

UK Moral Distress Education Project

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GIVE US YOUR NAME, THE NAME OF YOUR ORGANIZATION, AND WHAT ASPECTS OF YOUR ACTIVITIES BRING YOU INTO THE AREA OF PATIENT CARE?

I'm Ann Bale Hamric, and I am the Associate Dean for Academic Affairs at Virginia Commonwealth University in Richmond, Virginia. I have been a faculty member and administrator for about the last 14 years. Prior to that I did a variety of other things, began my career and practice. But I don't do direct clinical practice anymore. What I do do is ethics. I serve on ethics committees, and I've done ethics consultation and developed a system of moral distress consultation. So, that's probably as close as I get to patient care these days.

PLEASE DEFINE MORAL DISTRESS AND HOW IT CAN EVOLVE IN CARE SETTINGS.

Mostly we've studied it in nurses, but it can occur for any healthcare provider when they know or think that they know the ethically appropriate course of action but they feel that they can't carry it out. So, the critical element here is that in some respect the nurse or physician or respiratory therapist's sense of their core values or their sense of their core obligations or duties to patients get compromised. And it's that moral compromise that makes moral distress such a difficult phenomenon because it feels like people are not acting on their own agency, they're not being good people, because they are participating in what they believe is a wrong and they can't make it right.

GIVE US A FEW EXAMPLES.

There are a number of things written about in the literature. There is a lot of what I call root causes of moral distress. They tend to center in three areas, like, for example, in a clinical situation, where a family is pressing the healthcare team to continue to do aggressive treatment, and the team feels that this treatment is doing no good at all, and is actually causing the patient to suffer. But they can't get the family to agree to let them stop the treatment. So, that's an example of where people feel they are not acting in accord with their moral values for what they ought to be doing as providers with patients. There are also situations where people feel they have to work with people who are not as competent as the care requires. This was a big issue when we were moving nurses around from place to place and the nurses felt that they really were not competent in the care, and other people did too, but yet they were providing this substandard care and

feeling really terrible about it. There are situations where care providers think that physicians are providing what they call false hope, so that families are hearing, or patients are hearing that there is more to be done, where the rest of the team feels like there isn't anything else that ought to be offered to these people. So, those are just three examples.

COULD YOU SHARE A PERSONAL SITUATION WHERE YOU'VE EXPERIENCED MORAL DISTRESS?

Yes. It's hard to pick one. One of the ones that I teach from now was a situation a number of years ago in an institution where a young man had come in. He had an accident, and he had to have his legs set, and as part of his accident he had lost a lot of skin around the area, and so the grafts were not taking. So, he needed a plastic surgery procedure to try to graft some skin from other parts of his body, very benign procedure. He was a college age student. And the plastic surgeon did the procedure and then they moved the patient, stable, to what's called the PACU, the post anesthesia recovery area, and for some reason, I really don't know the exact reason, something went terribly wrong. There was discussion that maybe the oximetry that measures oxygenation wasn't working and didn't trigger an alarm. The unit was extremely busy that day with lots of people coming from surgery, and this young man was considered the easiest, most stable patient. And there was a shortage of nurses on the unit. The nurse got pulled away. She came back and he was blue. And he never recovered consciousness.

He had all these different physicians, anesthesiologist, orthopedic surgery, plastic surgery, and all of them basically said, "Well this isn't my fault," "This isn't my fault," and Risk Management said, well, just really don't say anything. And so they were not disclosing the error because everybody was busy fighting about what was the error, and the patient gets back to the unit, he isn't responsive, which makes absolutely no sense at all to his family, and so they keep asking the nurses what's going on, what's going on, and the doctors are not giving them the straight story. And the moral distress on the part of the nursing staff, who felt like lack of truth telling is a potent form of moral distress, they felt that everyone needed to be forthcoming but it wasn't happening. And the situation escalated to the point where one of the nurses took the patient's chart and walked into the room and put the chart on this young man's bed and said to his mother, "You need to read this," and walked out and quit. Do you see that moral agency compromise at the heart of that? She couldn't do it anymore. And she felt like she couldn't make the right thing happen, so she had to take this very extraordinary stance of going outside her team, going outside of the institutional mandate. And that's why she resigned.

YOU SAID YOU'RE INVOLVED IN SETTING UP SYSTEMATIC WAYS OF DEALING WITH MORAL DISTRESS, OR SETTING UP RESOURCES.

Well you're giving me a lot of credit. We are trying to understand what moral distress is and what it's not. And there is confusion around what this phenomenon is, really, and a lot of the work and discussion that has happened so far around moral distress has been focused on these difficult clinical situations. But part of what I'm seeing in the work I'm doing is that moral distress has a very powerful unit culture, team culture element, and it has a very powerful systemic or organizational element, because when people talk about moral distress, they tend to move from case to case to case. Meaning these are things that are happening over and over again and a lot of time they point to these deeper unit level or system level issue.

So, you're giving me too much credit to say I'm really changing that. I'm trying to draw attention to say that, if we want to do something about moral distress, we've really got to start looking at the culture of care that we offer on teams and on particular units. And we've got to start looking at the policies and procedures and systems we have. You see that risk manager in that story I told you was not trying to engender moral distress. He was trying to protect the institution's liability as he understood that at that point. This was a number of years ago before we realized we need to be disclosing errors. But that's a powerful example of how an institutional approach was actually promoting moral distress among frontline caregivers. Does that make sense?

IS THERE AN ORGANIZATION THAT IS DOING IT RIGHT? HAVE YOU NOTICED A SERIES OF PROCEDURES OR PROCESSES OR RESOURCES THAT IS ACTUALLY HELPING REDUCE OR ADDRESS MORAL DISTRESS?

Well, I know of an organization that has very good materials and is trying to really shine a light on it and that's the VA system. They have some ethics resources and they talk a lot about the ethical iceberg with the system problems being the part of the iceberg that's under the water that people don't see. And so they have a lot of very good resources. Now, how they are used within VA systems, I don't know the answer to that. I also know that there's strong work being done in terms of team communication and teamwork and inter-professional teamwork. And communication is a potent way to manage moral distress, particularly if people recognize that moral distress is something that ought to be talked about, that it's okay to bring it up, and people understand what it is. A lot of times that doesn't happen. So, if you look at the literature you do not see a lot of strong, evidence-based approaches to managing moral distress, and I think part of that is because a lot of the approaches to date have focused on the individual, and it's more difficult to say, "We as a system are going to take this on." Now you're going to talk to Lucia Wocial, and Lucia is in an interesting position as a clinical ethicist in Indiana Health, which is a multisystem hospital up in Indianapolis. She has tried to implement

some things which she calls Unit Ethics Conversations. And I think that's a promising approach.

We adopted a moral distress consultation service at the University of Virginia when I was there. And we have data on 18 consults. We're trying to write that up now. It made a difference for the people who consulted us, but I can't tell you that I think it made a difference in the overall system. There were a couple of consultations where I did escalate those to the level of the system, because I was so concerned about them, and I know that that is still happening there, but I don't know that there has been a very thorough assessment of what difference, then, did all this make at the institutional level.

FOR A STUDENT OR NEW NURSE PRACTITIONER OR MEDICAL PRACTITIONER, WHAT WOULD YOU ADVISE THEM IN TERMS OF THE SIGNS THAT THEY MIGHT SEE IN THEMSELVES OF MORAL DISTRESS?

Well, to me, there are certain key elements. First of all, there's always an emotional turmoil associated with moral distress, because you don't violate your core understandings of who you are very easily. There are plenty of kinds of emotional distress that are not moral distress, but moral distress is always emotionally distressing. So, the notion of people being agitated, feeling like they're doing the wrong thing, really questioning, feeling powerless. Powerlessness is a potent element of moral distress. "I can't make this change. I can't make it be different." It's also a very isolating phenomenon, especially in places where people don't talk about it and don't understand it.

When I talk on moral distress I can still be in a room of 200 nurses. We talk more about this in nursing than we do in medicine or other providers. But less than half of the room will raise their hand that they even know what it is. So, sometimes we don't know how to talk about it because we don't know how to pull out this moral element of what we are doing. So, the first thing I would say is to get knowledgeable about what moral distress is and to speak up about it. If you feel like you are being asked to do something that you think is contrary to what your obligation is to the patient, you talk about it, you ask for your team to come together and talk about it, that you say "I'm not comfortable with what's happening here and we need to look at what's going on." And that systems, particularly teams and units, welcome and recognize that on the part of any team member, can raise those concerns and the team should come together and address them, rather than make that person feel bad. And that happens.

IF SOMEONE WORKS IN AN ORGANIZATION THAT DOESN'T HAVE FORMAL STRUCTURES IN PLACE, ARE THERE RESOURCES THAT ARE THERE?

First of all, I would suggest very strongly that they contact the ethics committee. Most institutions, if this is a joint commission, an accredited institution, they have to have some sort of method for addressing ethical problems in the institution. And usually that's an ethics committee. Now, I wish I could tell you that all ethics committees were fully knowledgeable about moral distress. I don't honestly think that they are, judging from some of the comments that I've heard from some of the people who have consulted ethics committees. The case that I gave you actually had gone, earlier, to an ethics committee, and the ethics committee had said, "We don't have anything to offer here." They had missed the nurse's moral distress; they had just missed it. So, that would be the number one thing.

The number two thing, I think, would be to really try to look at what is happening with our communication patterns. Because a lot of times with moral distress, it's because providers feel like they have different kinds of obligations to patients. They have different perspectives on what their role is with the patient, what is the problem, what is my job with the patient, what is your job with the patient, and that people beginning to talk with one another about that can uncover some of the differences in perspective that lead us into trouble.

So, for example, one of the things that a colleague of mine and I really came to believe based on some data that we reviewed, was that physicians in intensive care units at the end of life are very focused on the survival of the few. You know, one in a hundred of those patients could walk out of the ICU, and if this is the one in the one hundred then I've got to help that patient. I've got to maximize their survival. Whereas the nurse is saying, but 99 of those 100 patients aren't going to walk out of this unit, and we are causing needless suffering in those 99, so nurses are focused on the suffering of the many. Well, who's right and who's wrong? They're both right. So, the issue is how do we bring those perspectives together? How do we bring that physician's understanding and that nurse's understanding of his obligation together to figure out what our plan is going to be for this patient?

AND THEN ADD IN THE ADMINISTRATORS, INSURANCE COMPANIES, AND FAMILIES.

There you go. It's very complex business.

IF YOU WERE TO PAINT THE PICTURE OF THE MOST FUNCTIONAL SYSTEM TO ALLEVIATE MORAL DISTRESS, DO YOU HAVE SUGGESTIONS FOR HOW CARE WOULD BE ORGANIZED?

Oh, you bet. You should come to some of my classes!

WE'RE HERE. THIS IS YOUR CLASS.

I know, but I don't have my PowerPoint! I can't remember all of this stuff. Alright, so, number one, I think collaboration among a team. Healthy collaboration where people see themselves as active partners focused on the patient. They talk together, they problem solve together, they make decisions together. That would be the number one thing. Secondly, a unit and a system that is attuned to the destructive effects of moral distress, and expects and welcomes and champions people coming forward if they feel like their moral values are being compromised. So, that they explicitly say, "We want to hear from you if you're disturbed about things that are happening." And teams come together and say, "How do we work with these patients and their families?" If we need to change a plan of care we can change it. We have early, proactive communication. We have ICUs that have family meetings with families, and that work out the goals of care, the plans of care, whether this person had an advanced directive, and what it was they wanted, how we can all be on the same page? That notion of being on the same page with patients and families is a really key thing.

IS THERE ANY ORGANIZATION DOING IT RIGHT OR PILOTING AN AREA OF PRACTICE WHERE THEY'RE DOING IT RIGHT?

I think there are a lot of people who, on a unit level, are trying. In fact there is a unit at the University of Virginia, and it's a challenging unit, it's the neurosurgery intensive care unit, so they have ethical challenges and moral issues all the time with that patient population. In fact, that unit led to the creation of the moral distress consult service because of a very difficult moral distress situation. In the ensuing five years since we first had that discussion, they are a unit that ought to be offering moral distress consultation. They do it right. They early and proactively address things. They work as a team. They jointly problem solve. They come together with these issues. And the last time they consulted the moral distress consult service, the two consultants came out and said to them, at the end of it, "I don't know why you guys asked us in here. You solved it. You knew what to do." So, I think there are places where there are leaders who understand this and work through it within their systems.

Now you can go to another unit at that same institution and you don't see that at all. So, what you're raising is, how do we get an institution-wide approach? And again, I would

suggest that that's a good thing for you to talk with Lucia about because I think that's an institution that made a big commitment to ethics resources. A lot of the institutions, the ethics resources are, I call it the "All-volunteer army." You know, we have other jobs, and we just serve on these committees, and we do these consults, but the issue of really building system change is not something that's on the radar screen. Now, I think you talked with Beth Epstein earlier, and the University of Virginia has reconfigured their ethics resources, and they brought in a new leader, and I think one of her goals is really to be more involved in this clinical system change. And that's part of what it's going to take. It's going to take some dedicated resources.

WHAT ASPECTS DO THE PATIENT, FAMILY, GENERAL POPULATION, CULTURE, CONTRIBUTE TO A SET OF EXPECTATIONS AROUND HEALTH CARE, AND WHAT DO ECONOMICS AND ADMINISTRATION BRING TO THE SITUATION?

Well, that's a multifaceted question. So, if you take the first part of your question-- What is it about public perception of health care and the way the public understands what we are about, I think there are some really unfortunate stereotypes, which is that we can fix anything, that we're miracle workers, that you can come to us and we have such an armamentarium of equipment that we can just tune you right up and send you home, and one of the most recent cases we had in our ethics committee was a patient who was in terrible, terrible shape, and she was not going to be able to have a transplant, and they put her on a left ventricular assistance device, an LVAD. She still had the expectation that she was going to go home and live independently. Well there was absolutely no way that was going to happen to her. But somehow that conversation and that understanding and that moving away from the expectation that we could fix her had not happened. It was very distressing to the nursing staff because they knew she was never going to leave that institution. And so I think that that's one of the issues.

The other issue you're raising about cost is that we, historically, in health care, have said, "We don't want to pay attention to cost." We have used a "Humanitarian" approach where we say, "If you need it, we want to provide it." And this issue of saying, if you need it we want to provide it, we can't afford that anymore! You need to start thinking about how to do this work efficiently, and we can't do everything for everybody. That gets very difficult when you're standing beside somebody's bed and you have a family member who is saying, "But you have to try one more thing." And we, too often, say, "Well we have this technology, we can try it." There are times when we should not be offering a certain technology, because fundamentally it is not going to do anything for the underlying disease process, and it's only going to compromise that person's quality of life at the end. But those are very hard conversations and we haven't gotten really good at doing that, either as a society or, even, within our institutions. So, I think we have sort some collision courses going on.

AND IT'S AT THAT INTERSECTION?

Moral distress can thrive.

SO THOSE WHO HAVE TO CARRY IT OUT ARE JUGGLING THE BALLS.

That's right. And one of the really interesting comments that we're beginning to hear in the work that some of us are doing, is we're beginning to hear people saying, "Why are we using all these resources? Why are we doing this? This is wrong, wrong, wrong." There's a very moving quote from a physician who said, "This is just wrong. Why are we doing this?" But if you think about the whole momentum of modern medicine it's very difficult to stand against that.

IS THERE SOMETHING OUTSIDE THE SPECIFIC AREA THAT YOU WANT TO SHARE?

There was a New York Times column on moral distress done by Pauline Chen. As part of that people could respond, and there were lots and lots of responses. One of the responses was from a nurse, who was talking about why she was leaving nursing, and that she was leaving because of moral distress, and she laid out all these reasons about how chaotic the system was, and mistakes were being made, and it wasn't anybody's fault, but everyone felt terrible about it and all these other things. And here's the last thing she said. She said, "I came to nursing because I care so much about patients, but I'm leaving it because I want work that doesn't hurt me as a person." This to me is the bottom line. Moral distress hurts people at their core. It hurts what they think of themselves as a person. That's why we have to take it very seriously, and that's why we have to start really thinking about how can institutions and systems deal with this, because it is taking a toll on providers. And that's not a toll that the healthcare system can afford.

I THINK IT'S AN IMPORTANT ISSUE. IT WOULD HELP IF WE COULD GET A SECOND IMAGE OF IT. SO YOU WANTED TO BRING UP THIS QUOTE AS IT RELATES TO THIS ISSUE.

Well, for me moral distress is very serious business, and that's part of the reason that I've tried to focus on getting clear about what it is and what it's not. It's not any kind of burnout, it's not any kind of compassion fatigue, it is this sense that I described in this quote from this nurse who was writing in response to a New York Times column on moral distress. She said, "I am leaving nursing precisely because of moral distress," and she talked about the reasons. I wish I had the quote but actually I have it in an article. But she said "I came to nursing because I cared so much about patients, but I'm leaving it because I want work that doesn't hurt me as a person." And so to me, that's why this

phenomenon is so damaging, it's because it cuts to the core of who we are as people and what we think about ourselves. That's why that nurse threw that chart down on that patient's bed and walked out and quit. She was hurting herself as a person to remain on that team where that family was not being told the truth about what had happened to their son. That's why we've got to take this seriously and be looking at what can we do as institutions to deal with it. I think there are a lot of small efforts going on. I think that's great. I think we need more, a lot more, research and work on this, but fundamentally, at the heart of it, no care provider should feel like they have to compromise their moral integrity to engage in the moral practice that is health care. It's very serious business.

PLEASE INTRODUCE THE CRESCENDO EFFECT AND HOW IT CAN UNFOLD.

I will, but let me talk about the moral distress consult first, because I think that that will just segue right into the crescendo effect. Ethics consults are classically about an ethical dilemma, where what's at stake is the decision to be made, and there isn't a good answer. In other words, there are solutions that appeal to one good and an opposing solution that appeals to another good, but you can't do them both. So, the issue becomes, within this case, within this particular situation, how ought we to decide? And we have developed really great understandings of ethics consultation.

In moral distress consultations, one of the things that is extremely interesting, many times people will call because of a case, but when you get in and you start to talk to them it isn't about that one case. They begin to tell you about other cases and other cases. So, for example, in one situation where we thought we were dealing with the problem of aggressive treatment of a child because a parent couldn't make a decision, within 10 minutes this team had absolutely poured out all these similar cases where they continued to be aggressive even when members of the team thought that it was wrong for them to do that. So, suddenly we're talking about five cases. We're not talking about one case. And the decisions had been made, but the issue was how people felt about it.

So, one of the things that you have to do in a moral distress consult is you have to really listen through all of that, because clinicians are very case-based in their thinking, because we take care of one patient at a time, so we tend to think that way, we tend to process things that way. So, you have to listen to these things and begin to pull together these root causes that you hear. "Well, what I'm hearing here is that some of you are really disturbed about the pain management that this baby's getting because of needing to keep their vital signs at certain levels," or whatever. You begin to pull out what you think are underneath the commonality of all these cases. Or that it sounds like when a baby is on this service, this service feels very strongly that they have to keep pressing aggressive treatment. So, talk about that. So, you start to pull together what I call these root causes that are contributing to all this distress. And then you have to start looking at what are we going to do about that as a team. What do you want to do about that as a unit? What are the ways in which the institution is not supporting your attempts to deal

with this? So, you're going beyond the case. You have to go beyond the case. And I think that's one of the major differences. And it isn't so much about decision-making, because you see when they bring in all these other cases, those cases have happened.

They're just on a crescendo, and this is where the crescendo effect comes in, we began to hear in these narratives this idea that one situation raised distress, and then that situation resolved but the staff was left with what's called moral residue, which is a really bad feeling that you did compromise your agency, and it's a very powerful and negative feeling that you're left with, and then here comes another case, just like that case, and so your distress rises again, in fact it rises even higher. And after four or five of those you have what we call a crescendo effect, which is that my residue and what is remaining from each of these cases is "crescendoing," and therefore, when a new case comes in, I just go "Oh, no, here we go again." And you will hear nurses and doctors say this "Oh, no, this is just like Mr. Jones." "Oh, no, I can't stand it, we can't do this again." And it is that residue; it's that memory, of these difficult cases where the distress was not acknowledged and dealt with that creates this crescendo effect.

AND THOSE ARE THE ONES THAT WILL FINALLY BUBBLE UP INTO OBVIOUS BEHAVIOR?

Right, right, or for example, I once had a physician say to me "Oh, you nurses are so emotional, everybody's just going to the moon about this patient we just admitted." And I said, "It's because he's too much like the five other patients that you had where there were bad results."

EXPLAIN WHAT A CRESCENDO EFFECT IS AND USUALLY WHAT'S THE OUTCOME?

First of all, I have to tell you that this is a relatively young idea that came up from the dissertation study of Elizabeth Epstein, who you interviewed earlier. Part of her dissertation was to tell me about what it was like to take care of a baby for whom a decision had been made to withdraw treatment, and then the baby had died. And she wanted to know what that was like. And part of what we started to notice in the narratives she was getting, was that all of these nurses and doctors were talking to her about other babies. She didn't ask about other babies. She asked about Baby X and they told her about Baby Y and Baby A and Baby B. So, we were going "What is this about?" because they would go into this great detail about "Oh, it was just like this and here's what happened," all these painful stories.

So, that's where we started to see this idea that you get into a morally distressing situation, and your distress rises. Decisions aren't made. You feel like you're compromised. You feel like you're an agent of pain and suffering when that's the exact

opposite of why you became a nurse or a physician. And then something happens. The baby dies, or the baby's discharged or something happens. So, the moral distress goes away. There's a decrescendo. But if what was going on isn't acknowledged, if we don't talk about how do we prevent this kind of distress next time, what could we do differently, how could we better listen to each other, how can we make decisions quicker, there's this residue that remains, that has been described beautifully by a philosopher and a chaplain, Webster and Bayliss, who wrote about moral residue as what remains from situations where you feel that you are morally compromised. And then here comes another situation. So, in this case here comes another infant with very similar things and again, if things don't go well, there's this distress crescendo, then something happens, but then there's more residue.

So, over time you get this crescendo in residue which means that you are much more on edge. If this isn't being dealt with in your environment, if people are not recognizing this and doing something about it, that's what I mean when I say nurses go "Oh, no, here we go again." I mean, the patient has just shown up. They don't even know anything about this patient. But it is evoking all of this residue that they are carrying between their ears from all of these previous experiences. So, if you say "What's the net result of that?" I think there are three net results that we have seen. One of them is that people quit, just like that nurse who threw the chart down on the bed. Another is that they get mad, and they object in some way. And they may do it in a passive aggressive way, which is no good because it doesn't change anything, or they may try to be very responsible and say "We're not going to go through this again, we have to do something different this time." Whatever. They may object with each other, they may object to other members of the team. That's usually what they do. But the third thing is this notion of, they get desensitized. And this to me is a very dangerous thing.

A sociologist wrote about this as what he called a routinization of the moral world, where he found that nurses, over time, just got very desensitized to things that were happening. It's almost like they put on these moral blinders and they just said, "Oh, you just get used to it." I mean, that's what they would say to him. "Oh, that's just the way things work here, you just get used to it." And this desensitization means that that's how they're protecting themselves from this crescendo, but that's a worry to me because they are pulling away from these patients. And we even have quotes from nurses who say "I just don't take care of patients like that, because it's too hard, and it upsets me too much, and so I just don't take care of them." So, sometimes these are patients that nobody wants to take care of and the nurses are drawing straws to see who has to take care of them. This is not a good situation for anybody, particularly the patient.

THANK YOU...