UK Moral Distress Education Project

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INTRODUCTIONS... TELL US YOUR NAME, THE ORGANIZATION YOU WORK FOR AND THE KEY ACTIVITIES IN YOUR ROLE.

I'm Mary Walton. I work at the Hospital of the University of Pennsylvania. I actually have two titles. I'm the Director for Patient and Family Centered Care and I'm the Nurse Ethicist. My roles are very much interrelated. I co-chair the Hospital Ethics Committee. I do a lot of work with staff around helping patients and families during the inpatient experience where I work in the Academic Medical Center. It's a very intense environment where there are constantly new and different options for care. Patients are very ill generally. We're doing a lot of work to really engage families in improving the patients' experience and care. It's, again, very interrelated. It could be an ethics consult around a conflict or it could be helping staff or families with the situation that presents challenges.

DEFINE WHAT MORAL DISTRESS IS AND HOW IT CAN UNFOLD IN THE CARE SETTING.

Moral distress is really described as a phenomenon or a feeling. When nurses feel that they have a very clear idea of what they want or need to do for a patient and something's preventing them from doing it. It could be something that's within their own ability to express a concern. Maybe they're not feeling very assertive or they're feeling there's a power hierarchy where they don't have the skills or knowledge, particularly nurses that are new in practice. Maybe this is really an intense experience. “I don't have the clinical skills or the communication skills to try and do what I believe is right.” It can be the structure and nature of health care. “I want to do something for a patient and I need my colleagues, whether I need a physician's order, or I need a pharmacist to work with me. I am working with residents or trainees, and they have a disagreement about what the patient needs. What I believe is right, someone else needs to collaborate with me to make that happen.” Maybe, they disagree. They don't see the situation the same way. The nurses left with the patient care experience, not being able to do what they feel is their obligation for the patient. They're prevented so it creates really an affront to their own integrity as a nurse, as a professional.

DOES MORAL DISTRESS ONLY AFFECT NURSES OR ANY HEALTH CARE PRACTITIONER?

I believe others do experience it. I certainly have worked with physicians in particular who feel that, "I'm not able to practice in the way that I feel is my obligation as a physician." I know from the literature also physical therapists and pharmacists have

experienced it. When I work around an ethics consultation, someone's called for help, it's interesting. Maybe, you're waiting for the group to gather. I remember a physician saying to me, "Every time I write this order, I feel I'm doing something wrong. I don't think this is right for the patient. All things considered, I know this is what I'm obligated to do." You really often feel like you're between a rock and a hard place where with what you personally, individually, believe is right as a professional but we work in a collaboration. Essentially, there are so many variables that impact what can be done for a patient.

WHAT ARE THE SIGNS OR THE EFFECTS OF EXPERIENCING MORAL DISTRESS?

When I talk to staff, I talk about, when you get that feeling, "Something doesn't feel right. Something's troubling me. I don't like it. I have that knot in my stomach when I see that patient is going to be my responsibility for the shift. When I'm leaving work, I keep thinking about it. This wasn't a day I want to relive. I didn't like who I was today. I keep thinking about it." Sometimes I joke when I'm teaching, say, you know, when you either go home and you want to run 5 miles and not stop or you've opened your bottle of wine before you have your jacket off, it just was a day that troubled you. That's where it starts. I really encourage folks to pay attention to that. If you got a knot in your stomach or you dread going in a room or talking with your colleagues about a clinical situation, what's that about? You have to unpack it. "Do I not know enough? Do I need to know more of the story for the patient or my colleagues who are seeing something differently? Do I need to push the system?" Start thinking about what's generating that feeling of, "I'm troubled. I don't like how I had to practice today."

ARE THERE COLLECTIVE SIGNS WHEN IT'S INFECTED MORE THAN ONE PERSON AND BECAME A BROADER PROBLEM?

Yes. I think how teams work together, how people see, how they handle the hard stuff. We use the term the ethical climate. How do you talk about the hard stuff? When everybody agrees, everybody thinks it's clear what's the right thing to do and everybody's able to do it, it's great. That's the wonder and the beauty of being in health care. When people have disagreements about what's right or they don't have the resources or the ability to do what's right, it changes the whole milieu. It can feel… people can become robotic. "I'm just here to do my job. Let me do the tasks." They compartmentalize. As a nurse, we know that feeling when you really connect with the patient and family. It's very powerful when you know you really helped someone. When you cut yourself off from that and you become mechanical, it's a degrading experience as a professional and, really, just as a human.

Again, patients in acute care setting, when you're in acute care setting, there's something significant going on. You want the people who are caring for you to be present, to be there, to have that sense of, "You care about me." You're open to me saying, "I'm scared," or "I don't like this," or "Help me with something." You're very vulnerable as a patient. Again, people that are mechanical, "I'm just here to do the tasks

and there are many tasks that need to be done." That feeling of being cut off from the emotion and the caring aspect is something that can erode over time if people feel, "I don't want to think about what's the right thing to do because I can't do it. Let's just get the task done." That's what's visible. I can go in and give your meds and treat you like an object or I can go and give you meds and you can have that feeling that I really see you as a person. You feel that you're treated with respect and dignity. It doesn't take any more time. It's very real if you've experienced it. This connection, this caring. You can see that sometimes people get worn down when they felt that they haven't been able to practice and can really infect a team.

GIVE US AN EXAMPLE OF MORAL DISTRESS FROM A PERSONAL EXPERIENCE.

Right. It's more careful to be generic. There are so many examples. It's very sensitive when people talk about, "I wasn't able to do the right thing and help me." I think I'll use the example because it's generic and it represents many different examples: a patient who's refusing what's medically recommended. They're in the hospital. They're very ill. There's a clear recommendation. Maybe it's for surgery. Maybe it's for an amputation. Maybe it's for discharge to a different level of care. The patient's very clear. Their values or their perspective on what they want to do or what they think is right is very different than what's clinically recommended. The folks that get involved in that process, "How do we push the patient to do this?" Nurses are often in a situation of seeing how maybe our physician colleagues who know we've got to make this happen. The resources in health care, you're extending the hospitalization. This is right. The patient just needs to consent. We pay a lot of attention to consent.

When patients refuse what we recommend, that gets people upset. Clearly, they don't understand so let's teach them five different ways. We don't elicit why they're refusing or why they see the solution differently. Nurses get very stressed. "This is wrong. I feel like we're badgering, pounding into the patient. I don't always feel I have the power to change that." Unless they bring it forward, we always worry the risk is that a patient will end up having something that they truly didn't consent, maybe, really isn't the right thing because their values are different and how we see them. Sometimes, patients who have some dementia, having some dementia doesn't throw away your rights to say, "I don't want an amputation. I may have a limb that needs amputated but I'm refusing."

T ELL US AN EXAMPLE THAT FOCUSES ON A HEALTH PRACTITIONER WHO EXPERIENCED MORAL DISTRESS AND WHAT HAPPENED WITH THEM.

The practitioner who's with the patient and seeing all the pressures on a patient to do something that the patient doesn't want to do but they don't have the power to change what's happening to change the process, they shut themselves off from it. I'm just going to go in. Physicians are controlling this or social workers are pushing forward to transfer the patient. Maybe psychiatrist is going to say the patient doesn't have the decision-making capacity. Maybe, the family wants it done, even though the patient doesn't. That

nurse or that practitioner in the room that really feels, "You know what? This isn't right." The patient has the ability to say, the right to say, "I reject it," even though clinically or medically or surgically, it's the right thing to do. It happens. The nurse, for example, might feel, "I can't stop the process." That erodes the ability to feel, "I have the power to make a difference for the patients."

The next time, the next patient, the next clinical scenario, that person might be less likely to speak up and say, "Let's get together. Let's talk about this. I'm feeling troubled. I don't think this is a right thing to do. Let's gather the team. Let's gather the patient, the family and the clinical team and talk about another way. Maybe, we can help the patient accept what we think is medically recommended. Maybe, we need to help the team see this a different way." When over and over again, you feel powerless to make a difference for patients, that shapes how you view the next experience. Maybe, I spoke up the first time. Maybe, I said, "You know what? This doesn't feel right. Let me tell you what I see. Let me tell you what the patient's experience is." Another colleague blows you off and says, "It's clearly clinically recommended. It's irrelevant." Depending on how assertive you are, how supported you feel, does the system support you speaking up, bringing and I'll turn it into a less popular view that's going to slow the process down or create problems for the team, for the unit of the organization.

HOW DOES YOUR ORGANIZATION COMMUNICATE, RECOGNIZE AND PREVENT MORAL DISTRESS?

The University of Pennsylvania Hospital, we have a Chief Nursing Executive who's very invested in ethics. The way she's showing that investment is to support creating a role for a nurse ethicist. The expectation is that we are talking about this and we are helping staff with it. For nursing staff, I do a presentation for every new nurse who's hired by the whole system actually. "Here's a presentation on nursing ethics and why that's important, and the components of how to be a moral agent, what moral distress is like and what are the resources to prevent or mitigate moral distress." There really are many. We actually have a tool that lists probably about 20 things that are options or resources in the system, one of which is nurses call me and talk about situations. They can call an ethics consult. We have support for ethics consult service. We've long had the policy that anyone can call an ethics consult and promoted that, that's a sign of strength. Asking for help, making ethical issues visible is a good thing. That's one way.

It starts with orientation. We have the nurse residency program. Six to nine months after they've been hired, I do an open ended session with them for an hour where they bring up their issues. We really focus on what troubled you, what did you do about it, who helped you, who could have helped you, what resources were available, did they work, what resources do you wish you had? I do a lot of work. The managers and the clinical nurse specialists are expected to pay attention to this. They call me many times to just come up and talk to the staff. They're troubled. I can tell you within the last week, I had several nurse managers saying, "We have a really tough patient scenario going on. Can

you come up and spend time with the staff?" They support that. I can think of a very busy unit where... Actually, a physician said this. “This is a really tough situation. I know this one nurse is really troubled.” He said to the nurse, "Would you want to talk to the nurse ethicist?" She said, "Yes." Her patients were covered for an hour. We went and sat down. She talked about what troubled her and she viewed things differently than the team and where the family was. We unpacked these feelings. That is considered something that's important and a value.

Our ethics committee is charged with education. We have probably 25 folks who are many disciplines. We talk about moral distress all the time because there is a difference of opinions about what's right to do. In an academic health setting, there are so many options and so many decisions. Reasonable people have to disagree about how aggressive to be, whether to offer this option, what is someone's right when they have some impairment or dementia to choose it in conflict with the family. We do organ donation. We do transplants. Organ donation is a heavy concept. We do debriefings after tough situations. Particularly donation after circulatory death can be very troubling for physicians and nurses as these new modalities come out. We have ECMO. It's a very troubling situation.

I can think of an example. It's actually a couple years ago. I use it. I think it illustrates the resources that we have in our organization. A patient who would have a very aggressive surgery that he had consented to; it was elective. A number of days post-op said, "Suffering is too much. This was a risk. I want to stop. I want to withdraw support." Happened in the evening. The nurse called the attending physician. Came and talked to the patient. Really tried to encourage the patient to stick with this. The patient was adamant. Over several hours, there was an ethics consult. There was a legal consult. There was a lot of discussion. The patient had his spouse with him. Over a number of hours, the decision was made. The patient is no longer giving consent to continue with this aggressive treatment. Support was withdrawn and the patient died. There was a lot of distress over that.

The nurse manager scheduled a session about two weeks later. Started at 7:00 in the morning. It's a big room filled with physicians, with nurses, with respiratory therapists and legal, psychiatry. I was there from ethics. We talked about that. There was a clear difference of opinion. The nurses who would work with that patient had heard their family plan about how the decision was made for the surgery, what they talked about before, how his wife had said he made me promise that if it was too much. Physicians on the other hand, felt very differently about it and felt that this was wrong to withdraw support. They used the term “I had an obligation.” “I really think this patient could have been discharged successfully with more time.” “I feel that this was wrong.” Two hours of discussion where people talked about their values and how concerned and clearly identifying what was the patient's right, what were team members' obligations. At times, decisions are made. I think what's important about that is that, there were resources at that time that it happened and there was planning for follow-up after. Still, that situation has been discussed time and time again about what can we learn from that and then

how do we help people deal with the situations that they're in.

HOW MANY PEOPLE IN YOUR INSTITUTION WILL EXPERIENCE MORAL DISTRESS IN A YEAR?

I am terrible with numbers. I think we are 1,500 nurses. I think there are 6,000 employees. We have 60 to 70 formal ethics consults a year. There are countless other situations that we don't track. I don't know. I don't know. I think every member of the ethics committee, 25 people that are of different departments, different units, all give examples of it on a regular basis when we discuss in the ethics committee. When we have grand rounds, people show up to talk about it. People talk about policies and procedures and how we have to revise them to improve care or develop resources. We attend to that.

FOR EVERY 20 NURSES THAT WORK IN A YEAR, HOW MANY ARE AFFECTED BY A SCENARIO THEY MIGHT WANT TO TALK ABOUT?

That they would want to talk about? A hundred percent of them, I think. Again, where I practice, the treatment options, the acuity of illness, the health literacy, understanding the complexity of what's there, the aggressive nature of what we offer in academic settings poses problems any given moment, feeling is this the right thing to do. How do I know it's right? Why do I feel it isn't right? What do I need to do to be fully practiced in the way that I want is challenging. There's not too much mundane stuff that goes on. People are suffering. There are so many options and stressors and values that play, efficiency, resource, allocation, research, understanding the options and helping patients and families. Do they really understand? Does anyone know what they're getting into when they agreed to have a heart transplant? Months of waiting for heart transplant, agreeing to an aggressive surgery. I really never have the experience when I walk onto a unit that people don't have anything to say, “Do you have a minute,” or "Can I call you?" They're many people invested in, "We want you to pay attention." If it doesn't feel right, we want you to make it visible.

PLEASE TALK ABOUT FAMILY EXPECTATIONS, HOPE, GRIEVING PROCESS AND THEIR PART IN HEALTH CARE PRACTITIONERS' EXPERIENCE.

Patients that are very ill maybe with something that's life threatening or life limiting, it's very tough for their loved ones to face what might be the future. There are times when patients say, "I've had enough. I don't want another round of chemo. I want support, life sustaining treatment withdrawn." Families disagree. Most people are ready and willing to do things for people they love. Patients often go along with things because they can see those caring individuals are at the bedside saying, "You can do it," and there's hope. I think for practitioners, sometimes they see that dynamic where a patient is ready to stop the aggressive care, ready to move into more of a comfort mode or not go for something

that's really very aggressive. Family members are encouraging and promoting that. Staff can have mixed feelings about that. Sometimes, they think patients overestimate the suffering. We've seen it 100 times. You'll be fine. Keep going. Maybe, not. Maybe they feel it's already been too aggressive and this suffering isn't going to produce a benefit that makes it worthy of that much suffering.

Seeing that dynamic between a patient who loves her loved ones and wants them, doesn't want to see that look where, "Turn off the dialysis," or "I don't want to do this anymore." Being in the middle of that and appreciating that dissonance between the patient with the nurse or physician feels or social worker feels the patient really wants or versus what they're willing to do for their family. Then, when you have a patient who maybe has an advanced directive and says, "I don't want this." Maybe, they've expressed verbally to staff, "If there's really not a good chance of recovery, I wouldn't want this." The patient's no longer able to speak. Now, the family is representing them. They're the surrogate decision maker. Staff, often feel like they know what the patient would want. The family is making the decisions then.

Families don't want to lose people they love. That is very painful. A lot of staff have to work through difficulties. How do we help the family in a way that helps them focus on what would the patient choose and can we help support you with this difficult decision? Sometimes, when staff get very distressed or very angry that I know this is not what the patient would want, I really don't think there's any chance of recovery, why is the family pushing, pushing, pushing? I say, Try to imagine the patient. What do you think the patient would say if they could speak to us now? Would they say, “Look at my family around the bedside. They need a few more days. It's okay to continue. Give them some more time.” To try and imagine that because when we prepare an advanced directive or we say we wouldn't want to live, we don't really know."

As humans, we do take effect what our decisions, how they relate to what our family would want. That is a very real life dynamic in a place where there's so much aggressive care that really can extend a life and save life. We've been in situations where the patient did recover and there was some surprise that that would not happen. That dissonance between what practitioner believes a patient would want and what a family who's now directing and giving consent for care is expressing. Can produce distress for staff. What's my obligation? How do I care for the suffering family? Really, enact my primary obligation to do what the patient would want.

ANYTHING YOU LIKE TO SHARE FROM AN EDUCATION POINT OF VIEW TO HEALTH CARE PRACTITIONERS?

What I think is important when you do the work of caring for patients as a nurse, a physician, a social worker, is paying attention if something doesn't feel right and really reflect on what's driving that. I like to think of what are the values that are driving that gut reaction or that intellectual feeling that this isn't right. Think about the values, what's important, why is it important, who is it important to. Then, talk about it. Invite a

discussion with the colleague. I think that is a first step to saying it out loud, "I'm wondering if we're doing the right thing." Invite alternate views. If you're troubled, you might feel very clear that this doesn't feel right. Seeing alternate perspectives can help you to really make you recognize it is right or you feel that there is a problem here and it needs to be addressed. There's a lot of different ways to look at it. Expressing that concern and inviting others, how do you see it? Do you see it differently? Have you ever experienced this before? Does this trouble you?

I think that's the first step in working through this and preventing moral distress because learning more about it, getting more of the bigger picture, understanding more of the story, we never know the full story for patients, for our colleagues. Trying to have an open discussion about how you see this, what do you think is important in this situation, what are the values that are driving that feeling of, "This is the right thing to do," or "No, this feels wrong." We're not doing what we should be doing for this patient, for this family. That is such an important step. Being silent longer means then when you finally do express it, you don't invite alternate views and you don't get to really deconstruct it or you stay silent forever and you become mechanical. You leave the profession. Your career really is changed because you don't feel that you're practicing in a way that fulfills the integrity that you feel and the obligations of your profession. That paying attention, expressing it and inviting other people to see if they share it or they see it differently, I think is really very crucial.

HOW MANY FOLKS LEAVE YOUR INSTITUTION EVERY YEAR? WHAT PERCENT OF THIS IS A RESULT OF MORAL DISTRESS?

I don't know the statistics. I know we have very low turnover in nursing. Some of that's a reflection of it's a good place to work. I think the economy. People have lots of options to change. I don't know. I think sometimes, nurses leave a certain practice here. Our health system is so large, people can move out of critical care, for example. They can move into an ambulatory setting. We really try to focus on if this isn't working for you professionally, there are many options in our institution. We have nurses that more around a lot. Sometimes, they say, "I need a break. I want to try something different. This has been so intense." I don't know statistics. I do know when I talk about why paying attention to moral distress is important. It's because we want to keep you here and we want you to feel this is a great place for you to practice. Express it. If this isn't feeling right for you, talk to us about it and let's see what other options are out there.

THANK YOU...