UK Moral Distress Education Project

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Interviewed March 2013

TELL US YOUR NAME, ORGANIZATION AND WHAT YOU DO FOR YOUR JOB.

My name is Marilyn Shirk. I work at Cedar Sinai Medical Center in Los Angeles. My role is mental health clinical nurse specialist, nursing liaison. It's a long title. What I do is a support role for nursing staff and other caregivers. The kinds of interactions I might have would involve stress management, interpersonal communication, conflict in work relationships. People would use me as a consultant around those work stresses including ethical issues.

EXPLAIN MORAL DISTRESS, AND HOW IT CAN UNFOLD IN THE HEALTHCARE SETTING.

Moral distress is that sense that you feel you should be doing something different than you're doing. It may even be that you don't know if you can do the other thing that you think is right, but you're conflicted. You're conflicted about the question. It is what I'm doing, the right thing to be doing. It may be that you know the right thing to do but there are other forces in the way that prevent you from being able to do it, whether it's by policy or cultural differences, your own personal value system and conflict with either family or patient or other healthcare providers. It can be a lot of things.

GIVE US AN EXAMPLE OF MORAL DISTRESS FROM YOUR OWN PERSONAL EXPERIENCE.

My own personal experience, it goes way back. I can remember it so well. I was a pediatric nurse and I was caring for about a 5-day-old infant who had such serious illness. She was born with her brain outside of her skull. It was called a ruptured encephalocele. It was infected. There was really no treatment at that time. This is many, many years ago. She was brought to our unit because it was infected and we were a contagious disease unit and we wanted to treat that. There were really no therapies for her. She had cleft lip, cleft palate. She was essentially brought to us dying.

We were caring for her. I was a very young nurse. I remember thinking, "Wow, if all we're doing is waiting for her to die, how awful that we have to put her through what we're putting her through?" There was essentially no other way than to keep comforting her and attempt to feed her, but she couldn't eat. We would attempt to feed. She would throw up. We would clean her up. She essentially died of dehydration. The morally distressing part for me was really wondering, "Why can't we do something better than

this, than to just watch her go from 8 pounds to 5 pounds to die at day 8 of her life?" I remember like yesterday what that felt like.

What compounded it was when she died, my charge nurse found the baby positioned, she said, on her face and looked at me like maybe I had positioned her in a way where she would suffocate. I was so clear that I had not done anything like that. I looked with wonder at this charge nurse who could even presume that I would intentionally smother this baby or put her in a position where she wouldn't be able to breathe. I remember positioning her on her side. I felt it was my punishment when the charge nurse asked me to carry the baby to the morgue as opposed to using another transportation device like a basinet or something. It's stuck with me all these 40 years. It's stuck with me that that whole scenario unfolded the way it did. The baby's death, to me, was today. The fact that my charge nurse suspected that maybe I had done something to hasten it was disturbing to me, but more because I thought she was so off-base. I never felt, "God, I did that?" I thought, "Wow. She would think I would do that?"

GIVE AN EXAMPLE OF A MORAL DISTRESS ISSUE THAT CAME UP WHERE YOU'VE HAD TO LOOK INTO IT AT THE HOSPITAL RECENTLY.

Probably within the last year, one that came up was a group of nurses were really clear on advocating for their patient in making decisions about whether or not he would ever go through an intubation or an attempted resuscitation. They learned this because he was deteriorating and they called an emergency response. It wasn't a code at that time and asked him. They got an interpreter. They got his attending doctor on the phone. They got it really clear. He never wanted to be intubated again. He knew he was at end of life and he never wanted to have an attempted resuscitation.

Within 5 hours, he was starting to deteriorate again. His daughter, even though she had been on the phone and understood that's what he wanted, in that moment, she decompensated emotionally and started to scream and yell at the care providers that they were killing her father, letting him die. The weird thing that happened was that the nurse who had done all that advocating was in another patient's room. The charge nurse was covering for her, but had not gotten all the detail about what had gone on 5 hours before. Didn't even have a moment to go check in the medical record when the patient's blood pressure is dropping, and he's about to arrest, and this family member is screaming at her.

They pushed the code button. The emergency team comes. The nurse comes out from the other room and says, "He didn't want this." She tries to talk to the doctor who's in charge of the code blue and says, "He didn't want this. We got it documented." By then, everything was in motion. Unfortunately, when we start something like that, we tend to keep doing as opposed to stop. He went off to the ICU. He coded again a couple of times before he died. I'm not even sure how they either didn't code again, or he just died.

The nurses were absolutely beside themselves at what they felt was a failure to successfully advocate for this man. On top of that, they're traumatized by being accused of killing him and how emotionally distressing it was to have his family member do that to them. They consulted with me. In the course of conversation, we talked about how they needed to take care of themselves. We have a process of debriefing a critical incident, and how it was also a learning opportunity because when we get something like a do not attempt to resuscitate, we sometimes don't really know a plan of care. We know what we're not going to do, but we haven't gotten really clear on what we are going to do. That became a great learning experience so much so that they ended up teaching their own colleagues and then took it house wide to each to teach the other nurses about their experience of trying to advocate for a patient in this emergency situation. We tend to default to the screaming family member, and how that's really not helpful to anybody, and what we could do instead. So we took this morally distressing situation and I think transformed it into truly exemplary professional practice.

WHAT ARE THE SYSTEMS AND PROCESSES EXISTING IN YOUR INSTITUTION RELATED TO SCENARIOS THAT CAN LEAD TO MORAL DISTRESS?

We have a critical incidence stress management team. If circumstances are such that something distressing has happened, and it's in that moral realm, besides getting ethics consultation, which is another resource, they could also have a debriefing for the emotional impact of an event. There are a couple of resources – the chains of command, the critical incident, stress debriefing, ethics consultation, even retrospectively. If it's before there's a conclusion, they might even be able to work it through and feel at least they have used all the channels open to them to address it including being able to ask not to be in the assignment.

Scenarios can happen where it's a totally ethical plan of care for this individual, but for this care provider, it may not be okay. Things like withdrawing a feeding tube, or turning off a ventilator that for that care provider, it may just not be okay for them. They're not required to do something that is against their own core values and beliefs. It tends to happen more around the feeding issues when patients don't want a feeding tube. The nurse, rather, care provider, may feel, "That would be wrong for me to withhold food from somebody," if that's the way they think about it. We have a policy in place to respect that and to allow for other caregivers to take over.

HAS YOUR INSTITUTION DEFINED MORAL DISTRESS FOR THOSE THAT WORK THERE? WHAT RESOURCES ARE AVAILABLE FOR THEM TO IDENTIFY OR DEAL WITH SITUATIONS CREATING THAT?

We're having conversations about moral distress. We have different in-service and unit-based conversations with the ethics consultant, with myself, so that cases that have happened that may still be brewing there, they never shared with anyone, we can use those as examples of how you might have accessed a resource and been able to end up

feeling differently about it if you had reached out and gotten that support. I think we've got more consciousness raising going on where we're using that language. I know in our ICU, they're even doing an ICU roundtable with the residents and nurses, and moral distress is one of the topics. Trying to help the healthcare team as a whole to see that what we do affects each other and that bringing it together, we need to use all those resources to help us sort through some of the more complicated stuff.

HOW DOES MORAL DISTRESS AFFECT THE MENTAL HEALTH OF PRACTITIONERS?

I think moral distress affects the mental health of anyone in healthcare by challenging your energy reserves, your commitment to the job. Sometimes, there's withdrawal emotionally because if it's going to be like this, I'll just protect myself. I'll shield myself. I won't get close. I'll just do the job. It's a state of burnout. The other would be maybe quit. We've certainly had nurses tell stories of something terribly morally distressing that was the end of their career. I tend not to know them because I'm in this environment where they're still working. The literature shows where nurses have left. I think it affects relationships. I think it can even cause distress at home. I think the mental health issues go quite broad when you feel like you're not in sync with core values and beliefs and you're acting outside of the sense of right.

WHAT ELEMENTS NEED TO BE IN EDUCATION AND TRAINING RELATED TO MORAL DISTRESS FOR STUDENTS AND NEW HEALTH CARE PRACTITIONERS?

I think what newcomers to the profession really need is good communication skills. They need to be taught how to articulate a sense of concern. "I'm concerned that..." "What troubles me is..." "Help me understand..." Any of those lead in questions. They don't just presume. I've got it right. You've got it wrong. This exploration of seeking to understand the situation we're in, and not accusing anyone of intentionally doing wrong, but just needing to be able to put into words that something bothers you. You may not even know why. There's just something about this. It doesn't seem right. "This is the way I feel when you're asking me to do that." I think those role plays and scenarios and practice will empower anyone coming into healthcare nurse, physician, anyone, to expect those kinds of conversations.

WHAT IS YOUR INSTITUTION DOING OR YOU WOULD LIKE TO SEE DONE TO FACILITATE THOSE CONVERSATIONS SYSTEMICALLY?

Systemically to facilitate the conversations is to make it a part of everyday practice. We have things like ethics rounds in the ICUs, onboarding of new graduates. There's a conversation about ethics. We have all the new hires in nursing get some time with our clinical ethics consultant to talk about the center for health care ethics, about using ethics consultation, what that's like. That it's just a conversation. It's a way to process

what you're thinking and feeling to know what next step you might want to take. We have a bioethics committee that has this on the table as far as, "Do we have policies that need to be revised or written that will address some of those scenarios that seem to always come up that are morally distressing?"

I'm thinking of end of life scenarios where we're doing way more treatment than anyone thinks is really going to be beneficial, yet we feel like the family needs us to do it, expect us to do it, demands that we do it. Yet, it's outside of any... We haven't even defined the standard. All experts in the room would say this isn't going to get us anywhere. We're trying to hone in on the kinds of policies that will support the health care team to define the limits of the standard so that you don't find yourself crossing a moral line going, "How do we get over here?" I remember one doctor years ago saying to me that the treatment... This was years ago. Saying that the treatment they were giving this patient in the ICU, he could not have gotten IRB approval for a study on an animal to do the things that he was doing to this patient, because there was really no science to support the interventions that were going on. We were beyond what we knew worked. They were just doing more of it because nothing else we were doing was working. Essentially, he was dying. The family was insisting. We were in that place where we did what people insisted us to do even if we didn't think it was good.

WHAT ARE YOU DOING AROUND PATIENT AND FAMILY EDUCATION OR COMMUNICATION FOR MORE UNITY?

Patient and family education, we're just beginning, just beginning to try to make advanced directives more of common conversation. It's been out there 20 some years where we're supposed to ask about them. So many times, the moral distress ends up in this situation of people having to speak for someone they really don't know what they want. More is safer, than less. We all end up doing things that we're not sure this person would want us to do. The education is about, "Let us know. Let us know what you want. Make sure your family knows." There are some new initiatives about getting the attending physicians to have these conversations in their offices, to make available through the Internet, through the hospital website, access to questions about advanced directives, even download the copy. We make the copies available. That's mostly the approach we're taking in terms of trying to inform patients and families.

WHY DID YOU DECIDE TO COME HERE FOR THE INTERVIEW? WHAT ARE YOU HOPING THIS PROJECT CAN ACHIEVE?

I decided to come and do the interview because I think we all have stories to tell. I think it's part of the bringing to the forefront the fact that we're living with this every day. It's so important to be able to talk about it, and to learn from each other, and to use some skills that will help us address it, to consider just part of doing business. It's become so common now that it shouldn't be the extraordinary day, it’s the everyday. We need more practice at dealing with it and having those conversations with each other, because if we

can't talk to each other, then we definitely can't address it.

ANYTHING ELSE YOU WANT TO SHARE OR ADD?

I think the only thing I'd want to add is that we need to know how we feel. So many people do a job. They're so focused on the objects of their job, that they're looking outward. They're reacting on stuff that's happening inside. They're not reflective, aware of processing, so that they can consider themselves as a part of the scenario. I would say the thing we need is self-awareness, self-reflection and really take some responsibility for that. We're not making a situation worse. We're taking some ownership on how we're handling ourselves so that we can contribute to bettering the situation we're in, rather than deciding that there's a bunch of bad guys out there and we're the victims.

THANK YOU...