UK Moral Distress Education Project

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INTRODUCE YOURSELF.

I'm Neil Wenger. I work at UCLA. I'm a primary care doctor and director of the ethics center. My job consists of being a doctor a lot of the time. I do quite a bit of teaching, a bit of research, but a lot of my time is spent directing the ethics center, meaning doing ethics consults, doing teaching in clinical ethics, and helping to direct the fellowship program.

YOU HAVE A FAIR AMOUNT OF TEACHING?

I do.

HOW DO YOU DEFINE MORAL DISTRESS? HOW DO YOU EXPLAIN IT WHEN YOU ARE TEACHING?

Moral distress actually is something that rather than being defined for a new student is something that gets reflected back to them based on their experiences. If I'm asked to define moral distress I think about it in a clinical context. When a clinician is asked or demanded to provide the kind of treatment that they feel that they should not provide as a professional.

GIVE EXAMPLES.

It arises most often when a clinician is not the major decision maker in a case. Therefore it happens a lot with medical students. It happens to nurses. It's not infrequently brought up by social workers. When they are tossed into a situation where others are making decisions and they must participate clinically in providing treatment or care of some sort that they feel is wrong. It usually is wrong either from some fabric within them, or what they see their role as being a professional.

RECENT EXAMPLE?

It's very common. A medical student may come to me and say I don't think that this patient really wants the treatment that her doctor has prescribed. I don't feel that I can talk to the doctor about it, or the patient doesn't feel that she can speak with her physician about it. There's distress and that's moral distress. It's quite common among nurses, especially nurses in the intensive care unit where treatments are being provided

that the care team in general believes will not benefit the patient, and the nurses acutely feel that as they're providing treatment minute to minute, hour to hour. As the doctors and different consultants pop in, the nurses feel that they're harming this patient in front of them and they feel moral distress.

WHAT EDUCATION TRAINING SYSTEMS ARE IN PLACE TO AVOID OR PREPARE FOR IT?

The ultimate answer to that question is to decrease the preponderance of situations in which care is being provided that the professionals feel shouldn't be. That means that care needs to be fully informed, that joint decision making needs to occur so that everyone helping to provide care knows that this patient wants the care that they're receiving. In that we can't always assure that that will occur, that there are enormous obstacles to communication about what care patients would want. Information isn't transmitted. Decisions aren't always fully informed.

Then we need to have outlets for those clinicians who are stuck in these care situations where they need to provide treatments that they feel are inappropriate and therefore causing moral distress. There's a variety of those. The pastoral care folk, those from spiritual care, will not infrequently interact with nurses and students, other sorts of trainees, residents, clinicians to draw them out and have them discuss the situations. There are specific programs for nurses. For instance, at UCLA, there are programs to help nurses identify when they're feeling moral distress and then receive help. For trainees of different ilks, be they medical students, I believe nursing students, residents, and fellows, we actually have set up certain mental health programs for them to be able to go reflect some of what they're feeling so that their moral distress doesn't build up.

ANY PREVENTATIVE PROCESSES THAT WOULD FACILITATE COMMUNICATION OR OTHER THINGS TO ALLEVIATE THOSE SITUATIONS?

I think what you're getting at are situations or systems that would draw out individuals who are feeling moral distress, begin to label it, identify it, recognize it as a prevalent issue within medical care and then help those individuals address it. I think that the real answer to these issues has to do with preventing the situations from ever arising in the first place. That means when you have a critically ill patient, making sure the decision making is occurring, focusing upon what's known about what this patient would want, and what is in the patient's best interest. It means having programs in place to deal with pathological grieving, which very few places do. Pathological grieving not infrequently leads to decisions being made that are not in a patient's best interest. That then leads very rapidly to moral distress among intensive care unit teams. It means making sure that when there are multiple choices to be made that there's a fully informed shared decision. It very frequently is not the case in a whole variety of settings.

CAN IT BE THE CASE?

It can. There are plenty of docs who do a great job of ensuring that there's shared decision making. Given the very highly technologically advanced care that we're currently seeing, often that is not a priority in ensuring the decision making. That decision making occurs in a way that always will benefit the patient the most.

WHAT ARE SYMPTOMS OF MORAL DISTRESS?

I think we're just beginning to understand how moral distress affects clinicians. The typical way that we think that moral distress affects a nurse, a doc, a social worker, or a pastoral care specialist is in burnout where one simply cannot provide the same level of care. You can't interact at the high level that one would want to in the doctor-patient relationship or the nurse-patient relationship because you can't bring all of yourself into it anymore because you're trying to protect yourself from the feelings that are occurring. We have clear examples of nurses who have left nursing because the moral distress has built up to a point that they could no longer practice their profession. I'm not aware of any doctors that have felt similarly, but we hear it from doctors as well, even rather seasoned wonderful clinicians who are quite capable, but find themselves hampered, and are incapable of providing the best possible care because of moral distress.

SUGGESTIONS FOR THOSE FOLKS?

I think that there are a number of routes that one can go down. One is to see if they can reverse the situations in which they are feeling the moral distress. Can we decrease the number of cases in our intensive care units where we're providing treatment that the doctors don't think and the nurses don't think is beneficial to the patients? Recently I was approached by a critical care doctor who told me that a piece of her soul had been taken by one of the recent cases. I asked her to actually write an essay about it. The essay was quite profound and she discussed how the conversations with the families tore at her, that she felt that they weren't acting in the patient's best interest, and they were actually forcing her to use the tools of medicine to harm the patient in the bed rather than help this patient. She told me subsequently, actually that writing the essay helped some. I asked her whether she wanted to continue doing it and thus far she said no.

IS IT CLEAR THAT THERE IS A HIERARCHY OF DECISION MAKERS?

There isn't much gray area in the hierarchy among the medical team. If you're asking whether in fact families are making best decisions and the decision making platform has tilted too far in one direction, that's a different question. The fact is that very frequently moral distress is seen in critical care situations where treatments are being provided that the entire medical team feels are inappropriate. Who feels the most moral distress? I

think it's the one who is in there most often with these patients. If a nurse is spending most of a 12 hour shift with a patient that she feels is suffering horribly, largely because of the medical care that they're receiving, it's likely that she's going to be battered by this moral distress as opposed to the doc that pops in and pops out one or two or three times a day.

EDUCATION OR TRAINING THAT CAN HELP PARTIES UNDERSTAND WHAT'S GOING ON?

I think that there are many things that could be done. My understanding is that different institutions have implemented different sorts of solutions. For instance, we have a regular ethics conference among our medical residents. The residents get to choose the cases that they want to present. Not infrequently it's a case that they feel moral distress over. Very frequently numerous residents have all taken care of the same patient. The conversations that occur in those rooms I believe help to diffuse some of this distress. It also gives them a sense that they're not in this alone and it begins to give them tools to help deal with those circumstances. Part of the problem is that some of the easiest tools to develop are defensive tools. You begin to build walls such that you're not going to feel the kinds of things that make you feel bad with moral distress. Therefore you don't build up the same sorts of relationships with your patients. What we need is for these residents and nurses and others to begin to use tools that are more adaptive to these circumstances that can help enhance their relationships rather than damper them.

THAT MEANS MORE OPEN TALK WITH FAMILIES FOR EXAMPLE?

It could mean. It could mean that one needs to leave work and do Tai Chi for two hours. I think different individuals have different ways of dealing with the circumstances. I had a colleague who demonstrated really quite significant moral distress. I was pretty surprised because I'd always seen him as being on a very even keel. Then I realized that he had injured himself and had stopped running and running was what kept him on an even keel. It allowed him to come in every day refreshed and do battle where he felt that care was not being provided the way that it should.

ANYTHING YOU WANT TO SHARE THAT WE HAVEN'T TALKED ABOUT?

I think it's worth recognizing that moral distress can be an acute condition. It isn't something that is only insidious, though that's usually how we see it arise. I have had the experience of walking into an intensive care unit room where the clinicians thought that they were providing inappropriate treatment that was making someone suffer. I looked for the nurse only to find her later curled in the corner crying. That's acute moral distress. This happens to some of our best clinicians, and I don't know that we can ever heal them from it afterwards. More importantly, it happens broadly across entire intensive care units when we have numerous patients being treated with the tools of medicine.

What we're able to do with those tools is truly miraculous, but the same tools are being used to essentially torture individuals prior to death. Those clinicians, who are using those tools in that way, never come away the same. We need much better mechanisms to help them deal with the feelings that derive from those actions.

WHAT'S FORCING THEM TO DO IT?

They are working within a system where at this point in time autonomy triumphs and we sometimes believe that decisions made by families, and very rarely by patients, but almost always by families, to treat patients in certain adverse health conditions is okay and no one is willing to say no.

FAMILIES AREN'T AWARE OR ARE ASKING FOR AGGRESSIVE TREATMENT AT AN END OF LIFE SITUATION?

There are a variety of factors that factor in. Sometimes families can't agree on the best course of treatment. Sometimes families are not adequate decision makers for their loved ones. Sometimes families misperceive reality and there's no one else to help them better understand what's actually occurring. Grieving pathologically is a very important part of this process.

CAN YOU EXPLAIN PATHOLOGICAL GRIEVING?

When one begins to grieve, when one is suffering a loss, there are a variety of stages in which one proceeds. Kubler-Ross described these quite a long time ago and some of those stages include denial. If one is stuck in a denial phase of what the circumstances currently are, one will make decisions that are not in the patient's best interests because they can't clearly see what's currently happening. Because of that, people will be kept on machines for days on end inappropriately, sometimes suffering during those circumstances. That means that the medical student, the nursing student, the fellow, the nurse, everyone caring is having to provide a treatment that this patient would never have wanted and these machines were never built to provide.

THERE'S A GAP IN KNOWLEDGE?

Correct. You might say shouldn't docs be good enough to be able to lead families to make the right decisions. In fact, many docs are very good at this. Much decision occurs in a team based way with the nurse and the social worker, the docs, and the consultants there all together with the family attempting to help them make all the right decisions. But it doesn't take a very large percentage of the patients to poison the entire unit where one nurse will feel that the patient that she has to deal with is inappropriate, and the other nurses all recognize that together they're not able to use medical care as they ought to be. Sometimes no one wants to be assigned to those cases or some nurses will

volunteer to do it in order to protect others. But in fact, the entire group of nurses is harmed as is the entire intensive care unit team. It doesn't take very many patients to cause an awful lot of harm.

HOW DO YOU RECOMMEND DEALING WITH A GROUP THAT'S BEEN POISONED?

It takes a lot of work. Very, very intensive group work either by a nurse who is somewhere within the institution or perhaps a psychologist or some other facilitator may very well be able to make considerable progress. Again, the answer is to reduce the circumstances, or at least the duration of those circumstances that are producing the injury.

ANYTHING ELSE?

I think that coming into the profession of medicine, whether someone is a nurse, whether someone is a physician, if one recognizes that they will be beset by circumstances of this sort and that there are ways to deal with these feelings earlier on and to identify what's the best way for you as an individual to deal with these feelings? Is it for you to play basketball or to run? Is it to see a therapist once in a while or to join a group? Is it to do some mindfulness work or to do Tai Chi or perhaps yoga? To realize how each of us as individuals deals with these feelings is a very important component of becoming a professional.

PROFESSIONAL HAZARD BUT HOW DO YOU MANAGE IT?

It is. I think being a professional in medicine means that you are likely to have moral distress. Knowing how to deal with it, where to turn, and dealing with it early is what makes one a good clinician for a very long period of time.

THANK YOU...