

UK Moral Distress Education Project

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PLEASE START WITH YOUR NAME, YOUR ORGANIZATION AND SOME OF THE ASPECTS OF YOUR PROFESSIONAL ROLE THAT WILL BRING YOU INTO CONTACT WITH PATIENT CARE.

My name is Cynda Rushton. I am a professor at Johns Hopkins University. My interface with patients and families is often through ethics consultation. That often involves situations where there's conflict that arises between family members, patients, members of the healthcare team about some aspect of care. Because of that, I often get invited in to try to help facilitate better understanding and maybe a clear path for resolution, if possible.

HOW WOULD YOU DEFINE MORAL DISTRESS? HOW CAN IT UNFOLD IN THE CARE SETTING?

Moral distress is really about the anguish that clinicians often feel when they are confronted with situations where their integrity is being compromised. One of the elements of this is that clinicians often recognize there is a moral problem. They go through a process of discernment, to think about what would be the right thing to do. Then, for whatever reason... Either because of internal constraints or the external environment, they really are not able to act on what they think is right. The consequence of that is often a very profound sense of anguish and suffering and a sense of violation of their sense of being a good nurse, good doctor or whatever their role is.

ARE THERE CERTAIN CARE SITUATIONS WHERE YOU SEE MORAL DISTRESS COMING UP ON A REGULAR BASIS?

Moral distress comes up in lots of different situations. The more common ones have to do with decision-making about end of life care. Sometimes they have to do with truth telling and how we think about informed consent. They might include things like privacy, where a patient's sense of privacy has been violated in some way or another. It also involves, I think increasingly, issues around respect and dignity where people who are particularly vulnerable, in life and the healthcare system, feel like they are not being treated fairly, that they may not have access to the kinds of healthcare services that they need. They may feel that they are being discriminated against, for one reason or another. And those situations can often be a part of a patient's story. From that, often, conflicts arise. It's a whole, wide-ranging set of issues that could cause people moral distress. Some of them, we would think about as more mundane, and some of them, quite dramatic. But I think what's common with all of them is this sense of not being able

to act in a way that is really consistent with who I am as a person, the values of my profession, what I care about in terms of my role and my service.

CAN YOU GIVE US AN EXAMPLE OF A MORAL DISTRESS SCENARIO THAT YOU WERE INVOLVED IN? HOW DID IT COME UP? WHAT HAPPENED?

My own personal experience is what got me involved in ethics and exploring these issues of moral distress. I started my career as a pediatric critical care nurse and thinking about how you provide the best care for children, who are unable to speak for themselves, and how do you advocate for their families, in these really complex situations. We had a very difficult case that involved a young person who had had a situation that resulted in not having enough oxygen to her brain. It left her in a persistent vegetative state. After many attempts to try to change that outcome, it was really clear that this was irreversible. At that time, her family had requested that we not continue the life-sustaining treatments that we were providing, a breathing machine and she had tube feedings. Basically, we were sustaining her biological functions.

At that point in time, there was a lot of fear in the healthcare system about cases just like this. The physician who was in charge of her care denied their request to discontinue these therapies. As a result of that, she basically lived in our unit for almost two years. She was, in many instances, moved around from unit to unit, from bed space to bed space, to accommodate other patients who had the potential to actually benefit from what we were doing. It felt like such a violation of her, as a human being. First of all, we were providing care that was sustaining her biological function, but wasn't restoring her to any awareness of her existence. Her parents didn't believe that this was the best way for her to be cared for. They stopped visiting. It caused them incredible distress and grief, to the point where she basically died in our company, without her parents.

That left a really indelible imprint on me, as a young nurse. How could we be doing these things to the body of this child, in a way that actually wasn't benefiting her and wasn't really benefiting her family? Part of the reason for that was because we didn't have the moral courage to accommodate their request. We, collectively, were fearful about legal risk, how it might be interpreted outside of our institution and our unit. That was one of many that propelled me forward to try to understand it better and to try figure out ways that we could work with this reality more skillfully and with more compassion.

HOW MANY YEARS AGO WAS THAT SCENARIO?

That case was probably 25 years ago.

HOW ARE MORAL DISTRESS ISSUES DEALT WITH IN YOUR INSTITUTION?

What we are doing now, in terms of addressing moral distress, is we've given people the language to name these situations as morally distressing. In the early days, we knew we

felt badly about them. We knew that there was distress, but we didn't really have a name for it. Now we have a name. We have some sense of what some of the causes are. What's missing is we haven't fully created the repertoire of things that we need to actually address the issues. That said, we are now putting in place more mechanisms for nurses and other people to ask for help. Like ethics consultation, where people recognize that there is a situation that is causing not only one individual, but many, moral distress and there is a process and a mechanism for people to ask for help.

One of my concerns about that is that the threshold for when people feel that it's appropriate to call for help is usually pretty high. As a result of that, we get called in, as consultants, when things are really bad, which makes it difficult, then, to try to patch things back together when they have already disintegrated. We are trying to figure out how to create the kind of climate where you can call the question way before people get to the point where they are so distressed that it's affecting them physically, emotionally and spiritually. The resources that they have available to them, within themselves, have been exceeded and it's really causing harm to them and probably, ultimately, to the patients and families we are taking care of.

WHAT EXISTS IN YOUR INSTITUTION NOW? WHAT'S IN PLACE, SYSTEMICALLY?

Systemically, there are mechanisms where people have been given the skills to identify these ethically challenging situations. We have done education around some of the more cognitive skills. We are also beginning to develop some of the relational and more internally-focused skills, to help people be more resilient. Partly because, although we wish that moral distress could be extinguished, I don't think it's very realistic. Given the complexity of our world and our healthcare system, it's not likely that that is going to be extinguished from our experience. What I am left with is thinking, "Okay. What else could we be adding?"

We are focusing on the idea of how do we build resilience. How do we help all the clinicians have more tools to deal with this reality, things like programs that help people develop stability in their mind and emotions, mindfulness-based strategies? Developing communication strategies, how do we speak to each other, as members of the team, more clearly? How do we talk with patients about goals care? How do we help them to navigate these often uncertain journeys they are on? We work very closely with our palliative care team. Often, we have very complementary approaches. Sometimes we need people who can help the team and the family to redirect goals of care or to clarify goals of care. That's a whole set of initiatives that works hand in hand with trying to identify occasions where we need to stop, pause and reflect, and also looking for other resources in our own institution.

DESCRIBE HOW, AS A CULTURE AND AS A GROUP, NURSES RECEIVE AND RESPOND TO MORAL DISTRESS EDUCATION AND SUPPORT? ALSO, HOW DO DOCTORS, AS A CULTURE AND A GROUP, RESPOND TO MORAL DISTRESS AS AN INPUT INTO THEIR HEALTHCARE PRACTICE?

It's a very interesting question to think about the differences between doctors and nurses and their response to moral distress. Most of the research has been on nurses. We are now beginning to understand a little bit better what the sources of moral distress are for physicians. Quite honestly, we don't have as much insight into the experience of physicians as we do nurses. This concept was first coined in the context of nursing. Unfortunately, for a long time, it was viewed as just a nursing issue. Clearly, it's not. It is an issue that affects the whole team. What we have learned is a little bit of a proxy, from the point of view of we've learned more about burnout, which can be a consequence of moral distress. The things that cause burnout include experiences of moral distress that haven't been worked with in a way where people can let go of them, be able to take that experience and learn from it, and to be able, then, to integrate it into "Okay. This is who I am. I've navigated successfully, without so much cost to myself." I think what we know about nurses is nurses tend to respond to interventions where there's an opportunity to discuss and dialogue. Whereas physicians may be more focused on one-to-one interventions. They are not, often, as engaged in group dialogue. Partly, I think, because of the culture of medicine that has to do with individual competence. Many of these conversations may threaten that sense of being confident. "If I have to ask for help or if I acknowledge my vulnerability..." I think those factors influence their response.

For some people, they take a very cognitive approach to these kinds of issues. It's just, "Let's get down to the facts. Let's have a protocol. Let's have a policy. Then the problem will go away." Unfortunately, that hasn't proven to be very successful. We have developed futility policies. We have developed policies on informed consent. Useful, but not sufficient, in terms of actually making the difference. One of the pieces that's been missing is really a fuller exploration, of both doctors and nurses, about their own emotional and, arguably, spiritual responses to these situations. Unpacking, a little bit more, about what's really at stake for people. Knowing yourself well enough to realize when you have actually gotten so empathically aroused... We see the suffering of our patients. It activates a response in us to do something. Sometimes that activation can become so intense that we are not focused on the patient any longer. We are now unconsciously focused on "How do I make myself feel better in this circumstance?"

I think that's a really important area, trying to figure out how we develop self-awareness so that I can notice, "I'm really getting angry in this circumstance." Instead of saying the problem is the patient, "What's happening, in me, that's causing this response? How do I work with that so that I don't destabilize the situation," and start, then, trying to convince the patient that the way they see things is wrong. Sometimes we can haul in the Ethics Committee as a way to say, "You are really not able to continue in this plan that we have created." Or we get the attorneys involved, and it becomes adversarial rather than relationship-centered. I think there are some real opportunities there. I also think that we

haven't really done as good a job as we could in looking at it from an inter-professional standpoint. It's not just nursing examining the sources and root causes of moral distress, but all of us, together, in this healthcare system that's very complex. It's very beleaguered right now and, I would say, relationally depleted. We don't have relationships with one another. We don't have a safe place where we can talk about what it's like to provide care that we think doesn't make sense.

We often don't have safe places where we can be honest with each other about the support that we need to be able to keep going into that room, where, every time I go in, I'm confronted with this person's suffering. Or I'm confronted with doing things, as a nurse, in particular, that feel like they're causing more harm than good, that doesn't feel consistent with being a good nurse. So I think we are trying to find out more about what the system issues are that contribute to these circumstances and that's an area we are beginning to work in, trying to look at "Here's a very difficult case where moral distress was very prominent. Now let's go back, in a systematic way, and try to peel back the onion." What was it about the system that contributed to a communication problem or contributed to a lack of clarity around goals of care for this patient? And how do we take it, from a systems perspective as well, as building the individual capacities to respond differently to these situations?

FROM YOUR EXPERIENCE, WHAT ARE SOME SYMPTOMS OR SIGNS OF FOLKS WHO ARE EXPERIENCING MORAL DISTRESS? WHAT KINDS OF EFFECTS CAN THERE BE ON PEOPLE WHO ARE GOING THROUGH THE SCENARIO THAT'S CAUSING THAT?

Moral distress often affects the whole person. There's a whole set of physical symptoms, that sometimes are overlooked, when moral distress is present. Ranging from a stress response... when the sympathetic nervous system gets activated, your heart rate goes up, your breathing changes, your digestion changes. All of those things can be acute. They can become chronic if they are not addressed. Weight loss or weight gain, people who are not sleeping, people who are experiencing all kinds of physical complaints, that "Oh, it's just my neck that hurts," are all signs of stress and distress. The body can often be a pretty interesting doorway into what's going on.

There are a lot of emotional responses. It can range from being hyper-vigilant to being very anxious, people feeling angry and having emotional outbursts to people who are totally shut down. They are apathetic. They are kind of lethargic. They don't have a lot of responsiveness. "I don't really care. It's not going to change," a resignation about the situation. You can see some of the symptoms of horizontal and vertical violence; these can be related to moral distress. People who have not been able to resolve those issues may end up taking it out on people who have less authority, taking it out on their colleagues or taking it out on their family. Depression is often a cumulative effect that is showing up, related to moral distress.

There are a lot of behavioral manifestations. Things like substance abuse, of all different types, is a symptom of a stressed person who hasn't been able to find a way to manage that well. It might be cynicism. It could be really being checked out of life and disconnected. It also affects people in a spiritual sense. Finding, "What does this job mean anymore? Why am I here in the first place? Why am I doing this?" That sense of meaning and bigger connection to life. People can get pretty shut down. It really does affect the whole person.

When you start peeling the onion back, often, the presenting problem may be anger. The thing I notice a lot is people say things like, "Why are we doing this?" It's almost the code word for "There's an ethical problem here, and we are having a hard time managing it." For me, that's the red flag, when people start saying, "Why are we doing this? Why are we doing this?" It's a good "let's pause and see what happens." The other thing that happens a lot is that team relationships begin to deteriorate. A lot of times, we get into a blaming stance with each other, or a victimized stance. "I'm just carrying out the orders of other people." Team communication can really deteriorate. Someone, then, is identified as "This person is the reason that this problem exists." It might be the family member. It might be the patient. It might be the physician. It might be the nurse. Everybody, then, loses their capacity to be more generous toward each other. They stop listening to each other. They begin to project onto each other, certain characteristics that may or may not be appropriate. It has some pretty profound impact on individuals, but also how the team functions.

GIVE US THE SCENARIOS OF HOW THAT PATTERN GETS STARTED BY SOMETHING HAPPENING? WHAT ARE THE BRIDGES BACK TO SOME FORM OF DECENT FUNCTIONING THAT INSTITUTIONS CAN OFFER?

It's important to ask what the red flags are. What are the things that can stop the process? Stopping the process of a situation where distress is present can range from an individual stopping their own thinking process for a moment of reflection, all the way to a formal trigger in an institution, where, when these characteristics are present, some system response needs to happen. When everybody is saying, "Why are we doing this? Why are we doing this," that ought to trigger a system response. It could be an ethics consult. It could be a patient care conference. It could be a family meeting. Something needs to get people together.

HOW DO YOU DO THAT? WHAT HAPPENS?

In our institution, the call for help can come from anybody on the team, including the patient. I recently had a patient call me and ask for help. I think she felt morally distressed about the care that she was receiving. It's important that the mechanisms, whatever they are, are accessible to anyone on the team who feels that they need help,

and that there is a support for people to call the question.

LIKE A FIRE ALARM?

Like a fire alarm. One of the things we've worked really hard in, in our institution, is to create that access, where it's not asking permission. Everybody is empowered to say "I'm struggling. I need help." As the person who often responds to that, my job is to listen, to try to uncover what the facts of the situation are. Often, the facts aren't clear. That contributes to people's distress. They haven't heard from all the different team members about different conversations or information that's relevant to a patient's care.

SOMEONE SEEING THIS, WHO IS IN AN ORGANIZATION OR INSTITUTION THAT DOESN'T HAVE A FORMAL PROGRAM, WHAT ADVICE WOULD YOU GIVE THEM? WHAT SHOULD THEY BE AWARE OF? WHAT SHOULD THEY BE PUSHING FOR IN THEIR INSTITUTIONS, IN TERMS OF AT LEAST INTRODUCING THESE ISSUES?

I think the first step is awareness, recognizing that moral distress exists, recognizing it in yourself, naming it as "moral distress." I think we have some pretty strong leverage points -- in our organizations, from the joint commission, from external regulatory bodies, professional organizations -- that one could use as justification for why an organization needs to pay attention to this. I would say it's not optional anymore. We absolutely have to have a commitment to an ethical practice environment or we risk the entire healthcare workforce and the quality and safety of patient care. I think it's not optional. I think there are lots of good resources now that organizations could use.

SUCH AS?

Such as The American Association of Critical Care Nurses has a position statement and a tool kit about how to recognize and address moral distress. In our ANA Code of Ethics, one of the provisions is that the nurse has the same duties to self as to others, including preserving her integrity. Those are important documents and important statements that empower us to move from feeling victimized and depleted to "We need to take some action." I think individuals can take action even in organizations who haven't made that commitment. It just takes one person to have the moral courage to step forward, to name the situation, to be willing to actually stand firm on what they know and motivate a conversation and a system to pay attention.

IS THERE ANYTHING YOU WOULD LIKE TO ADD TO OUR PERSPECTIVES ON THIS TOPIC?

One of the things that I feel is missing from our dialogue is around how we actually transform these distressing situations into compassionate action. Part of the answer to that is that we have to create a new narrative about how we identify and address these issues, that lets go of the story we have always told ourselves, that is very much, particularly in nursing, a victimized story. It's the story of a lot of pain and a lot of suffering, which is true. There is an opportunity to move beyond that. I think now is really the time to do that. Working on the ways to deal with these issues means that we have to expand our repertoire to social psychology, neuroscience, to other fields that can inform our work and help us to be able to have more tools in our toolbox.

One of the things that I have found really helpful is being able to actually have a more grounded place in myself, where I don't get so reactive to these situations. Where I am more able to see the limits of what I can do, to accept those limits, to accept my own vulnerability in these situations and to help let go of the burden we put on ourselves, that we are supposed to fix this problem. Many times, these situations cannot be fixed. Accepting that because we can't fix it doesn't mean that we failed. We've actually been able to do good by at least exerting some effort to try to address the problem, instead of constantly feeling like "I have not done enough," "I failed." That accumulates over time. Eventually, you start feeling really bad about your role, your self, your profession. That's what leads people to leave the profession, whether it's nursing, medicine or whatever it is.

There's a whole body of work that is around helping people to be a little more compassionate toward themselves and their limits, and also to help people to remember why they are doing the work that they are doing. In the midst of the distress, we often become so alienated from "Why am I doing this work in the first place" that we get focused on making other people do things that we think are the right actions. We miss why we are really here. That's a really important element of being able to move forward. People are hungry for this. Many people have stories after stories that have accumulated for years. Their backpacks are really full and really heavy. We need to now help them let go of all of that so that they can reorient back to why they decided to be a nurse or a doctor in the first place.

THAT MIGHT INCLUDE CHANGING THE INSTITUTION OR INTRODUCING A NEW INSTITUTIONAL STRUCTURE TO ALLOW CONVERSATIONS AND CULTURE TO CHANGE.

Exactly.

WHAT WOULD YOU LIKE TO SEE INTRODUCED?

That answer was about the individual. The other part, and they are absolutely essential, is that both individual interventions and a systemic culture change occur together. To me, it's the ingredients for how to move forward. It's a really interesting time in healthcare right now. On the one hand, things are in a lot of chaos. There is an opportunity, I think, to use that chaos to invite people into... we have to work differently together. We have to think differently about how we provide care. We have to think differently about how we sustain our workforce because they are a scarce resource. Organizations may be a little bit more open to suggestions that are not just about the problem, but part of the solution.

We have to get clear about what the many factors that contribute to these situations are. We need to do that more systematically, where we can document, through a process, "Here's the case. Here's the root causes. Here's the way forward, including individual and system reforms." Doing those things, simultaneously, probably has the most potential for making change. I often have thought that people have to suffer enough and long enough before they are ready to make change. It may be that we are close to that threshold in our own professions, in our healthcare system, in our society, I hope. It is a very important issue. It is one that we have to do something to address. Maybe these factors will create the environment where that can happen.

GIVE ME AN OPERATIONAL SUGGESTION WHERE WE COULD BE MORE PREVENTATIVE, SYSTEMICALLY, RATHER THAN DEALING WITH THE CAR CRASH AFTER IT HAPPENED.

Prevention is absolutely an important element of creating an ethical practice environment. That's where I think the systems analysis can be really helpful. What are the patterns of cases that cause us moral distress? And we could probably identify, really quickly, based on our ethics consultations, what the patterns are. We know the units. We know the characteristics of the patients, the characteristics of the team that are likely to result in a morally distressing situation. So, that kind of analysis, of saying, "Okay. We have some patterns here." One of the other patterns, that's very common, is when we deviate from our usual way of doing things; we are more likely to end up in the ditch. And so having some triggers, like patients who are in intensive care units for long periods of time; patients where, from the beginning, there is not a good therapeutic relationship established; where there is ongoing differences of opinion about goals of care; where there are issues of trust and distrust that are prominent in the communications. All of those are symptoms that, if we paid attention to them before the whole house was burning down, we might be able to do something different.

DO YOU HAVE AN OPERATIONAL SUGGESTION FOR HOW THE SYSTEM WORKS IN ADVANCE. RATHER THAN A FIREFIGHTING TEAM, A FIRE PREVENTION TEAM.

One strategy would be to have a set of triggers for different systems to become engaged, when patient characteristics and team characteristics create the red flags.

WHAT WOULD BE A WAY TO TRULY BE INVOLVED IN TERMS OF THAT TEAM?

One analogy would be the same way that we try to identify preventable errors in medication delivery. We need to have checklists and system processes that create red flags, that cause different people to respond. If you think about it like a medical error and trying to prevent a medication error, it would be who, on the team, has certain responsibilities for identifying a problematic case. Often, it's the nurse who can tell you "There's something about the patient situation, their diagnosis, their length of stay, their interactions with the healthcare team that lead me to be worried that this could become a situation where moral distress occurs." If that person was empowered to pull the plug and say, "Okay. We need to all get together. We need to have a family meeting. We need to have a patient care conference. We need to get these support systems in place for this family. Maybe we need to add additional consultants, like palliative care, into the system." That's the kind of thing that I think is going to make it possible to get these issues more upstream.

Everybody is empowered. When you see a situation where you are worried that it could result in a violation of integrity of the patient, of the family, of the team, everybody is allowed, invited, empowered to call the question. That would then trigger other system responses. It's like a code-- it's like when a person arrests on the floor. We have a whole system, a protocol for how we respond. Everybody knows their role. Everybody knows how to respond when that question is called. In an ideal world, if we could create that same kind of responsiveness and empowerment for everybody to feel "If I notice that a patient stops breathing, I should respond in a particular way." I would love to see us be able to respond to ethical conflicts in the same way. Everybody knows their role. Everybody has a sense of reliability that, when I call, there's going to be a response. All the people that are needed to take care of the situation will show up. We are all committed to trying to work through the situation in the best way, so that everybody's integrity is preserved. That would be my goal.

AND IT WOULD BE RESPECTED AS A SITUATION WORTHY OF EVERYONE'S ATTENTION.

Exactly.

THANK YOU...