UK Moral Distress Education Project

Stuart Finder, Ph.D.

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PLEASE INTRODUCE YOURSELF AND TELL WHAT SITUATIONS MOST BRING YOU INTO PATIENT CARE.

My name is Stuart Finder and I'm the director of The Center for Health Care Ethics at Cedars Sinai Medical Center. In that role I am also the chief of the clinical ethics consultation service. In that role, doing ethics consultations, I interact with patients, families, physicians, nurses, social workers, chaplains; you name it - the whole gamut of health care providers and those who are involved in patient care. Unlike many institutions, our ethics consultation service is not done through a committee. It's actually done one on one personally. When I say I interact it actually is me in the clinical setting in patients rooms and hallways and so forth.

DEFINE MORAL DISTRESS AND HOW IT MAY UNFOLD.

I'm not going to answer your question directly. The reason is that there are a lot of well published definitions of moral distress. People can read those. In my role in dealing with people who are facing moral challenges in decision making, what I encounter is something that I would actually call moral tension or moral disruption. What I mean by that is people come into situations with all sorts of beliefs and values but they're normally not thinking about those things explicitly. When you're confronted with a really challenging situation, and think about end of life situations where you have to make a decision for somebody else or maybe even for yourself about the level of care and the aggressiveness of care. In those situations what happens is your values come up so to speak and they're explicit. You confront them and in that confrontation with your own values then you actually get to see, "Do I really believe those? How do I move forward? How do I actually now make a decision and choose in a way that somehow fits with what I believe?" That to me is actually the more common kind of moral, as I said, tension or disruption, that occurs as opposed to the moral distress which, I'm going to say something about it I guess, is more concerned with people having a sense of I know what the right thing is to do but I don't feel I can do it. That seems to me a little bit artificial as opposed to the normal which is this more subtle and yet not subtle which is I suddenly confront myself and now how am I to act.

GIVE GENERAL SITUATIONAL EXAMPLES.

Often it is when you are confronted with very challenging clinical decisions. It may be that if you're a physician and you have to make a decision between this or that as a plan of care and it's not clear. We often think that physicians know exactly what to do all the

time and they often have to make very fine judgments. The challenge of we could go two different ways. It's not clear which one is actually better, but I know that there are risks with both and I'm responsible. In doing that I'm responsible, that's where you confront now, "How am I supposed to actually choose?" Or for the nurse, for whom decisions have been made, this is the plan of care, and now in the actual carrying out of it, because that's what nurses do, they carry out the plan of care, things aren't going exactly as one would imagine. Like if you're making a documentary film. You're filming things and you think it should work this way, but glitches happen. Nurses do that all the time. That's actually mostly if you think about 12 hours at a time because that's what they work, 12 hour shifts, they're continually implementing and then readjusting based on what happens. In that readjustment if it doesn't go just as you're imagining it should and it raises now a problem, there's the moment of confrontation for yourself of, "Is this the right way to go?" Then if you see on top of it that patients are starting to suffer, or patients are experiencing something negative, families are experiencing something negative, that's where the disruption really occurs because I'm doing what I think is the right thing, but I now see that these other people are experiencing something that isn't so good.

WHAT ARE THE EFFECTS?

There are a number of different effects that you can get from this kind of disruption. One is a sense of, for lack of a better word, an existential dread. It's like now that I'm disrupted I'm not sure. Am I doing the right thing which calls into question am I actually a good person, have I made a mistake somewhere, is this what I should be doing with my life? I know that sounds a little maybe too grand, but especially when you're dealing with, for instance, end of life situations and you have responsibility in someone's life or death, all those questions flood you. It's one of the challenges now becomes how do you continue to provide care for someone while you're having your own doubt, while you're having your own question. I think that's one of the common things that happen. The challenge is how to help people. When I do ethics consultations, how to help people be able to move forward in the face of those questions, not necessarily to resolve them, but to keep them as questions because I think they're really important for our self-understanding to be able to live in the questions but at the same time carry out the tasks that you're responsible for - being able to give these medications, being able to do whatever it is that your world demands.

HOW DOES IT PRESENT IN TERMS OF A BIG HOSPITAL?

This is one of the things. How nursing works is actually really important because we have an image of how to take care of patients and it's often based on Hollywood television, this idea of one on one. There's a physician, there's a patient, the physician takes care of the patient, maybe there's a nurse that does some things. We don't have a full appreciation but people who work in healthcare understand this that nurses in

particular actually work as a small community. In the context of working with colleagues you start to pick up whose maybe not quite right today and it may be that you do the usual banter like we all do with colleagues. Did you have a hard night last night or what's going on but it's a way of trying to discover is it something about the patient care, is it something about what's going on there, or is it really just about you personally. I think that's one of the ways we start to learn.

When you now expand that sense of the community, not just a group of nurses that is working together 12 hours at a time, but you have the physicians who continually have patients on this floor or in this ward. Over time they start to know the nurses and they develop a sense of relationship. The same thing happens with the social workers who are working with the patients, the families, the nurses and the physicians on a regular basis. Patients and families go, but nurses and physicians are the same. They develop a relationship. In the end how it is that you start to get a sense of others moral disruption or distress is because of these relationships. Fundamental to working in a healthcare environment turns out to be the same as working in any environment where you're with others. It's the relationships that you build and that's the key. It's paying attention to those relationships.

GIVE ME A LAUNDRY LIST THAT WILL COME UP. HOW DOES IT DISPLAY?

The way in which you get a sense that people are in distress is the usual emotional things. People will maybe become angry quicker than usual. They may have a little bit more anxiety about things. The opposite is they may want to be... They'll be more standoffish. In healthcare then you have the elements of black humor. People will start to make fun of the situation that they're finding themselves in and they make it a joke. It becomes a way to distance. You get these language cues. You get the emotional cues. Then sometimes you get the really dramatic emotional cues that people will tear up. People will cry which is obviously normally not seen as a good thing to do in public. It's not that that happens out in the hallway. It's that that happens in the break room or people are going to the bathroom and then they come back and you can get that sense of their redness. It's looking for physical cues, linguistic cues, some of those social interaction cues. Those are the tip offs.

WHAT HAPPENS WHEN IT GETS MORE SEVERE?

Then you have real distress in the sense of physically. People actually will exhibit physical ailments. They will have stomach upset. They will be really jittery. People might start missing work. There are a number of those. It's not unique to healthcare. It's the way in which all of us process things where you see manifestations of stress. The key here is the community that you work with. If that local community is strong enough, people can actually publically acknowledge that. That's one of the biggest challenges. Can we work in a way in which if I see you are starting to have a deviation from the norm, I can ask you "How are you doing? It's not that usual "Hi. How are you?' "Oh I'm

fine.” The social surface level of surface level interaction. Can we talk directly about really how you’re doing?

CAN YOU GIVE A SCENARIO WHERE YOU HAVE HAD OR WITNESSED MORAL DISTRESS?

In my line of work doing ethics consultation in the clinical realm, I encounter it all the time. I’m going to give you a scenario that is one that no matter who you are, if you are watching this, you can appreciate. End of life is one of the most dramatic types of situations where our moral sensibilities are called forth. To me one of the most dramatic situations was an end of life situation. It had to do, as it often is for other people I think as well, with a teenager. This was a teenager who had not had previous medical problems. It was an accident. A mixture of medications that were in and of themselves benign, but which happened to be to this individual’s chemical makeup, a bad combination. She started to get sick and unfortunately had all of those complications. Nothing is 100 percent certain, right? You take a drug and they always tell you, the commercials on television, there’s small chance this might happen, that might happen.

This teenager had everything go wrong. Ended up in the ICU for a very, very long time. It was a very prolonged death. When I say very long time, I mean several months. Over those several months, continually at each point, instead of getting better, would start to get better and then something significant would happen. She had a massive stoppage of the heart. She had kidney failure then liver failure. Go down, come up, go down, but over time it was this slow trend downward. For the nurses that were taking care of this individual, it was really challenging. Everyone knew that this teenager was not going to survive. Until actually the last two days of this teenager’s life, there was nothing acute that was going to be the cause of death right now. Everyone knew what was coming. We were trying everything we could to stop it. Nothing was working.

Now it’s like you are taking care of someone. You know she is dying, and it’s a teenager. This is a teenager who’s talking about, “If I can get better (because she’s still talking), I can go to prom.” I can do all of those things that represent the youthful spirit and value of life. Really hard. Ultimately what happened is nurses had to be rotated in and out. They could not take care of this patient for more than one day at a time. Even though from a family perspective, having the same nurse day after day is really good. Nurses were just completely overwhelmed. The physicians started to not come around as often. When they did come around, they would spend two minutes in the room and they were gone.

There was almost a shunning of this patient and family because people were so overwhelmed. Now if your commitment to someone is to take care of someone, your role, institutionally, professionally, is to take care of someone and at the same time you find yourself unable to go into the room, there’s where the moral disruption occurs. Then distress ensues. How do you justify that I don’t want to take care of you anymore. I don’t want to have to be your nurse tomorrow. In fact, I hope I’m on the other side of the unit, so I don’t even have to see you because it’s too distressing to me. Wait, I’m not doing

this because of me, I am supposed to be committed to taking care of you. There's where you get that bifurcation of what are my commitments? What are my values? How is it that I move through because it looks like I'm abandoning my own commitments? Again, if you're the physician it's same thing. My commitment is to take care of you and yet I find myself not wanting to even go into your room.

DID ONE PERSON TALK TO YOU ABOUT THE MORAL DESTRUCTION AND HOW DID THEY COPE WITH IT?

In this particular situation I've been describing, there were many individuals and that's why they called for ethics consultation. Many individuals talked to me about that. Part of the effort I made was to find ways in which we could have a support network that was more explicit than usual of how people would process through sense of guilt, sense of powerlessness, and sense of abandonment for the patient. Part of it was to make it explicit; we are all experiencing this, so let's make it explicit as opposed to shoving it down.

In making it explicit, there's an appreciation of turns out it's not just me. We're in the community. We're having a sense of community. There's one of the keys in terms of dealing with this kind of moral disruption is to see that we actually are connected. It's about relationship. I'm not on my own. In fact, I've never actually been on my own, even though the rhetoric often is that it's just me. I'm the only one responsible. I'm the only one that somehow has to carry this load. We actually are always doing this in relationships. My job is to make that explicit and then to help people process with one another their experiences. The load's not quite as heavy on me, if you and I share it.

CAN YOU EXPLAIN THE RESOURCES AVAILABLE SYSTEMICALLY THAT ADDRESS MORAL DISTRESS AT YOUR ORGANIZATION OR GENERALLY?

Hospitals deal with moral distress in different ways. At my institution there are a number of different access points. One is obviously clinical ethics consultation. This is part of what we acknowledge as a legitimate reason to request ethics consultation. Many institutions don't include this. That may be somewhat unique to our institution. We also have a dedicated nurse liaison whose background is in nursing and counseling. She's a psych nurse liaison. Her primary role is actually to help nurses when they encounter these situations.

If it is something that really escalates, we also have, through our employee assistance program, a crisis response team that's available twenty four hours a day. There are about thirty people on the team and the team has a beeper. These are people who are committed that when you have the beeper, if you get called, you can be in the hospital within ten minutes. Twenty four hours a day someone has the beeper. They're whole deal is to deal with immediate crisis when people are so distressed they're at their wits end. We have different layers depending on how severe it is; we have these different

mechanisms. Many institutions might have a mechanism like our nurse liaison, where there's some mechanism within the nursing structure to deal with this through the chain of command. The employee assistance programs may or may not address this. Many employee assistance programs are associated with people who have drug problems, personal problems, but not work related. It may or may not. I can't answer that.

WHAT'S THE CULTURE OF DOCTORS SHOWING VULNERABILITY?

One of the most interesting things about the field that has developed around studying and addressing moral distress is that it has been almost entirely focused on nurses. Only really in the last five to ten years has there been acknowledgment that physicians also experience deep moral distress. Really only in the last five years or less has there begun to be some sort of systematic study about this in the physician population as opposed to nurses. For physicians, this really is a taboo situation. We really don't talk about this. This is not the kind of thing you're supposed to acknowledge, because it becomes a sign of weakness. If in the sports team, if you're too injured, you're supposed to man up and take it. Keep playing. This has been the attitude among physicians for decades. Now there's starting to be some recognition, you need to acknowledge this. You need to reach out. Once again, you need to work with colleagues. You need to see yourself as part of teams, as part of a community.

ARE YOU SEEING SIGNS OF CULTURAL CHANGES?

Very, very slowly, yes. There is beginning to be some cultural change in some parts of medicine. If you think of medicine as a spectrum, I'm making it very generalized here, on one end are the surgeons and the super specialized surgeons, cardiac surgeons let's say, the other end are general internists. On this side where you have the general internists, there's starting to be some recognition. The nature of that kind of medical practice is one in which they're more concerned with longitudinal care of the whole person. At the other end of the spectrum where you have super specialized surgical type of interventions as the focus, we're probably still decades off. The kind of personality that is required to that kind of medicine is not tapped into these concerns about moral disruptions, moral distress. That's more of the technical aspect of how do I actually get this thing to do that under these physiological conditions.

GENERALLY SPEAKING, ARE THERE CARE MANAGEMENT OR COPING STRATEGIES THAT COULD KEEP MORAL DISTRESS FROM OCCURRING OR REDUCE ITS IMPACT?

The nature of taking care of critically ill people is such that there's no way in my opinion to avoid the kind of moral disruption or moral distress that occurs that we have been talking about. I think it would be wrong headed to think can we eliminate it. The issue is really how to acknowledge it, and in some sense normalize it such that you can actually

help people when they're in those moments. Not have them feel that somehow it's about them and they're wrong. They're ostracizing themselves, because this isn't how I'm supposed to be. I don't think the strategy is to say let's try to prevent it. It's how to recognize it, how to normalize it such that we can embrace people in those moments of crisis. Help them through. It takes time.

The other thing is from an administrative point of view, you have to have a willingness to spend time, which means money. You have to have that willingness that you can actually take care of people. That may mean sometimes maybe somebody needs to be relieved of their duty and not have that be a penalty, but have that be a positive. Still have them paid, but have temporary leave. I'm going to give you an example. There was a nurse who was a hospice nurse. She had done her original training in England. She had worked in a pediatric intensive care unit in England. The practice in her hospital was when a child died, because it's very distressing to have children die in general, no matter whether you had been working one hour that day, or you were on hour eleven, it didn't matter. Once that child died and you finished all the things you need to do to prepare the body to go the morgue, you were actually sent home. You still got paid for the rest of the day. The idea here was they recognized the severity of the experience. That was one of the ways to deal with the moral distress. It wasn't to eliminate it. It was to acknowledge it happens. Now how do we actually take care of people who are possibly in that kind of distress? That requires institutional commitment that many of our institutions probably at this point are not ready to do.

WHAT DO ORGANIZATIONS REQUIRE, SIMPLY, FOR PROPER INFRASTRUCTURE TO DEAL WITH MORAL DISTRESS?

If you could completely design from the ground up an institutional structure, you need to have, first of all, you need to have individuals who are by role devoted to facilitating conversations, meetings, debriefings, and retrospective review of situations that were generated by distressing situations. You have to have actual personnel full time whose job it is to address moral distress or moral disruption. Two, in an ideal world you should absolutely have a mechanism in which people cannot be penalized for having time away as a way to recover. There would be some way in which we could still pay them. Maybe shift them to a different type of function for a short time so they can rejuvenate. Three, we need to really have ongoing de-stigmatization of emotional distress. I say emotional distress because the truth is nobody likes to see or be around somebody who is crying, or is visibly, emotionally distraught. Even though we all know that that's part of what happens. We have to actually actively de-stigmatize that. This is not just the care we direct to our patients, it's part of taking care of ourselves. We need to allow that kind of display which shows the emotion, shows deep moral commitments. Those are tip offs of people's experience. That should be embraced as opposed to shunted aside.

IN TERMS OF PATIENT'S EXPECTATIONS AND THE REALITY OF CARE, ARE THERE ANY ISSUES THAT MAY CAUSE MORAL DISTRESS?

There are several issues that really turn out to be key I think in terms of the cause, or exacerbation of moral disruption or moral distress. The most obvious one as a society we are all subject to, which nobody looks forward to, wants to ever talk about, or address the fact that we're dying. Every single one of us right now, we're all dying. Unless you're twelve, you're still growing. The fear of death and the overwhelmingness of death in our culture, and this is not unique to California or the United States, this is a human thing. Our fear of death really makes it difficult to talk about the context of illness. Illness itself becomes one of those things that pops up into the front view, "Oh yes. This might be the illness that leads to my death." No one goes into the hospital for good things unless you're delivering a baby. You go into the hospital because something is really wrong. I can't take care of it at home, I can't take care of it in the doctor's office, I can't take care of it wherever I am. I have to now go to this next level of intervention and intensity. That triggers this issue of death. That's one thing.

The second thing is that although we don't want to speak about it, just like death, the idea of ableness versus disabledness. When you get seriously ill, part of what you're confronted by is the limitation of this thing. Nobody wants to end up coming out of an illness situation with a less functioning something. The fact that we're embodied is another one of those elements that pop up in illness. That makes it really challenging to talk about what's at stake for us. That's where the moral disruption occurs, because suddenly I'm confronted with what's actually at stake for me. Whether I'm the patient, whether I'm the loved one of a patient, or I'm the care provider, what's actually at stake? Death and the fact that we're bodied and the potential for being disabled, these are two fundamental social elements that are embedded in the context such that moral distress or moral disruption pops up. It can pop up at any moment.

IN TERMS OF OUR INABILITY TO FACE DEATH, WHAT ARE SOME WAYS WHERE THE FRICTION OF EXPECTATIONS AND REALITY CAUSE ISSUES WITH MORAL DISTRESS?

Whether you are a healthcare provider or a general person in the world, most of us have the expectation in a general way, when we feel good, and we're healthy, if we get sick, medicine will help us. Medicine will help us means I'll still be this way. I get a little sick. I get a sore throat. I take some medicine. I'm back to like this. As you escalate the significance and seriousness of illness, the expectation doesn't always correspond with that seriousness. There is still the expectation of "I'm going to be just like this." That's one of those places where the rub occurs. As you get more critically ill or more chronically ill, the life that you're expecting to get back to, doesn't always match with what physiologically, psychologically, emotionally is happening to you.

The challenge is then how we get all on the same page. Patients, families, and care providers. That's where you can have the contact where the disruption occurs. Where

our values suddenly emerge out, and things aren't as we imagine them to be. Now, what does this mean for who I am as a person, what I value, and how I go forward in life? It's that sense of expectation matching the reality of what's happening to me. Those who work in healthcare are just as susceptible because if 95 percent of the patients I take care of get better. For that 5 percent that don't, I'm often unprepared, even though I should be prepared because I deal with the 5 percent all the time. Often we're not prepared in the healthcare world to take care of people who are now undergoing a radical transformation. Their expectations are not going to be met. Their world view, it's changing. How do we take care of them? It turns out I'm not in sync with that kind of change and that kind of disruption.

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD ABOUT MORAL DISTRESS AND ITS EFFECT IN INSTITUTIONS?

I believe there is literature on this. I will leave it to those who want to tout literature to worry about it. Here's one of the things that we need to be really clear about. Working in the healthcare environment can be very difficult. The emotional concerns get pulled out. Also, the moral concerns get pulled out where I confront beliefs and values. That's the disruption that occurs. Unless you are paid a lot of money, it's very easy to say "Why should I continue to do this." We have levels of burnout among almost every layer in the healthcare world. That burnout translates into people dropping out, except for those who are paid very well. If you're paid really well and you become accustomed to that economic lifestyle, it's hard to get out.

We have two problems that we really need to address. One is how we can actually compensate people in a way that doesn't treat them simply as cogs in a wheel. Certainly the lower level you are in the healthcare world, physicians are at the top. Nurses are at the next layer. Then you've got all these layers of people, the technicians, the technologies, therapist who are even lower down, let alone the people who we never talk about, the people who clean the floors and the walls, and the beds, who are actually experiencing this as well. We don't pay much attention to that. Economically, we see them as interchangeable. This is something we as a system need to think about. How do we actually take care of all the people who are involved, who experienced this kind of disruption, and not treat them as throwaways?

WHAT ROLE WOULD YOU LIKE TO SEE EDUCATION PLAY IN THIS PROJECT?

One of the most important roles that education can play is that you go into the healthcare world knowing this is actually going to be part of your experience. So you are not caught off guard. If you're caught off guard, you are even more susceptible to the negative effects of this disruption. One of the things that happens is we treat moral distress or moral disruption as a negative, and hence something to be removed. I would suggest that this is actually endemic to being a healthcare provider. You're going to have periods of being very distressed, of confronting issues about yourself, about your work,

about your environment that you might not know how to deal with. This is going to happen all the time. If you know this is going to happen, you're at least prepared.

The other thing is, if you know this going to happen, you can help create an environment in which you can support others. When I'm not going through it, maybe you are. I can work to help create an environment in which we can take care of one another, setting up a moral community, so we are not simply people who occupy roles. We treat our environment as a community. We treat each other as community members, people that we share deep affiliation with. You can only do all that if you begin with recognition. That's the role of education, to begin with the recognition that this is part of the environment. Don't treat it as something strange that pops up and then you have to be reactive. Treat it as something that is endemic, part of the context and the experience of being a healthcare provider, so we can work through it continually forever.

THANK YOU...