

## **UK Moral Distress Education Project**

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### **PLEASE TELL ME YOUR NAME, YOUR POSITION AND WHAT SITUATIONS BRING YOU MOST DIRECTLY INTO PATIENT CARE?**

My name is Beth Epstein. I am an Assistant Professor at the University of Virginia School of Nursing and I don't have direct patient care, but I do research in the newborn intensive care unit -- pediatric intensive care unit. I also serve on the Ethics Consult Service and the Ethics Committee.

### **HOW WOULD YOU DEFINE MORAL DISTRESS?**

I would define moral distress as being a situation in which a person feels as though they know what the right action to take is, but they're constrained from taking that action for whatever reason. It's not simply a situation of being constrained, but it's being unable to do what's morally right and that is potentially damaging, and that is why this is such a problem.

### **WOULD YOU GIVE US A FEW EXAMPLES OF HOW MORAL DISTRESS MIGHT UNFOLD IN A CARE SETTING AND WHAT ARE SOME OF THE EFFECTS OF MORAL DISTRESS IN THOSE EXPERIENCES?**

Sure. Moral distress unrolls, I've seen it most often in ICU settings, Intensive Care Unit settings, where one of the most common causes is prolonged aggressive treatment when the patient is not doing well and the prognosis is very poor, and so treatment tends to go on and on and on, with no good outcome in sight. It gets to a point where nurses, physicians, respiratory therapists, social workers, everybody feels like, "Why are we doing this? We're torturing a patient for no reason." People don't go into the health professions to torture people. That's why it's a problem. I see it most in the ICU settings, but now we know that it's everywhere in healthcare and more and more we're gaining insight into situations that cause moral distress.

### **WHAT ARE SOME OF THE EFFECTS OF THOSE SITUATIONS?**

The effects of moral distress, short term effects are anxiety, frustration, feeling like you're taking part in something that's morally wrong. That's what it feels like when you're in that situation. Over the long term, multiple situations of moral distress create an air of fatalistic perspective, like "here we go again" and "we can't control this" and "here's another situation just like we had six months ago that didn't turn out well, and I'm going to torture this patient too." Very fatalistic perspectives. Ultimately we know that nurses

and physicians, at least, consider leaving their positions. I've known several nurses to leave the profession altogether. It takes years to gain experience so that you're comfortable in an ICU setting, that's a high-technology skill set. What I worry about is that healthcare institutions lose decades of good skill sets and talent by losing people from the profession.

**CAN YOU SHARE A PERSONAL SITUATION WHERE EITHER YOU EXPERIENCED MORAL DISTRESS OR WHERE YOU HAD TO DEAL WITH A SITUATION WHERE THERE WAS MORAL DISTRESS?**

Sure. There are many. Years ago we had a situation, a patient who had multiple serious problems, a pediatric patient with multiple serious problems, and had been in the unit for an extended period of time and just had one thing after another. Ultimately, finally, he had an infection that couldn't be cleared and a surgical problem that was irreparable. The surgical issue, it just wasn't possible to repair the problem. The staff, nurses and physicians, were really struggling to take care of this child because everything they did caused pain. He was in pain with suctioning, with turning; everything they tried to do was painful. They knew that the child was ultimately not going to survive. There was just a feeling.

The family was having a difficult time coming to the realization that the child was not going to survive. The team couldn't, and most teams won't, unilaterally withdraw aggressive treatment without the parents having come to that realization. It was waiting for the parents to understand. That is fairly common. The healthcare team often arrives at an understanding long before the family does, and that's often to be expected. In this case, it took a long time. In the meantime, for 12 hours a day, the nursing staff would have to provide aggressive treatment to a child that they just knew needed to be let go.

The staff had a long talk about what would be good steps to take care of this child. What can you do to help this child while you're waiting for the family to arrive at the understanding that there's nothing more that can be done. It ultimately was a really good conversation. They felt like they had a plan to treat his pain and be able to at least address the discomfort and reduce the number of really invasive procedures that they were doing and really assess what he needed to have done and what could be set to the side. After that conversation I think the staff felt a lot better because they felt like they had some power in terms of doing what was right. They knew ultimately that they needed to withdraw the aggressive treatment and give him some peace and dignity, but until that moment, there were things they could do and they identified those things. I think that was very empowering for them.

## **WHEN EVERYONE GOT ON THE SAME PAGE, THEY COULD FIND THEIR BALANCE?**

Right, right. One of the big issues was the family was having trouble even visiting and they called in frequently and so, it wasn't so much poor communication within the team, but it was the ability to touch base with the family. They were really struggling. So we talked about how do you bring the parents back in. How do you re-engage, because the staff really felt like they needed to have this conversation about withdrawal and they also knew that it scared the family -- that the family just didn't want to have that conversation. So we talked about, "How are you going to pull this family back in and help them trust what you have to say -- establish a relationship with them."

Instead of when mom or dad calls saying, "We really need to talk about end of life care and transition to comfort care..." something like that; asking instead, "This must be really hard for you. How are you feeling today? Would you like to come in and hold him because he would love to be held?" Letting them be parents and snuggle with their child and bond with him and know that the staff really care, not only for their child, but also for them as a family. Within a couple of weeks they had re-established a good relationship with the parents. The parents came in and held him, realized that he wasn't doing well and they ultimately agreed that the best thing to do was to let him go.

That was a good lesson for me. So, in several cases after that I've said, "OK. How do we re-establish trust with this family? How do you establish a relationship with this family?" Because once you have a relationship and you've established trust, that's very empowering for the family, because they know they can trust you. And it's very empowering for the staff because you have the connection and you can have an honest conversation and that made all the difference.

## **WHAT ARE THE TOOLS, PROCESSES, OR ACTIVITIES AVAILABLE AT YOUR INSTITUTION TO ADDRESS MORAL DISTRESS?**

At the University of Virginia we have a unique way of addressing moral distress that's system-wide. It's available to everyone who works in the UVA Health System. That is a moral distress consult service. It's paired closely with our ethics consult service, but it addresses moral distress specifically, rather than ethically challenging problems. The ethics consult service will address patient-centered ethical challenges and they often involve interviewing the patient, interviewing the family, involving patient and family in decision-making and that kind of thing. Morally distressing situations don't usually involve, we don't talk to the patient or the family because usually they're not the center of the problem. Usually it's a unit level issue like poor collaboration or communication, or at the organizational level, a lack of policy or a policy that obstructs the ability of the staff to do what's right.

We meet with staff and talk to them about what the morally distressing situation is, and then we ask the staff to come up with solutions. Usually they're baby steps, not big

solutions, but baby steps toward the change that they would like to see in terms of collaboration, communication. Sometimes we've had to take problems to the ethics committee which would address a new policy, if that needs to be done, or revising a policy. But usually, it's a unit level issue. The consult service is the only one that I know of in the United States, and there aren't that many strategies that have been identified in the literature. Any strategies are important, and probably each institution will address moral distress in their own way. I think it's important that these strategies be disseminated so that other institutions can at least think about how they might take on a moral distress consult service and tweak it to fit their institution. It's certainly not going to fit every institution.

### **IN YOUR EXPERIENCE, WHAT USUALLY TRIGGERS AND KICKS OFF A CONSULT AND WHO DOES IT?**

It usually comes from the nursing staff or the nurse manager who notices that there has been a morally distressing situation on their unit for a while, for days or weeks, and their staff is coming to her or him saying, "What are we going to do about this patient? This is awful." They identify moral distress in their staff and then they give us a call.

### **COULD YOU TELL US, IN YOUR EXPERIENCE, HOW DOCTORS DEAL WITH MORAL DISTRESS OR WHETHER THEY EVEN ACKNOWLEDGE IT?**

Doctors do acknowledge moral distress, increasingly. I think moral distress was first identified in nurses, amongst nurses, and it's gotten a reputation for being a nursing issue. But it's not a nursing issue at all. It's all healthcare providers. We now have strong evidence that moral distress exists in nurses, physicians, respiratory therapists, social workers, chaplains, nutritionists. You name it, it's there. Increasingly physicians are aware of moral distress. They sometimes participate in moral distress consults, not nearly as much as they should, and it's something that we're working on to try to get them included. A lot of times it's a time issue, they just don't have an hour to sit down and talk about a morally distressing issue. But we know it's there and I know that a lot of physicians are interested in addressing it. We have to figure out how to address it effectively for that population.

### **WHAT PERCENTAGE OF DOCTORS KICK OFF THE FACT THAT THEY'RE HAVING MORAL DISTRESS ISSUES?**

In my experience, I haven't had any physicians who've called the moral distress consult service. It's usually triggered by the nurse manager or an advanced practice nurse. But, they will participate if they know about it. They feel it. I don't think they know that they can call us.

## **WHAT IS THE CULTURE AMONGST DOCTORS THAT WOULD MAKE THEM EITHER IMMUNE OR UNCOMFORTABLE ACKNOWLEDGING MORAL DISTRESS?**

I think that it's not just physicians, it's nurses and other staff as well, who think that they're weak and think it's their personal problem, that they must be unable to handle these kinds of difficult situations and it must just be them. That's pretty common. When I teach about moral distress to staff as an inservice or as a lecture somewhere, you can see the light go on in people's eyes like, "Oh, there's a word for that." "That's what I've been feeling this whole time?" Recognition is a big part of it. I don't think that anyone in any one profession is particularly in denial about it. I think they just haven't had an opportunity to know and to acknowledge that moral distress is real and that they're not weak if they experience it. Actually, it's a good sign if they experience it because they're morally in tune to their profession. You can't be a healthcare provider on any level and be morally immune to what you're doing. It's morally difficult taking care of sick patients and their families and once you become numb to it, that's a problem.

## **WHAT SITUATIONS OR WORK ENVIRONMENTS COULD LEAD TO MORAL DISTRESS ISSUES?**

Work environments that lack collaborative practice or that have strict power hierarchies tend to, in my experience, tend to be the ones that evoke moral distress amongst the staff. Moral distress is a red flag for me for problems with collaboration and communication. Whether that's intra-team or team-family, team-patient collaboration and communication -- they're a red flag for a problem. In a work environment that is highly collaborative, you still might have situations of moral distress, but they are aware of how to deal with them. They can recognize it earlier and deal with it earlier. Those are the situations where I see moral distress happening.

## **ARE THERE CERTAIN CARE SCENARIOS THAT CREATE MORE PRESSURE FOR CAREGIVERS?**

I think moral distress tends to arise frequently when we're caring for critically ill patients and patients who have a fairly high potential of dying. End of life situations can be very morally distressing. They're emotionally distressing, there's no doubt about that, and that's expected and that we can handle. That's fine. If you're not emotionally distressed about a dying patient, there's something wrong. But moral distress is not a welcome sign, it's a sign that something's really not going right for a patient. Maybe it's affecting the quality of care. That's when I see moral distress most often, in critical care situations and end of life situations. It's not always that way, we've had situations where a patient is not dying, but has raised a safety issue and the staff is unsure of how to manage poor safety, a violent situation, and that had nothing to do with the end of life. But usually, most of the cases are in the ICU setting where tensions are high.

## **WHAT RESOURCES ARE OUT THERE FOR PEOPLE THAT COULD HELP PREVENT MORAL DISTRESS OR HELP THOSE WHO ARE EXPERIENCING MORAL DISTRESS?**

There's more and more literature out there now available to people who want to address moral distress in their institution when there's no current strategy to do that. That's more and more available. I've been contacted and I know my colleagues have been contacted in terms of doing a guest lecture, or coming to a conference to discuss moral distress, lead a workshop to teach staff about moral distress. That's increasingly common. More and more studies are out there regarding strategies that people could use, taking a preventive ethics approach, some articles are out there now. That is one of the biggest gaps, though, in the current state of the sciences, the good solid studies on strategies to address moral distress.

## **WHAT CARE MANAGEMENT STRATEGIES OR APPROACHES COULD KEEP MORAL DISTRESS FROM OCCURRING OR REDUCE ITS IMPACT?**

That's a tough one. What I see as probably the most productive way to address moral distress is a couple of things. One is to know it exists and be able to recognize it when it starts to happen, especially in the ICU settings and in end of life care issues where this really happens the most, and to take a preventive ethics approach to recognize situations that cause prolonged aggressive treatment. There are pretty common red flags. Deeply entrenched religious beliefs or spiritual beliefs. It's good for families and patients to have strong religious beliefs, but when they contradict the medical reality, the staff starts to have a problem and there tends to be some friction. Identifying that that's a potential problem may allow the staff to address and talk to families about, "What do you believe?" "What to you is a miracle?" "What does that mean to you?" To establish trust right then and work with that family as you go along, rather than wait until the patient is really doing poorly and now you've got to make a decision and you've come up against a family with religious beliefs. The last thing you want to do is to step all over their religious beliefs. It's much easier to know what those beliefs are and how they influence families from the very beginning than it is to try to skirt around them toward the end. It's impossible. That's one flag.

Another flag is discontinuity of care. In the ICU there are 120 different nurses; there are 15 different physicians; in a teaching institution there is a new resident batch that starts at the beginning of every month; and there tends to be just kind of ...One resident described this to me as a train. Once the train gets on the tracks and starts to roll, it's impossible to derail it, it's very hard. That has a lot to do with the number of caregivers. You just get onto the tracks and you just keep rolling and it's hard to make it stop if there isn't a consistent provider being involved from the get-go, whether that's a physician or a nurse or a social worker, somebody. That's another thing. Starting early identifying potential things that can cause moral distress and addressing them early, I think is

probably the key to reducing moral distress ultimately anywhere.

**WHAT EDUCATION IS CURRENTLY PROVIDED IN THE TRAINING OF NURSES AND DOCTORS AS IT RELATES TO EMOTION DISTRESS AND MORAL DISTRESS AND WHAT IS THE DIFFERENCE BETWEEN THEM?**

In nursing schools we tend to be skills oriented. There are courses on end of life care, but there's very little...increasingly there's more ethics content, but in terms of moral distress, I don't know that it's standardized in nursing education. In fact, I'm pretty sure it's not standardized in nursing education. When newly graduated nurses join a staff, I'm afraid that they're unprepared for the realities of healthcare. The same is probably true for medicine. In medicine I know there's an increasing focus on the Humanities and on caring in addition to the hard sciences, pharmacology, pathophysiology, microbiology, all of that. There's also this, "How do you talk to patients?" content that's important. That may help, but I don't think that there's specific content on moral distress in medical school, or physical therapy school or any other school.

**FOR ASPIRING STUDENTS, WHAT IS THE REALITY GOING TO BE, BEING A HUMAN BEING IN THE HEALTHCARE SYSTEM, AS IT RELATES TO MORAL DISTRESS.**

For aspiring healthcare provider students I think it's important for them to understand that they will enter the field with an exquisite knowledge of skills. They will also enter the field with a very rough idea of what it takes morally and personally to take care of very sick patients every single day. In order for them to survive, they are going to need the support of staff around them. They are going to need to really think about how they see themselves and their role, what their purpose is in their life, what called them to their practice and to be true to it. I think you can't survive on skills alone. You've got to let yourself be a human being. Let yourself be compassionate, and don't lose that compassion.

**CAN YOU EXPAND ON HOW IT RELATES TO MORAL DISTRESS AND EMOTIONAL DISTRESS?**

Emotional distress is expected. That's not to say that you don't attend to it; it is sad to take care of patients who are dying or who are very, very sick. It's distressing to do that over and over and over again. That can take its toll. But what I personally worry about most is the situations where you feel like you're doing something that's morally wrong, you've been asked to engage in morally-wrong action. That hurts for a long time. At least in emotionally distressing situations if you can care for a patient who's dying and provide them dignity and peace, you can walk home knowing that you've done the right thing for a patient.

If you're in a morally distressing situation, and you feel like you're doing something that's really wrong, you can't go home and live with that. It's hard to sleep at night. There are resources out there. This is not something that is a signal that you're a weak person or that you weren't meant to go into the healthcare professions. This is a sign that you are a morally-engaged person and you've identified something that's wrong and you do have the power to address it. You need to address it in order to sleep at night.

### **IS THERE ANYTHING ELSE YOU FEEL IS IMPORTANT THAT YOU WOULD LIKE TO SHARE ABOUT MORAL DISTRESS?**

You've asked the right questions. I think it's important, though, to understand that this is not just a nursing problem. This is pervasive in healthcare. There are multiple ways, now, to think about moral distress - the next steps. We've identified it in all healthcare professions. What does it really mean when it's present? Is it really a red flag for poor quality of care, poor collaboration and communication? What are some good solid strategies and how are we going to test those? I think there are multiple research avenues available for aspiring doctoral students or researchers out there who would like to pursue this.

I think for staff who are interested in addressing moral distress, there's nothing to stop any staff member from creating a collaborative group to identify and address moral distress in their unit or at the organizational level. I think it's important that we all move in that direction. Moral distress is a threat to the healthcare system because people at any point in time, probably 10% to 15% of the staff are considering leaving their positions or leaving the profession. And so, this is a big problem and I'm thankful for this project because I think the word will get out and people will understand that the power is within them to make a difference.

### **WHAT STRUCTURAL INSTITUTIONS WOULD YOU LIKE TO SEE STEPPING FORWARD OR COULD PLAY A ROLE IN MAKING THIS A STANDARD PART OF EDUCATION PRACTICE.**

I think for nursing and medicine, the accrediting institutions could take this on and recognize this as something that needs to be embedded in the curriculum, for one thing. I think that, in terms of research, the NIH, one of the major grant resource providing institutions in this country, they could recognize moral distress and its potential impact on patient outcomes and patient satisfaction. They could provide a priority for addressing moral distress in the healthcare professions and in healthcare settings and allow research funding to move forward. For researchers, that is a difficult situation because there just aren't that many funding institutions that are interested in moral distress, but it's a big problem and I think the NIH would be wise to recognize that.



**IN THE HEALTHCARE WORKPLACE, WHAT ELEMENTS ARE DRIVEN BY PATIENTS' ATTITUDES OR FAMILY ATTITUDES THAT CAN CAUSE ISSUES THAT ARE DIFFICULT AND CAUSE MORAL DISTRESS?**

I think that patients are admitted into an environment that already exists, and within that environment, as within any family or community, there are norms. If you want something, you know who to talk to get it, and those things are already entrenched in this environment. And so, a patient who's admitted with a complex diagnosis or with a strong family value system that doesn't blend well into that environment, it's no fault of the family for sure. It's just that the environment isn't set up to handle whatever the situation is. That can set up some conflict and it's important, it has very little to do with the patient and the family, and much more to do with the already existing culture. So addressing the culture is one of the key issues. Addressing collaboration and communication. Then when a patient comes in with recognizable issues that we can say, "Oh, you know, we've seen that kind of patient before." "We've been down this road before...let's keep an eye on this." We can recognize those early and address them early. I think that's what's going to be helpful as well.

**IS THERE AN INDIVIDUAL, PERHAPS A SOCIAL WORKER-TYPE, WHO CAN BE BROUGHT INTO A SITUATION AND IDENTIFY THE HUMAN DYNAMIC ISSUES THAT NEED TO BE WATCHED?**

There are social workers who do keep an eye on some patients. They do know the family dynamics and they could play a much bigger role in addressing potential morally distressing situations. I think they could hold a very important role, actually, personally, because they know how the family has been functioning. They establish trust with families right off the bat and nursing does too. Medicine can, they have fewer points of contact, but they do establish trust well. So, any of the professions could establish trust and identify these situations.

**IF YOU WERE GIVEN A BLANK CHECK TO REDESIGN THE SYSTEM FOR 50 YEARS IN THE FUTURE TO PROVIDE BETTER HEALTHCARE FOR FAMILIES AND FOR PRACTITIONERS, IS THERE A DIFFERENT DYNAMIC IN TERMS OF A ROLE, MEMBER, OR A PROCESS OF COMMUNICATION YOU WOULD LIKE TO INTRODUCE AS PART OF THE HEALTHCARE TEAM?**

I wouldn't introduce anybody new, because I think the people are already there who could do this. I think it could be any member of the team; nurse, physician, social worker, anybody who could say, "You know what? This could be a long admission. This is going to be a complex patient. I'll take the lead and I'll be the contact person throughout. I may not work every day, but I'm willing to be the person who can liaison with the family. I can be the person who can speak with, get the people involved who need to be involved. Even when I'm not working, I'll designate somebody to be that contact person." We don't coordinate care. We just care on a daily basis and it rotates,

and the family doesn't get to know anybody and they don't know who to trust and don't know what people's roles are. So, if one person, and it could be any person on the team, could just say, "I'll be the contact person for this admission." That might provide the stability that the team needs. I think those people are already there.

***THANK YOU...***