of the approach. It's something that somebody else cares for. Hopefully, I wasn't like that.

One formative experience I had was through the Schwartz Center just three or four months after 9/11. The Schwartz Center is an entity that started here in Boston. Kenneth Schwartz was a health care lawyer who, at a relatively young age, developed lung cancer without any risk factors. He was a very health-conscious guy and developed lung cancer, and he eventually died. He was moved and touched by the compassionate care that he received at Dana Farber, I believe it was, or Mass General. But his family and

his friends created the Schwartz Center after he died.

The whole focus of the Schwartz Center is to support the idea of compassionate care through a lot of different avenues. One experience is this idea of Schwartz Center rounds where clinicians can come and meet once a month and talk about not just the medical aspects of a medical story, but the religious and spiritual aspects, the impacts on us as people. So they really support these efforts to support compassionate care.

In 2002 I did a Schwartz Center fellowship, and it was an all-day, every Monday, five-month experience. For those of you who are familiar with chaplaincy training, basically it was a unit of CPE, or clinical pastoral education. It was CPE, but this was a very special CPE unit, because none of us were planning to become chaplains, per se. We were all medical professionals, so the class at Mass General, the CPE unit was for physicians and nurses and social workers. There was a pharmacist and a psychologist on my team, as well as a respiratory therapist. The idea was to go through CPE training, not with the intent to become a chaplain, but to learn some of the pastoral skills that chaplains use, in order to use them in our own practices. For example, if we were nurses, our clinical experiences would be at the bedside. For me, it was in

the clinic and fetal diagnostic laboratory. We would take these experiences to our class every Monday, and for five months, we would get better at giving compassionate care. There was didactic stuff, so we learned about different traditions. There was a different speaker every week to talk about Buddhist tradition and Islam, Judaism, Roman Catholicism, the whole line. But the whole idea was for us to learn techniques and language of chaplaincy and to apply it at the bedside or in the clinic.

That experience changed my life and changed my practice. It was partially because it was right after 9/11, but how often do you take that much time to stop and think about what you're doing? I had been in practice for about ten years at that point at Children's and was in need of something else. It really changed my life. I appreciate other people on the medical team because it's clearly a team effort. It takes a village to care for the children and families at Boston Children's. This experience of CPE changed the way I practice medicine.

OWENS: You mentioned that every interaction is a team effort to care for a patient in the line of work that you do. What can you say about how that team works to provide compassionate care? Is there an emphasis? Are some institutionally inclined to provide a different kind? How do you manage different kinds of roles and training without working at cross-purposes?

LACRO: First of all, we need to recognize that as physicians, we spend a very short period of time with that patient and family in the hospital. It's really the nurses and other health care professionals that are running around the bedside, all day. So any important discussion at Children's for seriously ill patients, especially in the ICU, or even not in the ICU, needs to involve all the caretakers, especially nurses, because they're there twenty-four hours a day, and they hear all the stories and they meet more people, because all the visitors come in, and the families. I

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think on average they have a much broader appreciation of what that family unit is really like. So they're a huge part of any big decision or management plan.

OWENS: Have you found that being able to be attentive to these non-medical needs – these non-physical needs, we'll say – of patients has helped the relationship more? Or has the patient gotten better as the result of this? What can be some of the outcomes of a refreshed and more profound relationship with your patients and their families?

LACRO: I think it certainly helps to have a better understanding of where they're coming from. Part of CPE training was just learning what their belief system was. What's important in their lives? What are the practices that are important for them to sustain hope? It gave me a different set of tools to help children and their families sustain themselves. I think the experience is more real the more you know about people. It's not like I didn't do those kinds of things before, but it's almost like I got more permission to talk, just like it was on my list of questions, how is faith important to you? What does this all mean? What is your community of support? What can I do? How should we modify our care to help effect not only the medical goals, but also the spiritual goals?

I think that's the difference the chaplaincy training gave me. Understanding where patients and families are coming from spiritually and religiously can help you find hope. It's a different way of

understanding, apart from the medical facts.

OWENS: On the flip side of that, how do you care for your own spiritual and religious needs in an environment that, for many people, would be overwhelming? Especially over a thirty-year career?

LACRO: Home life with my partner is very important. I think just being grounded. Exercise is important for me. I have a spiritual community. I'm Roman Catholic, but also gay, and that introduces a completely different level of questioning and conflict. I've been a member of Dignity, which is a community for Catholic GLBT people, since about 1990. That's my spiritual home, my spiritual family and community. I'm also a singer and musician, and the music I've been singing for the last fifteen years has been all from the Renaissance, which is deeply spiritual and mostly religious, although not always.

OWENS: Why is it that palliative care appears to be marginalized from the core of medicine and maybe from nursing as well? Can you say a little bit about what palliative care is, what it could be, and what it's not right now?

LACRO: At Children's, palliative care involves what is called a PAC team – Pediatric Advanced Care team. I'm actually much more hopeful that you presented the question about the place of palliative care, at least in our hospital.

Maybe most people think about palliative care as what you do at the very end. You live a long life and then you know you're going to die, and then that's when you get the palliative care team. It's almost as if when they call the palliative care team, that's how you find out it's not good. The approach at Children's has been very different. First of all, a lot of studies show that involving palliative care sooner rather than later actually makes people live longer. So it's not just about dying, but it's about living until you die. I think the approach at Children's Hospital with the Pediatric Advanced Care team is to

involve them sooner, even when there is no likelihood that a patient's actually going to die. There are things that they address and handle much better than other physicians, like comfort and spirituality. Just calling themselves the PAC team, rather than palliative care, helps to reduce resistance to that first meeting.

There's definitely a huge value in palliative care, even in the more traditional sense of palliative care, in terms of making the best of a situation at the end of life. My own sister's care involved palliative care. So there's definitely value there, but I think the movement is towards using the same palliative techniques earlier on in disease to improve life.

SELECTED QUESTIONS FROM THE AUDIENCE:

DEAN OF THE NURSING SCHOOL

SUSAN GENNARO: What changes have you seen in the field of health care? Also, you talked about comfort earlier; given all we are witnessing in this opioid crisis, have there been changes in terms of providing comfort?

LACRO: I think there are challenges in dealing with chronic pain, and the regulations and the difficulty with prescribing. That's not part of my practice, largely. I think when it comes to end of life care, I don't think there's much conflict in terms of use of opioids for comfort. I think the challenge is trying to find a balance of opioids and other anti-pain regimens to manage chronic pain.

THEOLOGY PROFESSOR JEFFREY

BLOEHL: I was interested to hear the word vulnerability come up. I wonder if you could say something about the vulnerability of the doctor? You were talking about person-to-person care giving and the doctor, as a person, has to contend with and maybe show some of his own vulnerability.

LACRO: When I mentioned vulnerability, I was thinking about my own as well. It's vulnerability, but I think it's also a path to richness in a relationship. It's not universal, by any means, in the medical field.

OWENS: What's at risk when you're vulnerable with your patients or their families?

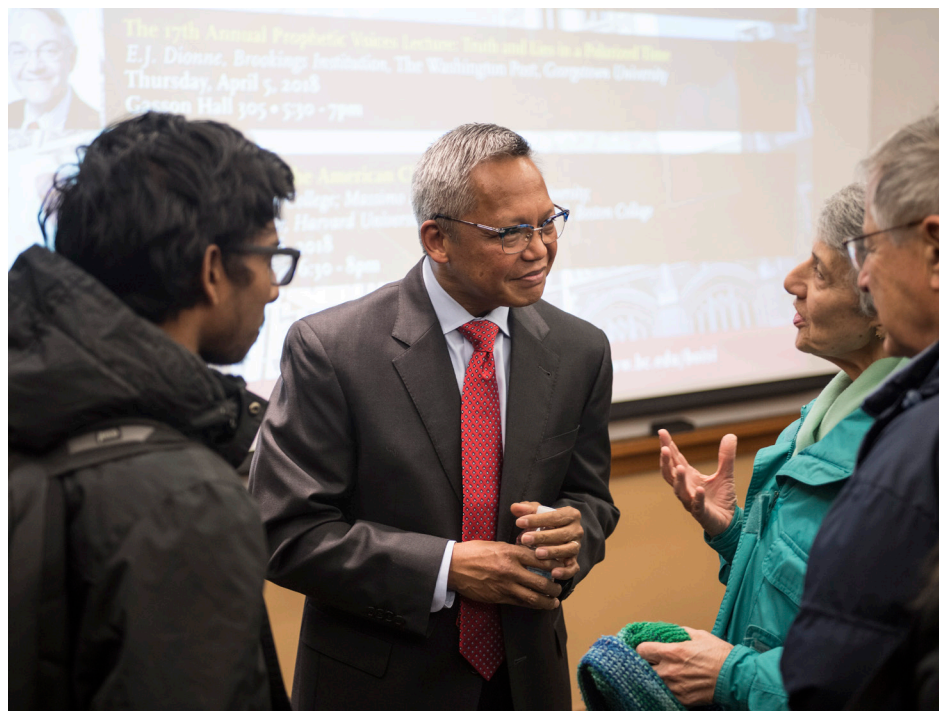
LACRO: I think most of us are just trained not to be open to fear: It's not about us, it's not about me. But it's hard to have a conversation about important things in life and not talk a little bit about yourself. So it's not like I'm opening my heart out like I am today when I'm with families. It really depends on the moment. But I think maybe clinical pastoral education (CPE) helped me to be aware of that and be open to some of that.

Our field also often misses the opportunity to create spaces for community where we can be vulnerable together. That's one of the goals of Schwartz Center rounds, these monthly rounds where people talk about a case. I always get frustrated when it's all medical, medical, medical, and I always want to say, well, what does that mean to you? What were you thinking? How hard is it for you? There's really not enough opportunity for sharing vulnerability among us as professionals, because that's where it needs to happen first.

The CPE class that I took in 2002 has an alumni group that meets at Children's

once month and has continued to meet since 2002. There's a core group of six or seven of us and we get together at 7:00 in the morning on Wednesdays once a month. That's where we can talk about anything amongst ourselves. We need more of that for everyone. These are six people in a huge institution. I think everybody hopefully will find other opportunities, whether it's at home in their own family or within their spiritual community. For me, that small group, is for professional stuff; for spiritual, religious, social justice stuff, it's my Dignity community, my family. But there have to be places to open up.

STUDENT QUESTION: I am a student here currently doing research on the experiences of Muslim refugees in the US health care system and in Western countries. Many Muslim refugees report being discouraged by the health care system because they are forced to bounce from provider to provider and constantly have to re-explain their situation. They also report experiencing a general lack of interest in helping them coming from providers. My question is how do we begin to talk about compassionate health care and religion when patients



are constantly going from one provider to another?

LACRO: That is definitely a challenge. Again, I can only speak from my own experience. We have a lot of Muslim patients at Children's. I hope that that's not the experience that they have where we are. But I think we do have to find a better way to develop journeys and establish relationships. It's obviously not just reserved to Muslim immigrants. There are other immigrants from other parts of the country, and I worry a lot about immigrants, currently, as the grandson of immigrants myself.

I also worry a lot about the bigger issue of access to health care in general, whether you are an immigrant or an American without means. We have to do better at providing good health care for everyone. That's my pitch for universal health care. Here we are, in the United States of America, and there are things in our medical care system that I'm not proud of, and we could change them.

The situation that you bring up is part of that, being able to provide for all. We have the luxury at Children's to have interpreters for just about any language. For the ones we don't have in-house, we can get on an iPad and actually have a conversation, or at least a phone conversation at any hour. We need to be able to provide that to everyone.

STUDENT QUESTION: You mentioned that you think that spirituality is somewhat discouraged in medical school training. I am wondering if you think that speaks to a larger societal issue where we are uncomfortable speaking about this in the way we are uncomfortable speaking about death, for instance?

LACRO: Yes, it's something that people who are going to specialize in palliative care should have some access to. Hopefully as students in training, you recognize the importance of that and start taking these classes, which I think are becoming more available, but oftentimes just as an elective. Maybe it should become more of a requirement.

STUDENT QUESTION: Thank you for coming. It has been a pleasure listening to you. Earlier on you were saying that in children's health care, you tend to see the children's parents want to talk about faith or religion. My mother always told me that the biggest tests of faith are during times of harm. During your time as a physician, have there been any instances when you have seen patients start to lose faith either religiously or generally?

LACRO: Good question. Absolutely. I think illness is one of the biggest challenges of our faith. How to deal with that question really varies in every context, and that's why we need to be talking about these things. A spiritual assessment can be as simple as what's your religion? So often, in the hospital, somebody gets tagged as X religion, whatever it is, Roman Catholic, Buddhist, whatever. Then certain assumptions get tagged to that label, which may not apply.

I think part of the work of spiritual assessment is really trying to figure out what's important, not just what's your religion or even what your spirituality is, but what does this all mean to you, and how is this hard, and how can I help you? I think illness is one of the biggest challenges of faith. If you think about it, why would God allow this? There are different ways of answering that question, but I guess my job, whether it's trying it myself, or really getting a professional chaplain to do that, because it's a time of crisis and a challenge of faith.

Ultimately, I think it is a search for hope. The way I like to frame things is asking how can we find hope in this situation? I'm dying. But how can I be hopeful? That's a difficult conversation to have, but it's one that we need to have. Is it trust in an afterlife? Is it satisfaction of a life well lived? Whatever it is, having those conversations can help the patient overcome this challenge, this spiritual crisis. In the medical field you see spiritual crises every day, small ones and huge ones. If we, as providers, the nurses at the bedside or physicians, are not providing that care, then we need to access other professionals who can do that, such as a chaplain.

THEOLOGY PROFESSOR ANDREA VICINI, S.J.: In the audience there are many people who are preparing for medical or social work professions. Given your wisdom and experience, what would you like to tell them?

LACRO: Two things, one maybe positive, and one maybe a challenge. The careers that you have chosen are amazing. Even in the saddest of moments, even in the worst of medical circumstances, there is hope and resilience. Careers in medical care, whether it be in medicine, or nursing, social work, psychology, they're great fields.

I'm worried that it's getting harder for us to do this work authentically, given the regulations and the billing requirements and all that stuff. Do your best to fight that. It's going to be your generation's responsibility to reverse that trend, because I think that over-regulation has made our lives as providers incredibly difficult. I don't put that out there to discourage you from the careers that you clearly feel called to do, but I do warn you that there are obstacles and barriers and stuff that we need to fix to make our work easier and more effective. What we're required to do just do not really make any sense. There are forms that we have to fill out, checks on the medical record. We have to do what's important for that family, for that child, for that encounter. Sometimes you have to break the rules.

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