UK Moral Distress Education Project

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CAN YOU TELL US YOUR NAME AND THE ORGANIZATION YOU WORK FOR AND WHAT SOME OF YOUR DAY TO DAY ACTIVITIES ARE.

I'm Dr. Lucia Wocial. I'm the nurse ethicist for Indiana University Health. I'm also an adjunct Assistant Professor at the Indiana University School of Nursing. And when people ask me about my day to day activities it's pretty hard to describe because it varies from day to day. The most concrete thing I do is teach at the Indiana University School of Nursing. We have a required course in applied ethics for undergraduate nursing students and I teach one of those sections. In my role in Indiana University health, 40 percent of my time is supported through the Fairbanks Center for Medical Ethics, which is a foundation supported freestanding center for ethics within the Indiana University of Health, and 40 percent of my time is supported through the Department of Nursing in Indiana University Health. So, I coordinate our unit-based ethics conversation program, which is an informal opportunity for people to talk about ethically challenging things that they face in their clinical practice. I'm a member of our ethics consultation service, so I take calls for ethics consultation requests. I serve on the nurse executive council so our chief nurse executive sometimes refers to me as the moral compass of the Department of Nursing. So when she has an ethics issue or a question I'm a resource to her. We have an ethics fellowship at the Fairbanks Center and I'm a content expert and senior affiliate faculty member so I do a lot of teaching within the ethics fellowship.

WHEN YOU SPEAK TO STUDENTS AT THE BEGINNING OF THEIR CAREERS HOW DO YOU DEFINE MORAL DISTRESS TO THEM AND HOW DO YOU SUGGEST THAT IT COULD UNFOLD IN A CARE SETTING?

Well, when I define moral distress and moral distress is something that I'm passionate about in terms of my area of research interest, and something that for me is near and dear to what I know people will encounter in their clinical practice, and it's something that will affect their ability to care for their patients. So, what I say to new students is that, loosely speaking, moral distress is the feeling that you believe you know in your heart the ethically correct thing to do but something or someone keeps you from doing it. And that could be something internal to you; it could be something external. But basically you feel like your integrity, who you are as a clinician is compromised. And you're feeling like you can't do what you know is the right thing to do. It's not just "Oh, I feel bad it's a really sad situation." It's much deeper than that.

So, I counsel people that they're going to encounter it and that's not a bad thing. The good news is if you encounter moral distress you still care. You still want to do the right

thing for patients. The bad news is it's hard. It's hard when you think, "I really want to do the right thing and I can't do it for some reason," or, to do it would be risky, it would compromise something, there's a risk involved. So, when I talk with new people I try and let them know that this is something they'll encounter in clinical practice and it's not because people are doing anything wrong, it's sometimes because people genuinely disagree about the right thing to do for a patient, and health care is complicated. It's very complicated and complex. So, it's something that they're going to encounter.

CAN YOU DESCRIBE SOME SCENARIOS OF MORAL DISTRESS?

Absolutely. Both in our unit based ethics conversation program and in our ethics consultation service, one of the most frequent reasons people call for help is when they're involved in the treatment of a patient and it's clear that the treatment isn't going to achieve the goal that the patient had set. Typically it's an end of life situation. In health care we're trained to help restore health, cure illness whenever we can, and it's really hard when we can't achieve that goal. And there are times when either the patient, the family, or sometimes clinicians have a hard time accepting that the interventions we're providing are actually so burdensome. And you hear people talk about this, that there are things worse than death in terms of when you hear a clinician talk about feeling as if they're torturing a patient. They're not helping them. And to ask a clinician to do something that they in their heart know is hurting a patient with no benefit... In critical care I would do things that I know would hurt a patient. And I do it because there's a benefit. It's going to hurt a little bit but in the long run it's going to be a good thing.

There are clinical situations where I just can't see anything good is going to come of this other than prolonging your existence here on Earth, and in order to do that I'm going to have to inflict painful things on you. And I can't justify that. I can't excuse it. And I think for me the most powerful things are when you hear physicians, nurses, chaplains, social workers, respiratory therapists, anyone involved in the care of patients--- And we hear it all too often. Once is actually too many times. But when you hear people say "I feel like I'm torturing this patient. Don't make me do it anymore. This is wrong. We have to stop. We have to help people accept that we're not going to fix this."

And the thing that's most troubling for clinicians is I know if I can't fix it, and I accept that, I can't stop the dying from happening, but I can make it better. I can give people an opportunity to come to closure. I can relieve their suffering. I can help families begin to heal before a patient dies. I think those, for me, are the times when people are genuinely struggling. And I've had physicians say to me, "when a family member begs me, as a physician, do something, it's really hard to say, I'm sorry, your loved one is going to die." And I get that. But feeling like you're torturing a patient is really hard. And a lot of times people just need support saying "I have to stop. I can't do this."

WHAT ARE SOME OF THE SIGNS AND SYMPTOMS OF MORAL DISTRESS?

Well, like any other stress symptoms, there are physical symptoms, there are emotional symptoms. People can have a variety of things, I think. I tell people if your moral distress is high, you may get into what I refer to as "Moral outrage," where you're, maybe angry, disgruntled, distancing yourself from patients. If I were going to measure your moral distress, say, on a scale from 0 to 10, and I ask how you're doing, and you say it's 10, you've maybe got headaches, maybe you're over eating, you're emotional. And if you're 0 you're present at work, but not there. So, you're physically present, but you're distancing yourself from patients. Sometimes clinicians will ask "Can I take a break from this assignment? I just need a timeout." There are all kinds of ways that it manifests itself.

I would guess that the classic thing is when people feel brave enough to talk to somebody and say, "I think things are not right here." That's really how I know it's moral distress. Anything else can be confused with almost any other stress response. But it's when they can actually speak out loud and say "Something's not right here and I think what we're doing is wrong," and that's the opportunity to probe. So, I guess that's for me what I would say is the overriding symptom that distinguishes it from other types of stress.

ARE THERE SIGNS IN A GROUP?

I think, for me, the situation I described where, let's say somebody on the team feels like they're torturing the patient and it's a really bad thing. When I see it manifested in an entire unit, what I see more than anything else is clinicians who, by and large, have an amazing capacity for compassion, tolerance, and patience, lose that. And if they can't convince a family member, for example, to switch the goals of care to comfort, they fall back on what I call "Social justice arguments" for why we need to change it. And this is very uncomfortable and very awkward, but people will say--- Not to a family member, but they'll say it among members of the health care team--- "This isn't worth it. It's costing too much. Who's paying for it? I'm paying for this. This is wrong. As a society we can't keep doing this." So, if you ask me "How would I know an entire group or unit of people is in moral distress, group moral distress?" That would be it, is when they go to the broader context, not just this individual situation.

TELL US ABOUT A PERSONAL SITUATION OF MORAL DISTRESS.

Well, I can tell you for me, in what you'll hear a lot of times in literature, my "Exemplar moment" for moral distress. Throughout this conference we were asked to think about these sorts of situations, and I can clearly identify the moment when I knew that I wanted to go on and study ethics and know that nurses had an important role to play in the care of patients. My clinical background is neonatal intensive care. We were caring for a baby who had a complex constellation of anomalies. And at that point I was expert in my

clinical practice. I could anticipate things that were happening. Came to work one day. A new nurse had been taking care of the baby. Based on the report she gave me I knew that the baby was going to code, have a cardiac arrest, need resuscitation. And sadly, I was right. We coded this baby for three hours. The baby went from being on oxygen and on full feeds to on a ventilator, paralyzed; we were breathing for the baby on multiple medication drips for blood pressure. Total turnaround. When we brought the mother in, the physician in charge says to this mother, "I'm cautiously optimistic about how this baby's going to do." I thought to myself, "Really? Really?"

Two weeks later, we had not moved one iota from where we were that day. Still paralyzed. Still on the ventilator. Now in isolation for an infection. And this mother, her life circumstances, was only able to visit by phone for a brief period of time every day. And so a different physician is on the phone with the mother--- And we do this not on purpose, but it happens--- Families will call and say "How's my loved one doing? How's the baby doing?" And we say "The baby's stable today," because the baby didn't code. So, we think it's a good day. And the family hears "The baby's better." So, here's this physician on the phone saying to his mother "The baby's pretty stable and we haven't had any events and---" remember when I said earlier there's moral distress and there's moral outrage? Well if it were zero to 10, I was at 25. So, here's the physician on the phone talking to the mother, and I blurted out in the middle of her conversation, "Why don't you tell this mother what it means to have readings in the teens, what that's doing to this baby's brain?" And then I shrank back and I thought, "Okay, I can get a job someplace else, that was totally inappropriate, very unprofessional, what am I going to do?"

I waited, and the physician got off the phone, and fortunately for me I had worked in that unit for a number of years and I was respected by my physician colleagues. It was a very collaborative practice. And I said to this physician "I'm so sorry. That was terribly unprofessional of me." And she said "No, you were right. When I explained it to her that way, she understood what's going to happen. She understands now that the only way she's going to get to have time with this baby is to switch the goals of care. We're going to make an arrangement, and she'll be able to come in." And she was able to come in and hold the baby while she died. And if we hadn't done that, she wouldn't have been able to hold her ever again. Because she was not going to survive. It was not going to happen. And so for me in that moment I understood so many things about the role of nurses in ethically complicated situations.

And I didn't at the time, I wouldn't have been able to tell you "moral distress" at the time, but when I first read an article about it, bells went off in my head, and I knew that's what it was. I knew that it was wrong to keep doing what we were doing, because it was like Sisyphus rolling the stone up the hill. We were not going to change the outcome. The only opportunity we had was to make it possible for this mother to spend time with this baby before she died. And we made that happen. And my intervention with this physician made that possible. That's a really powerful thing for nurses to realize is that because you're a nurse you see things differently and if you know something's not right you can

make a difference if you learn how to speak up and help people see what you see.

HOW DOES YOUR ORGANIZATION FACILITATE CONVERSATIONS AND PREPARE PEOPLE TO ENTER SITUATIONS OF MORAL DISTRESS OR HELP RELIEVE THOSE SITUATIONS?

I'm very fortunate to work for an organization where we have an ethics center, which is fabulous. There are not many organizations in the United States that actually have the job title of "Nurse Ethicist." There are a lot of nurses who do work in ethics, other duties as assigned. This is my job. This is what I do. That speaks volumes to nurses in the organization about the organization's commitment to support nurses. It's actually written into my job description to support the ethical lives of nurses. So, one of the things the organization does is clear. I'm there; I'm visible. I write a monthly column in our electronic newsletter for nurses. I'm present. We have our unit based ethics conversation program which is open to anybody who would like it. I meet with every new nurse coming into the organization, describe the ethics infrastructure, tell them about our unit based ethics program, and invite them. I'm the only Wocial in the book so anybody can send me an email, anybody can call me.

I serve on the ethics consultation service. We have an open access policy for ethics consultation. Anybody involved in the care of a patient who has an ethics question about the care of a patient can consult the ethics consultation service. We don't accept anonymous requests because you can't call up and say (*whispering*) "Psst, got a problem." You can't do that. But we know because of power differentials, sometimes there's a need to request confidentially for assistance from ethics. So, we have this open access policy. Our ethics consultation service is inter-professional. We have physicians, nurses, chaplains, social workers, we have a lawyer, we have administrators for the hospital, and all of them take ethics calls. If I'm carrying a pager there's always a team of people available to me on call to help sort through an ethics case. When we have an important and difficult case, we invite clinicians who are part of the ethics consult to come to our team meetings to hear us talk about how we identify the best recommendation for how to manage the patient situation.

So, I would say I'm very fortunate, and one of the reasons I came to Indiana University Health was for this position. I'm the first one they had in this position. The Fairbanks Center reports to a senior vice president for values, ethics, social responsibility and pastoral services. How cool is that? We report to someone whose job it is to sit on the board and remind key leaders what our mission, vision, and values are. He's a man of integrity, Dr. Steve Ivy, and you couldn't ask for a better job, to work in ethics with people you respect whose integrity you trust, so I'm very fortunate.

HOW IS MORAL DISTRESS BEING INTRODUCED TO DOCTORS AS OPPOSED TO NURSES AND HOW IS IT BEING RECEIVED?

So, one of the many gifts we have at Indiana University Health and Indiana University, we have a very collaborative model with Indiana University School of Medicine, School of Nursing, and IU Health, and I have colleagues in the Medical School. I'm an identified resource to help people grapple with moral distress, so I have physicians in the Medical School who have invited me to come and speak to their students who are taking an ethics elective who have an intentional interest in exploring ethical issues. I would say it's a stretch goal for us, like everybody else in the United States, to develop inter-professional education, to get out of our silos. We're making progress toward that at Indiana University. We haven't succeeded yet.

For me one of the treat gifts at IU Health is, our ethics committee is a subcommittee of the medical staff committee. So, it's physician-driven. It's a physician-led organization. I have been identified and treated with respect by my physician colleagues in that community, and that communicates a huge message to other physicians in that community that this is a resource. And I'm identified as a resource for moral distress. And it's a language. When I first came to IU Health, there were a number of physicians who would say "I've never heard that phrase, 'moral distress,' can you say more about it?" So, I think it's making its way, in our practice, through people learning to name it, talk about it, I think you see studies in the literature.

There is an abundant body of work for nursing and it's now growing. You see it for physicians, medical students, you see it for pharmacists, you see it for all kinds of people. So, I think it's really interesting. Moral distress has been around in the nursing literature for, I feel really old when I say this, more than 30 years. It didn't generate as much interest broadly until there was one article in the New York Times written by a physician about moral distress, and I think that one article by Dr. Chen has really sparked peoples' interest. And there was an editorial, I feel really old now, this is 2013, so I think this would have been 2011, in JAMA, an editorial about these clinicians have moral distress because they feel like they're providing inappropriate care. And I was so excited when the editorial was about "Maybe we should start paying attention. Maybe this matters in an important way." And it was about physicians, nurses, everybody. And for it to come out in JAMA is huge. It's both good and bad. It's a recognition that it's a really big problem, but to gain the credibility of "This is important, and it's not just because clinicians are burnt out or upset or they don't want to be doing what they're doing, it's because they feel like something's not right. And we need to pay attention."

YOU'VE JUST BEEN AT A CONFERENCE OF PEOPLE ALL OVER THIS COUNTRY AND POSSIBLY OUTSIDE THE COUNTRY.

Yes. Canadians.

WHAT WAS YOUR IMPRESSION OF THE RECOGNITION OF MORAL DISTRESS IN ORGANIZATIONS OF DIFFERENT SIZES, DIFFERENT REGIONS, ETC?

Actually I want to answer that question by telling you where we are now, where we've come from. Five years ago moral distress would have been an "Ah-ha" for a lot of people. It would have been new. We would have been explaining it over and over again. Now it's talked about as an open issue. Regardless of the size of the institution, it is in the language of healthcare clinicians now as sort of a given. It doesn't matter in terms of the size of the organization. I don't think for anybody in the office that I knew, that I was exposed to, for anybody, that moral distress was not something that was recognized and identified.

Now, how it was supported is another matter. I think there were a lot of people, particularly after some of the presentations that I did, that came up and asked me about "What does it mean when this happens?" or "What does it mean when that happens?" And a lot of times for me when I hear stories of moral distress it's a reflection of failures of leadership, leaders not recognizing the distress that their staff is experiencing and not knowing how to lead people through managing ethically challenging situations. And it doesn't matter the size of the organization. I've had people say these big name organizations, very famous, number one on this list and that list, and they work in a place where moral distress is rampant because of the culture. And another unit down the hall, same institution, completely different. So, it's not the size or the resources. In ethics we talk about this all the time: It's really about the relationships you have with people. Whether or not I have moral distress and the size of my organization, how I'm going to manage it, is going to depend on what's my relationship with my support system in the unit, so I don't know that there are disparities. It's not based on size or stature or importance. It's based on the individual relationships in the little world that I live in.

SOMETHING YOU WANT TO SAY, OR GUIDANCE YOU WANT TO PROVIDE. ANYTHING YOU WANT TO SAY.

I'm not very good at this, but I think this is really important and I think it's something that's driven me and makes me passionate about moral distress. It's one thing to name it, but if you name it and use it as a weapon, it's a problem. When I say use it as a weapon, you can't go to somebody and say "Oh, I have moral distress, we have to change this." No, that's not good enough. You have to be able to say, “What's the nature of your distress?” If you think the right thing isn't happening or something or someone's keeping you from doing what's the right thing, you have to be able to articulate what it is. Earlier I talked about leadership issues. So, if I have moral distress, I have to be able to know how bad is it? Because I'm not going to be able to help you with it if I can't help you measure it and then provide some kind of an intervention and then measure it again and see if I've made it better.

So, one of the things that I have this vision for how to help people with moral distress, and I mentioned some of this is a leadership issue, it's a culture issue. I have to know

how high it is in me, but I also have to count on my leaders keeping a pulse on where I am. So, what I've done is try to create a tool. I'm a clinician at heart and I worked in critical care. We want to fix things. So, what I've created is a tool, it's called a moral distress thermometer, and the idea is anybody's who's ever been in the hospital and somebody's asked them "What's your pain on a scale from zero to 10" and you identify it's a five or a six and I know as a nurse I'm going to give you an intervention and I'm going to come back in a little while and I'm going to measure it again. So, you have what amounts to a moral distress thermometer. Here's the definition of moral distress. Do you have it? Mark where you are on the scale. Okay, that's great. Then check these little boxes and tell me what's contributing to it because that's going to help me intervene.

If you get a bunch of nurses, physicians, all the clinical care providers in a unit and you get them all to say what their moral distress is and then you create, and I wish I had a picture, you create a picture of, it's a rainbow thermometer, and at the bottom is purple and it goes purple to red. Wherever the mean score is, it's blue. Blue is kind of a soothing, normal color. You go one standard deviation away and it goes green and purple. Two standard deviations, yellow and it's still purple. People in the red zone, and if I can walk into the lounge and go, "Okay I know what my moral distress was because I measured it, I took the tool," and I'm looking at this thing going "Wow everybody on the unit's a five and I'm an eight, I've been an eight for a couple of weeks now." And my manager on the unit, because this is a leadership issue says, "I've got four people who are stuck at eight. I've got to do something about that, because I know, the research shows if I don't help them, they're going to leave. They're not just going to leave this job, they're going to leave the profession." And that's a problem. Nobody should have to leave a profession because they felt like they were doing the wrong thing. But I'm a leader, and if you don't talk to me, I can't help you. But if I see this thermometer I can sort of gain a perspective of how everybody's doing and the reason that sort of visual aid is helpful is that this is hard to talk about.

When moral distress first was talked about a lot of people felt "Oh, it's a personal failing, it's me, I'm weak---" That's not it! But we know, just like when someone wants to call for an ethics consult, in the old days ethics was seen as "They're going to come in and police my practice; I've done something wrong." That's not it. I'm an ethics geek, and if I could say one thing to everybody coming into clinical practice: I've never seen anybody harmed by being able to have and being supported through a careful conversation about what you think is the right thing to do. Never.

I've, in my role as an ethics consultant, I've had physicians of 20, 30 years call us up because of a care situation they're asking me to do something I just don't think it's wrong. And what I say to them, "Okay. Let me put it to you this way. If you could do what you thought was the right thing to do, no consequences, just got to do it, it's the right thing, I'm going to give you a magic wand and you get to do it." Well, they almost invariably say "I would stop treating this patient." So, I say, "Okay, great, so we know what you think is the right thing to do. So, what you're telling me is, if you could say to this family 'You can't make me. You're asking me to do this and I just can't do it.' Let's talk about what that means." And I walk them through what it would be like to say to a

family member "I know what you're asking and what you're asking me to do would make me hurt your family member and I just can't do that." And physicians look at me and say "That's okay, I can do that?" Yes. That's the right thing to do. You're a clinician.

And at the beginning of a conversation like that their moral distress score is way up here. And when they understand and feel the support of someone, particularly when I'm in the role of the ethics consultant and I'm representing the organization and I say "Yes Doctor so and so, yes Nurse so and so, you're not inappropriate. What you're saying is an important thing. I'm assuring you that you are a good clinician." You can see their moral distress stop. Even if the family doesn't choose. Even if we can't help them see what we see, and they are unable to switch their goals of care, the fact that the clinician is given support for what they think is the right thing to do – it affirms that they're not crazy. They haven't lost their compassion. It's an important thing.

So, for me we have to be able to measure it so we know that when we provide an intervention that it's better. Or worse. The worst thing that can happen is if I provide an intervention and suddenly I've made it worse. So, I think if you were going to ask me what would I say, it's that you have to be willing to talk to somebody about the difficult work that you do in clinical practice, and to know that there will be times that you think that what you're doing is wrong. That doesn't make you a bad clinician. It means that you should talk to somebody.

THANK YOU...