UK Moral Distress Education Project

Tilda Shalof, RN, BScN, CNCC

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My name is Tilda Shalof, and I'm a staff nurse at Toronto General Hospital in the medical surgical ICU. I've been there for 28 years, and I'm a staff nurse, I work day shift, I work night shift, and I take care of patients. I take care of very sick patients that are critically ill. By definition that means they are catastrophically ill. They are almost all unconscious, intubated, they're on life support, they're very seriously ill. Unstable. Things happen very quickly. Their condition can change very quickly. Many of them have undergone lung or liver transplants, those are two of the specialties that we focus on at Toronto General Hospital, liver and lung transplants. And many of them have multisystem organ problems, so many different problems and combinations of problems. Very few of our patients have just one problem. They have many problems and they're very very sick to say the least.

WHAT IS MORAL DISTRESS? WHY IS IT AN AREA OF INTEREST?

Moral distress… Now, I've been a nurse for a long time. Thirty years. Thirty years ago when I studied nursing we talked a lot about moral distress. We were taught the definition. And so for this project I raced back to the definition. And it seems to me to be the same definition that was used then, which is when you see a problem that you feel that you have no agency, you can't do anything about it. You see a moral issue that troubles you greatly, that's in opposition to your own values or beliefs, and you as the nurse – I think it's a specifically nurse concept, moral distress, I don't know if other disciplines use it. But you see this problem, you see this moral dilemma, and you feel that your hands are tied, that you can't do anything about it. And as I said, I studied that definition many years ago.

I don't feel that way at all anymore, now, 30 years later, having practiced all these years. And the reason is because I don't practice in terms of my moral beliefs; I really try to practice in terms of the patient's beliefs. So that's the first part of it because I really believe in the concept of patient autonomy and I work in an organization that focuses on that, really, that's the philosophy of the organization. It's called patient centered care, and it's all about what the patient wants, the patient's values. Try to do what we do in accordance with the patient's beliefs. Because I work there and because I believe in that philosophy, it really goes hand in hand. So I really don't have that initial problem of doing things in opposition to what I believe in because I'm doing what I believe the patient wants.

And the second part of it, that I feel I can't do anything, I don't feel that way either. I think because I know there's a lot of can-do to alleviate any feelings of distress or to alleviate

the situation where there's a problem and no one's talking about it. I speak up now. I've been a nurse for a long time and I've worked with some very powerful nurses and doctors and other members of the team. I work in a fabulous place where I really have a lot of opportunity. I'm encouraged to speak up, and I do. So I had a lot of moral distress for many years. I'd kind of be a fool if, after 30 years, I was still having a lot of moral distress. I guess I found a way to sort it out in my mind, and that's how I do.

DO OTHER PEOPLE YOU WORK WITH SUFFER MORAL DISTRESS OR WHERE A PATIENT CAN'T VOICE THEIR NEEDS?

Yes. That is a huge problem. There are two parts to that. When I see colleagues who have this problem, well, I very much pride myself in being a mentor. I try to help them, I really can identify when they have that problem. I try to give them the encouragement to speak out or to do something about it. I'm a big believer in writing. I love to write. I've written some books about my life as a nurse, and I really encourage nurses to write or to speak out or to find some avenue to express what they want to say about our work. And then the other part, you said, what was the other part?

…SCENARIOS WHERE PATIENTS AREN'T ABLE TO VOICE THEIR NEEDS.

This is a very big problem. This is where the problem is for me, because, as I said, I like to practice in accordance with my patients' views, values, what they want. Rarely do we know that. That's the problem. That is a problem. So, we do not know what our patients want because they're not able to tell us. And even those who went ahead and wrote a living will, I do not find that in the clinical setting to be a useful document, because a living will can be interpreted by all the people involved, the family members, the doctors, the nurses, the ethicist brought in – by all of these people in a multitude of ways.

ARE THERE SITUATIONS WHERE MORAL DISTRESS CAN COME UP?

So there are two big problems in the ICU that I do face in my practice. One is colleagues who don't feel the agency to speak up, don't feel the confidence, let's say, to speak up. Don't feel they know how to speak up, don't know how to express their moral distress, so they stew in it without doing anything about it, and I like to be a mentor to those colleagues and to really give them the encouragement to do something about it, mostly to speak up. We have a lot of opportunities. We have team rounds, we have staff meetings. We have so many opportunities really in the place I work. In fact, speaking up is really encouraged. We have a model in our unit. Every voice is valued. And I think it really is true. Now, that is one problem.

Another problem is, as I say, I like to practice in terms of what my patients want, so I don't bring in anymore, as I used to, what I believe is the right thing to do, in terms of end of life issues, or, let's say if they want a certain treatment that whatever I think about

really doesn't matter. I believe that I'm there to carry out my patient's wishes. Now, the biggest problem is that we don't know our patient's wishes in most cases. It's a very big problem in a sense, it's a great problem. But what do we do? We ask the family to speak on behalf of the patient. Our patients are too sick or they are comatose or sometimes we paralyze them because they are so sick, for various reasons. Even if they were awake and able to speak it's not the time and place to have that kind of conversation. So we don't know our patients' wishes.

We don't know very much about our patients. We depend on family members to tell us. And families are all different. There are all kinds of different families out there, all kinds of different of relationships. Some families are very accurate and reliable and can tell you all about the person. Some know very little about the person. Sometimes there are no families. So often we have difficulty getting at what the patient wants, and that is a big problem. I know that living wills, people write these living wills. I have never found them to be helpful in a clinical setting, because even if the living will is available, attached to the chart, there for everyone to see and to read, I have seen so many situations where it has been interpreted in a multitude of ways, in the way that the person interpreting wants to interpret it.

IS THE CANADIAN, ONTARIO SPECIFICALLY, HEALTHCARE SYSTEM WELL SITUATED TO HELP PRACTITIONERS TALK ABOUT THINGS THAT ARE BOTHERING THEM?

I think what makes it easy for me to be this kind of empowering healthcare professional that I am, to be able to speak out and to be able to feel I have an opportunity to take action, is not so much the healthcare system but it's the work culture that I work in, the kind of really healthy environment, the team that I work with. I've been there a long time so I'm very much a part of it. I don't know what's out there in terms of how others feel but I think that if they feel that way I think it has to do with experience, feeling empowered, being a mature professional, and personality as well, having an opportunity to work with some very powerful people in terms of power, in terms of having the courage to speak out. So with regard to the Canadian healthcare system, I wonder how that does impact on moral distress. I really don't know. I think the care is the same from what I can see and having traveled down in the states and visited many hospitals through my work as a speaker about nursing issues and healthcare issues. I don't know if the care is any different or the debate is any different. Just the way things are paid for is different. I'm sure that that has manifested itself in some way in the care but I can't quite see it.

WHAT WOULD YOU SHARE WITH STUDENTS ABOUT MORAL DISTRESS?

I just want to go back to the thing about the healthcare system. I have to say that there's probably nothing that would cause me greater moral distress than if I had a patient that I couldn't give that patient the care they needed because of finances. That would cause me enough moral distress to quit nursing altogether. I cannot conceive of that ever

coming into my mind when I'm giving care to a patient: Whether or not they can afford this, or whether if they were richer they could get better care or different care. I cannot conceive of that. I could not work in that, and that would truly be moral distress for me. Whether any clinical decision was ever made based on financial ability? I would be out of there so fast. I just could not cope with that, because that is against my beliefs.

WHAT GUIDANCE WOULD YOU GIVE TO STUDENTS?

Well, the fix for moral distress, the antidote, the cure, the solution, is courage, moral courage, just courage. You've got to say what you think. You've got to speak up and take the risk of making a fool of yourself. Taking the risk, it's just summoning up your courage because you believe strongly in patient care. Just having courage. You've asked me about how to advise a younger practitioner or even an older one who is struggling with this issue of moral distress and feels that they can't speak up. You have to speak up. There are so many things. The stakes are so high. Peoples' lives are in our hands. If you see an error, if you see a problem of any kind, you have to speak up. And if you don't work in that kind of healthy environment where you feel that you can speak up, you have to either move, go to a different job where you find that kind of environment or you have to be part of creating it. It has to be paramount because of safety for patients, it's just all about safety and doing the right thing for patients.

CAN YOU TALK ABOUT THE EFFECT OF CULTURE?

Well this is very interesting, I'm glad you asked about different cultures of people. The staff, you're referring to. Yes, there probably are cultural differences, but I think if the same expectation holds, whether it's from a culture that doesn't encourage nurses to speak up. Listen, now they're in this culture and they have to speak up. And they have to learn that that's part of the skill of being in this environment. You have to learn it. It's absolutely necessary to speak up. That's why we live in the free world and that's why we live in a democracy. That is why we live here. Speaking up is so important. And if they don't have that skill, well, I'll help them. I will show them how. I will give them what they need to do it.

DESCRIBE SOME OF THE PROGRAMS THAT HAVE BEEN PUT IN PLACE AT YOUR HOSPITAL TO HELP PEOPLE FACILITATE CONVERSATIONS?

Well I think in terms of individuals and how they've mentored me over the years. I do work in this organization. I know the hospital very well. I don't think I could rattle off the mission statement but it's there in a sign in the elevator. I'm sure it's a very good one. I don't know what it is. I know that the CEO of the hospital has this sort of open door policy. You can email him. I like that idea. I've gotten in the elevator, I've talked to him. I feel there may very well be a hierarchy where I work, I don't subscribe to it. I don't feel that anyone is above me or below me, that's just my belief, I feel that if I want to speak to

the CEO I'll go to his office and I'll speak to him. Maybe that's just me, I'm just quirky, but I just do that. And I feel I have something to say and everyone should be listened to, and everyone, no matter what they're doing in their job, is important in a hospital. And that's just the way I see things. So I guess I'm a bit of an individual. I don't know what the organization has provided for me. It's a great organization, but as I say, there've been some individuals that I can tell you about who've influenced me to practice in this way more than the organization. Organizationally, we have group rounds where everyone's invited. It's multidisciplinary. Everyone who's involved in the care of the patient is invited. Sometimes we even invite the patient or the patient's family. If they're willing, they're part of group rounds too.

INTERVIEWER DESCRIBES A DIFFICULT END OF LIFE SCENARIO.

IN THAT SITUATION, WHAT CAN YOU DO?

Well, you've described a situation where someone is very sick. The chances of them surviving are next to nothing. They're probably nil. And yet we come to the point where we are about to resuscitate the person. Their blood pressure is dropping. They're going to a lethal arrhythmia, ventricular tachycardia, for example – and the situation of whether or not to resuscitate arises. And this is a very common situation. However, it really happens in a moment. It is really a process of talking to the family. For every patient that comes into our ICU, we have lengthy family meetings to discuss the plan of care.

Every family's different, but when it comes to the point that it looks like further treatment will not be beneficial, we most certainly have a family meeting at that time and explain all that. The doctor or the nurse, as many people as are necessary who are directly involved, sometimes another surgeon, whoever it is, and every member of the family who wants to be present. I've been present at family meetings where there was one person; I've been present at family meetings where there were over thirty that have filled a room. They insisted they all be there, including children. I looked over and I saw this five-year-old child, and I actually questioned, "Do you think this child should be here?" But that's another story. We obviously suggest that it be just the closest of people that would be involved in this but in some extended families and different cultures, they have large families. They all want to be in or at least hear what's going on in this discussion. So we have many of these family meetings. Sometimes we have them twice a day.

Now, if it comes to a situation where the family, and they use this phrase all the time, they "want everything done." Even in the scenario you describe in which we believe that there is no chance of survival, and that doing a resuscitation, which is a very, I would say, violent thing, it involves compressions on the chest, we often break ribs. It's horrific, but worth it if there's a chance of survival. But even in those situations, if I am convinced that that is what the person wants, on the basis of what the family tells me, we always bring it back to the person in the bed. We always say "What would that person want? Have you ever discussed this with that person? What were that person's values? What

are that person's values?" Because they are still alive, of course. "Have they ever had a conversation with you and they talked about this?"

And various members of the family will maybe give the conversation: I remember one who said "Oh, I remember I went with my father to a nursing home once to visit a relative. He said, 'At least they're still alive.'" So the son brought that forward and the daughter brought that forward as evidence that the father thought life above all. So that was the reason to continue to offer treatment, aggressive treatment, resuscitation efforts, until of course the father died. But in that family's mind that was the right thing to do, and in a sense I guess we're treating the family. But the family is the spokesperson for the patient, because the patient did not make it known. I'm not blaming the person.

How can we possibly imagine these situations? But I think it's important and incumbent on all of us to make it known. I don't personally believe in living wills because I don't think that the law needs to be involved in this. I don't think legalese captures the poetry of what goes on here. But I do think that you have to have conversations with people who are willing to step up and make these difficult decisions if you are not able to make it. I hope that people will do that for me. I had open heart surgery recently, and I had to make my wishes known in case things didn't go well. And I did. I don't know if people will carry it out. If I was not going to survive or be the kind of person I want to be...Anyway.

IF YOU KNOW THAT PERSON SHOULD BE LET GO AND A FAMILY MEMBER SAYS "DO IT" AND YOU KNOW YOU WOULD BE TORTURING THE PERSON TO DO IT--

In the situation where I have to participate in a resuscitation of a patient who I do not believe will survive this resuscitation, I believe that what I am doing is causing, in fact, harm, and causing indignity, and pain and suffering. But because I'm doing it at the behest of the family, it's very difficult. I won't say it's not. I don't like it. But I have to be guided by the family. What else can I be guided by? I believe in patient centered care. This is, at least, how I've rationalized it. If the family says "Dad would have wanted this," I frankly can't believe anyone would want this, but they say it, and they know their dad. Maybe it's a religious thing. Maybe it's a cultural thing. Did you know Toronto is very multicultural? I've cared for people from every country in the world. Different cultures, different religions have these beliefs. I'm there to respect that. That's how I've rationalized it. I would never want it for myself or someone I love. I speak to my nursing friends. We speak about this endlessly. And that's how I deal with a lot of moral distress as well, I should mention, is that I have this close knit group of friends and colleagues and we talk about these things endlessly and we agonize over it, it's true. We agonize, yes, but it's our job, and I don't take it home with me.

People make these choices for their loved ones. I think it's misguided. But it's their beliefs. I've had to learn to respect it, and I do respect it now. I think that maybe they don't really know what we're talking about. That's why I invite them in to see it. I don't shield it from them. It's very ugly. It's very unpleasant. But if you keep them out in the waiting room, then they will not see what we're really talking about here. I let them watch

while I'm suctioning a patient. I let them watch while I'm doing these things that are very painful and uncomfortable. So I can't believe that anyone would want this. But I know certain religions-- I'm Jewish and I know there are very orthodox Jews who want this. Who believe in life is paramount, life in any form is paramount, and if that's their belief and that, as they tell me, is the belief of their loved one, the person in the bed, I follow it. It sounds like it's just following orders, but I do believe I'm following what the patient wants as told to me by the family or the friend or whoever's closest. That's all I have to go on. The patient didn't write it out in a letter. Living wills can guide you but as I said I don't really find the way that they're written to be helpful. I don't feel that the law is there, that people should be writing these things. They have no clue about it themselves.

THAT ALLOWS YOU TO FREE YOURSELF FROM THE DECISION?

Yes, because I'm there to carry out the patient's wishes.

… AND IF IT'S AN OBLIGATION OF FAMILY?

The family telling me the patient's wishes. They say that we want him resuscitated. We want. I say, "Listen, it's not about you." I'll often remind them, I say, "That's what you want. What about him?" But many times they'll tell me that his beliefs are their beliefs, too. They're from the same family, the same culture, and it's not often that they will advocate for a decision that's very different from their own.

IS THERE ANYTHING WE NEED TO DO IN TERMS OF EDUCATION OR AWARENESS?

I wonder if people were to come and see the ICU. That would be one thing, I think, because we, as nurses, one thing we always say behind closed doors is that we would want none of this. Isn't that telling? Even the transplants that are touted as such saviors of people, and I suppose that if I needed a liver or a lung transplant, maybe I would feel differently. As it stands now, from what I've seen, I would not want any of it. And yet, it's what I offer to people and I give to people. I wouldn't want any of it. If I had a heart attack would I want it? Maybe, but only if I could return to the condition I'm in now. And that's my standard. But that's me. And I've told that to my people who are going to be my decision makers. But that's me.

So then in order to get people to understand this, maybe if they came to the ICU. Maybe if they stopped glorifying medicine and thinking that medicine can fix everything, and glorifying doctors, and realizing how much we cannot fix. One of the things we cannot fix is multisystem failure, when there's hypertension and diabetes and obesity and a conglomeration of problems that many people have. They come to the end of these chronic illnesses, this is very hard to fix. It's also impossible to fix old age. People do die. And we have tried to reverse that many, many times unsuccessfully. And then if we do

save them, to what are we saving them? It's not what I would want. But that's me.

THANK YOU…