

## **HIV and Postsurgical Complications in the ICU: A Role Play Transcript**

(Modified from: Nancy N. Dubler and Carol B. Liebman, *Bioethics Mediation: A Guide to Shaping Shared Solutions*, United States: United Hospital Fund of New York, 2004, p. 186-215)

### **Background**

Frankie Abruzzi is a 37-year-old man, currently in the intensive care unit (ICU). He admits to IV drug abuse in the past but claims he stopped using drugs several years ago. Seven years ago Frankie tested positive for HIV, and five years ago he was started on AZT. Also significant in his medical history is a heart valve replacement several years ago due to endocarditis (inflammation of the tissue surrounding the heart) contracted through his drug use.

In August, Frankie was referred by Dr. A. Schwartz to Dr. B. Heinstein, an oncologist, because of an elevated white blood cell count. A bone marrow biopsy was done, and Frankie was diagnosed with a very early stage of CML, a form of leukemia. Interferon was started six weeks later but was discontinued shortly thereafter because Frankie continued to spike fevers.

While in the hospital, Frankie developed abdominal swelling due to fluid buildup. He also developed an acute retroperitoneal bleed, for which he was transferred to the ICU. The bleeding was coming from his right kidney, which was removed one week ago. Postsurgery, Frankie has not recovered consciousness. He is on a ventilator, and so far weaning attempts have proved unsuccessful. He also has low blood pressure and has developed renal failure, for which he has received dialysis on three occasions. Unfortunately, because of Frankie's low blood pressure, dialysis has had to be discontinued, at least temporarily. There is no health care proxy for the patient and no living will.

The day dialysis was started, Frankie's parents walked into his ICU room and were shocked to see him hooked up to yet more tubes and machines. They asked for a do not resuscitate (DNR) order. The surgical resident provided one and Mrs. Abruzzi signed it. The social worker, T. Chen, witnessed the signing. The parents also told Dr. Heinstein, who was Frankie's attending physician at the time, that they wanted dialysis stopped and no further aggressive treatment instituted. Dr. Heinstein explained to the family that he could not agree with their decision about resuscitation, dialysis, and other treatments. In his view, the patient's condition was potentially reversible. Dr. Burrows, the renal attending, stated that though Frankie was critically ill, if his blood pressure could be raised it would make sense to resume dialysis. If it could not, then the issue of dialysis might be moot. At this point, a staff nurse in the ICU, M. Aquino, called the Ethics consultant.

**Ethics consultant:**

Good morning. Thank you all for agreeing to come together this morning. I think that I have met most of the staff and I had a brief opportunity to talk to Mr. and Mrs. Abruzzi earlier today. Good morning to both of you. I especially appreciate your coming since I know something about this case and realize that this is a very difficult time for both of you.

Let me explain my role today. I am trained as a lawyer but have worked at this hospital for 25 years and have developed the program in medical ethics. In 1978 I founded the Bioethics Consultation Service, which is often asked to participate in discussions about cases in which difficult decisions need to be made. It is my task, or the job of my two colleagues in the service, to try to convene all of the parties so that everyone can hear each other. We don't come to make the decision. We come to be certain that all of the medical facts are on the table and that all of the options for action have been stated and considered. When possible, our goal is to help the patient, family, and medical staff to reach a consensus about a plan of care that all are comfortable with and that will guide the medical interventions provided. So that is why I asked you all to come together today and I thank you all.

Now, let us take a moment and have each of you introduce yourself and explain your role in Frankie's care and treatment. (Introductions omitted.) Thank you all very much.

**Mr. Abruzzi:**

Can we talk about the DNR order now?

**Ethics consultant:**

Well, if you would not mind, I would like to put that off for just a while. One of the issues in thinking about a DNR order is what the physicians hope or expect might be the possibility of recovery. So, if we could put off the discussion for just a bit perhaps I am hoping that we will have more facts to consider and discuss together. I promise you, Mr. and Mrs. Abruzzi, that we will not end this discussion today before we have decided about the DNR order. I realize that this order seems the most important decision to be made, but let us try to understand what is happening medically with your son, first, and then consider all of the possibilities for actions, second. Is that OK? (All participants nod assent.) Good.

**Ethics consultant:**

As I think everyone knows, Dr. Schwartz and Dr. Heinstein, you have differing opinions about what the course of Frankie's treatment should be. So, would you mind beginning, Dr. Heinstein, and telling us what you think is going on with Frankie's new diagnosis of cancer. I am sure that we all appreciate that for Frankie's family this seems to be the last straw; how could their son get any sicker? But I must admit that sometimes, as a nonphysician, I am amazed by how sick a patient can seem and how hopeful the physicians can remain. So, Dr. Heinstein, could you review the medical facts and tell us what you think is happening with Frankie.

**Dr. Heinstein:**

Well, let me explain why I did not want to agree with the DNR order that the –

**Ethics consultant:**

Dr. Heinstein, let me interrupt for just one moment. If you would not mind, could we leave the discussion of the DNR order for a bit later? I promise everyone that we will get to this discussion before we break. But for now let us all try and understand what is happening with Frankie. I realize it is a very complicated picture and difficult to sort out, but since the family is responsible for deciding about this order, I would like them to have as much information as possible before they have to grapple with this task.

And, before you return to the issues, Dr. Heinstein, may I ask you and all of the other medical staff to try to speak in terms that a nonmedical person would understand. One of my mentors once said, “Remember, the doctor speaks doctor and the nurse speaks nurse and no one speaks patient or family.” So, let us return to Dr. Heinstein. Thank you for letting me add these few words –

**Dr. Heinstein:**

(after summarizing the medical facts as set out above): So you can see that we can’t hold off on the DNR decision for very long.

**Ethics consultant:**

So, Dr. Heinstein, let me just understand from your perspective, you came in as the oncologist for the patient, and he has a leukemia which you think is possibly treatable. He may get better from this leukemia, but we would have to get his blood count up and get him back on dialysis, but you think he could get better.

**Dr. Heinstein:**

Yes, indeed.

**Ethics consultant:**

Dr. Schwartz, could you give us a little history of you and the patient and tell us where you think the issues are now.

**Dr. Schwartz:**

Well, I started taking care of Frankie several years ago, but transferred the care to Dr. Heinstein when he developed the leukemia because that really wasn’t in my area of expertise. I’m more of an infectious disease physician. My area of expertise is AIDS/HIV. His subsequent problems have necessitated that we work with many different specialists because, as you know, at this point HIV is a disease that affects many different organs and one person can’t really be responsible for all the parts of Frankie’s care. I think that I have a slightly different perspective than Dr. Heinstein does in the sense that although many of the parts of Frankie’s current disease are treatable in isolation, I have to wonder if he does have a cardiac arrest that requires resuscitation, given all the many different problems he has, what the final outcome would be if we resuscitate him.

**Ethics consultant:**

Could we hold the resuscitation discussion just for now. Again, what I hear you saying – and this is a hard one, so please make sure I have it right – is that he is very sick. He's got HIV disease, which has had a complicated course, and he now has leukemia, which has a complicated course. Can you give us some sense of how these two layer on each other? What does it mean to Frankie as a person, from your perspective as an HIV specialist, to have these two things together?

**Dr. Schwartz:**

I would just like to add also the renal disease, which is significant in terms of his prognosis.

**Ethics consultant:**

And is that a result of his HIV?

**Dr. Schwartz:**

They are all connected. The cardiac disease, the kidney disease, they really are all part of the same problem. It's very difficult to separate the causes and really not as important as understanding that there are many different things happening to him at the same time, each of which has a grave prognosis, which makes the hopefulness of his leaving the hospital very slim.

**Mr. Abruzzi:**

So you think it probably doesn't make sense to resuscitate him?

**Ethics consultant:**

Well, again, Mr. Abruzzi, if you would just bear with me for a minute, we will get to the decision about resuscitation. I just want you to have a feeling of what the physicians are saying. I think what Dr. Schwartz is saying is that he has HIV disease, which he has had for a long time. That's related to his cardiac disease, which is now a free-standing problem. It's also related to his kidney disease. He's had one kidney removed and the other isn't working, and he now has leukemia. So what I hear from Dr. Schwartz actually is a bit of a different presentation than from Dr. Heinstein. That is, he has all of these things happening at once, which is a little bit different from Dr. Heinstein, who is focusing on his leukemia. We will get to the DNR discussion, if you would just bear with me.

**Mr. Abruzzi:**

Whom do you agree more with?

**Ethics consultant:**

I don't agree or disagree with either of the physicians. I would only point out that they seem to be focusing on different aspects of Frankie's illness. That is not surprising. Dr. Heinstein is an oncologist, a specialist in the treatment of cancer. He is addressing this aspect of Frankie's illness which he was asked to do. Dr. Heinstein is really focused

now on the leukemia, as he should be. He's an oncologist and we brought him in as a specialist to look at this problem. Let us see first what the different perspectives of the physicians are and then see whether or not they disagree.

**Mr. Abruzzi:**

That's not exactly what I'm talking about. I don't disagree that the deck is stacked against my son, but as long as there is one live card left to play, I think it's wrong for us not to play it. But even if you try dialysis, we still think resuscitation is wrong.

**Ethics consultant:**

That was very helpful. The only thing I would ask you is to leave words like right and wrong out because that won't help us. Your perspective, I think, is very clear, and, I think, very helpful. So can we put the DNR discussion aside for just a minute? So, two slightly different perspectives: one from our specialist whom we brought in – "Let's get this leukemia under control. I think we can." And Dr. Schwartz, who seems to be saying there are so many problems going on that it might not help to look only at the leukemia. Is that a fair statement Dr. Schwartz?

**Dr. Schwartz:**

That and I guess my question about even if we can control many of these problems medically, what it's going to mean to Frankie who is the person that we're trying to treat.

**Ethics consultant:**

Maybe it would be helpful to get two other perspectives before we go on to talk about where we go with this. (Turning to Nurse Aquino:) You are the nurse caring for the patient?

**Nurse Aquino:**

Yes, I'm in the ICU. There are a group of us who care for the patients there, but I care for Frankie.

**Ethics consultant:**

And you've known him now since he's been in the ICU?

**Nurse Aquino:**

Yes

**Ethics consultant:**

Would you like to add anything?

**Nurse Aquino:**

I think that what we've been really struck with is the anguish that Mr. and Mrs. Abruzzi have been going through trying to make a decision. We see them there at the bedside, and we know that they're hearing different things from different people, and we know that they really love Frankie and they are really trying to make the very best decision for him. The nurses just feel that there is not enough for them to grapple with to make the

decision that they're going to have to live with, no matter what happens to Frankie, whether he has a DNR or doesn't, whether he has treatment or not. They need to feel comfortable in their decision. I think the other thing is that the nurses are struggling with it too because we're there every day with Frankie. Mr. and Mrs. Abruzzi are there a lot of the time, but we're there 24 hours a day. We're taking care of Frankie and bathing him and taking care of all of his needs. We know that some of these decisions are going to have real consequences for us as the primary care givers. So we're really concerned about making sure that this is a decision that everybody understands.

**Ethics consultant:**

You're lucky you have such good nurses. That makes a real difference. But I think that, Ms. Aquino, you raised a very important point, which is what I hope comes out of these discussions is not that they will have to make a decision but that we'll all reach an agreement that we're comfortable with so that won't put all of that responsibility on them. (Turning to the parents:) Obviously, you have the authority to make decisions for Frankie – you're his parents. I think it's a very important point that, at best, we try to share the burdens of those decisions. Mr. Chen, do you have anything to add?

**Mr. Chen:**

Yes. We've talked in the ICU. I'm the social worker for the ICU. I see many situations like this, and I talked to the Abruzzis. We talked at length about Frankie. From their point of view, they have a lot of feelings, obviously, about what's gone on to date. The sense that I got from talking to them is how overwhelming the situation is with their son and how unexpected all of these things are. He went in the ICU and now one of the things that hasn't been mentioned, but I think should be, is that he is now on a breathing machine too and he's not even conscious. He got dialysis and Mr. and Mrs. Abruzzi came into the ICU and they were really shocked to see all of this. I can understand that. So we talked a lot about their feelings and their dismay and their anguish and their sense of hopelessness because of all these things that are going on. It didn't seem like it would be this bad initially. They shared with me that they really wonder if Frankie is ever going to get better, and that maybe it's time to say, "Look, there's nothing more that we can do," and just let Frankie go in peace. I heard their saying that, and I can sympathize with that feeling. I can really see how under the circumstances they could really feel that way. So I've met with them frequently. They are going through a very difficult time and are confused about what to do. I think that's very understandable.

**Ethics consultant:**

I wanted to make one more comment. (Turning to the risk manager:) Ms. Henry, I'm not exactly sure why you're here, but let me just make one comment based on what Mr. Chen said. In my role in this hospital over the last 25 years I've observed that hospitals are very good at making decisions to go ahead with treatment. They are not as good at making decisions to stop. One of the things that happened in bioethics discussions over the past years – the past decade really – is the sense that the perspective that maybe it's time to stop has to be of equal importance in these discussions. We're here to care for the whole patient and if the patient isn't going to make it, it's our obligation to recognize that and support a process of dying. So, let me just ask Ms. Henry why she's

here and then let's sum up where we are. Then I think it's time to ask Dr. Schwartz to give us a summary of where you think we are and then begin to open the discussion of what our options are and how you might arrange those options. Does that make sense?

**Ethics consultant:**

Dr. Schwartz, I'm going to come back to you in a minute to give us a summary, and if you can bear with us one more moment Mr. and Mrs. Abruzzi, I know that Ms. Henry is here and she sometimes has some very useful perspectives to add.

**Ms. Henry (to the parents):**

We haven't met before, and the ethics consultant asked initially why I was here. The risk manager's job is to make sure that decisions that are made are in keeping with hospital policy and with the law. Most of the time there is no problem, but sometimes in difficult situations there can be. In a situation like this where we're talking about possibly limiting the right to treatment, it's helpful sometimes for me to know what's going on and for me to be able to help you to know what the requirements are.

**Ethics consultant:**

Ms. Henry, just a point. Thank you for being here. You and I have worked together for a long time and I think it's helpful to have the administration which Ms. Henry represents as part of the discussion. And, Ms. Henry, you know that I respect those issues a lot, but again, can we put them aside for a minute? But let me make my perspective on this case clear. Mr. and Mrs. Abruzzi are the family of the patient and we're going to look in a bit at what the patient would want and what they would want, but it's very clear to me that they have the legal right to make this decision and the moral right to make it. I understand, and thank you for being here because it will be helpful for you to hear their perspective, but I don't think here's any question in this case. As Frankie's parents, they really do have the right to make the decision.

**Ms. Henry:**

Well, we need to talk a little bit about limiting life-sustaining treatment in the absence of knowing what the patient would want.

**Ethics consultant:**

If we need to. But we may not in this case. So let's go on to Dr. Schwartz. Sum up for us how you would characterize medically what happening now.

**Dr. Schwartz:**

Well, I think Frankie has multiple organs involved in his disease. He's currently on a respirator. He has many conditions in and of themselves that could be treated and if he had them alone, there would be the possibility of successful treatment. Although none of us can really predict what the outcome of serious illness is, in cases like Frankie's. I think it would be very unusual if he were to be able to leave the hospital.

**Ethics consultant:**

So if I hear you correctly, you think that Frankie, given all of the problems with the different parts of his body and different organ systems, would it be too much to say that you think he may be in the process of dying?

**Dr. Schwartz:**

No, I think that's a fair statement.

**Ethics consultant:**

OK. I think we really need now to begin to grapple with what we're going to do. We've heard two very different things. We have two views here and in both cases, I think, Dr. Schwartz and Dr. Heinstein, you both agree the probabilities are not great, but we've heard Dr. Heinstein say, "We can treat the leukemia," and we've heard Dr. Schwartz say, "Even if we treat the leukemia, it may be that he's just overwhelmed by all of the medical things that are happening." So you, Dr. Schwartz, think it's OK to stop and you (Dr. Heinstein) think you shouldn't. It's OK to keep on going. Mr. and Mrs. Abruzzi, which of those interpretations seems to make more sense to you? How have you experienced his care here and how are you thinking about what's happening?

**Mrs. Abruzzi:**

Well, I just see him being more and more overwhelmed. Every time I come in there are more tubes in him. He's not at all responsive. I just don't want him in pain anymore.

**Ethics consultant:**

Well, let me assure you, just on that issue, that we take the treatment of pain as an ethical issue, not just as a medical issue. There are studies now that show that 55 percent of the patients who die, die in pain. On our team we think that is ethically unacceptable. And so, I think we can get agreement from Dr. Schwartz and the ICU nurses that he will not be in any pain, that he will have a level of sedation and analgesia that will keep him comfortable. Do you have any problems with that?

**Mr. Abruzzi:**

No.

**Ethics consultant:**

All right. So let's put that one aside. We promise you that he will not suffer and be in pain. That's a medical issue, and a nursing issue.

**Mrs. Abruzzi:**

It's just hard because he's gone through so much. He's a real fighter. There's absolutely no question about it. It's hard because now when we come in we see him unconscious with all these tubes. It's just very distressing.

**Ethics consultant:**

Tell us a little bit about Frankie. You say he's a fighter. It's real important for this discussion not just because he's your son and you love him but I'm going to suggest to

you that as we move on to figure out together what to do, what he would want is very important. So who he and what he wants is really a critical next piece of the discussion, so tell us something about him.

**Mr. Abruzzi:**

Well, he had a rough life. He has HIV and a problem with his heart and then the cancer. For a lot of people that would just mean depression, that would just mean a sense that your life is over. He's never been like that. These have been really tough obstacles for him, but he's gone on and tried to live and enjoy life. He's the type of person that sees the bright side in everything. He's a real joy and he's a very hopeful person. Obstacles have never slowed him down. It's been very hard to see him unconscious here because we don't see that side of him. It's almost like when he's unconscious he's not here anymore. Part of me says, if he were just awake now he'd be saying, "I'll get through this, Dad. Don't worry about it." He's just strong that way. Seeing him now is just like he's not there. He's a real fighter.

**Mrs. Abruzzi:**

I'm sorry. Could I share my perspective of Frankie as a person?

**Ethics consultant:**

Sure. I just wanted to understand something from Mr. Abruzzi and then that would be very helpful. Mr. Abruzzi, it sounds to me like you're saying that if you ran a summer camp you would want Frankie in your bunk. He's a really good, optimistic guy. As his illness went on, did he keep that optimism? So he wanted to have his kidney removed because he thought that was the next step, and he agreed to start dialysis. Let me rephrase the question. When his other kidney began to malfunction and he knew this was a whole new ball game, he was still making decisions about his care, and he wanted to go ahead and get the machine that would supplant his kidney, the dialysis machine. He wanted to do that?

**Mr. Abruzzi:**

Yes.

**Ethics consultant:**

For me, that's really important because one of the things when a patient can't make a decision, like Frankie clearly can't, we try to figure out with you what he would want. That's our first step. What would he want? Has he told us anything? Has he said anything specific, or has his behavior indicated anything? So that's really important. Dr. Heinstein, is there something you wanted to say about what Frankie would want?

**Dr. Heinstein:**

Just two things. It was months ago when I made the diagnosis of leukemia. At that time, he did not have a do not resuscitate order. He did know he had the diagnosis of both HIV and the leukemia.

**Ethics consultant:**

He did know?

**Dr. Heinstein:**

Of course he did. At the point at which he had the renal failure and had to have the nephrectomy, he wanted everything done. So the family and all of us thought that dialysis would be a good way to go because Frankie was such a fighter. I totally agree with that. My only problem right now is that of the options we have, the do not resuscitate, the dialysis, and the treatment for leukemia. We don't have a chance to treat any of those, and I think Frankie would want us to try something.

**Ethics consultant:**

That was very helpful. Let me tell you why I found that helpful, and tell me if you agree. Dr. Heinstein just identified three choices we have to make. One is whether to continue dialysis, two is whether to have a DNR order, and three is whether to treat the leukemia. OK. Let's say that those are the three choices we now have to make because that's helpful to me because it tells us where we have to go. I think that the piece about what Frankie would want is very helpful. So Dr. Heinstein is saying that as long as he could make decisions by himself he went ahead. Patients, if they are lucky, have a loving family to make decisions. So when you were all making that decision together, which I assume you did, he wanted to go ahead, whatever the chances. So he wanted to go ahead with the nephrectomy when he had his kidney removed, and he wanted to go ahead with the treatment of his leukemia. And you supported that with him.

**Parents:**

Absolutely.

**Ethics consultant:**

So my question to you now would be, do you think he would change his mind now and why, or maybe, Mr. Abruzzi, if there is a chance, as Dr. Heinstein says, that maybe the leukemia will get better and maybe he'll get over this crisis – which Dr. Schwartz is not sure of. Part of the problem in medicine is we don't know what's going to happen. We can't give you promises that if you take route A this will be fine. We can't tell you that. So there's a lot of uncertainty, but I want to know whether you think Frankie would want to go ahead now with the leukemia treatment, because I think that is the key issue. If we go ahead with the leukemia treatment, then at least for the moment, it doesn't make sense to have the DNR. (To Dr. Heinstein:) In other words, if we're going to go ahead with the leukemia treatment, the DNR doesn't make sense. Is that your opinion?

**Dr. Heinstein:**

More accurately, I think we should at least do the treatment whether we have the DNR or not. We should at least do the treatment.

**Ethics consultant:**

So you think you can separate those two?

**Dr. Heinstein:**

I can separate them, although my preference for Frankie and what I think is the better position is no do not resuscitate order, given the fact that everything that's happened to him is reversible.

**Ethics consultant:**

So you would agree, too, that there are three decisions, and they are separate. One is whether to go ahead with his dialysis, which isn't an issue now because, as I understand it, he's too sick. But, if we went ahead with the leukemia treatment – that's decision one – it might put him in a position where we could institute dialysis. That would be decision two, and then the DNR is a separate decision. Dr. Schwartz, does it make sense to you to look at those three decisions separately?

**Dr. Schwartz:**

Well, yes. I'm not uncomfortable doing that. I think that they can be separated.

**Ethics consultant:**

OK. Good. So now let's come back to Frankie. What do you think he wants? What would he want?

**Mrs. Abruzzi:**

I'm not sure what he would want, but he's a fighter. His father's right about that. I wouldn't want him to be in any pain.

**Ethics consultant:**

But remember, we will not let him be in any pain.

**Mrs. Abruzzi:**

You're sure about that?

**Ethics consultant:**

Absolutely. Absolutely. Has he ever talked about other people who were in a similar situation, either people he knew, people in the family who were critically ill. Has he ever talked about their treatment?

**Mrs. Abruzzi:**

No.

**Ethics consultant:**

So let's again put that aside for now.

**Mrs. Abruzzi:**

So there's no pain, even when he's unconscious with the tubes and everything. It's so hard. When somebody can talk they can tell you. You can see it on their face. You can see it in their reaction. When they just have tubes in them and they are unconscious it's hard.

**Ethics consultant:**

Nurse Aquino, could you talk a little bit to us about how nurses figure out when a patient is in pain? I agree with you. That for me is the most important ethical issue. So I think it would be helpful if the family understood how the nursing team reacts to pain.

**Nurse Aquino:**

Well, I think we try to do a couple of things. First, I think just what you're saying. When people have tubes, the assumption would be that they are experiencing pain, just like anybody else. So we start from that perspective. We want to make sure that the pain is treated. We treat the pain, but also every time we turn Frankie, every time we try, we have to sometimes take out the fluid through his nose and suction him, we look to see if he flinches. We look to see if he grimaces in any way. We look to see if we have any evidence at all that he's in pain. And, we've gotten pretty good at knowing that. You're right. It's not like having the person tell us directly. Obviously, it's not the same, but we're experienced. We're here all the time, and we're pretty good at trying to judge. Working with Dr. Schwartz and the other doctors, this is an ICU where if we're in doubt, we treat the pain. We don't say, "Well these people aren't experiencing pain because they are unconscious." We are really up on all the latest stuff and we really try to treat the pain. The doctors and nurses are in agreement about that.

**Dr. Schwartz:**

I just wanted to add that what you are feeling is pain, and it's a different kind of pain than you are worried about Frankie feeling. So when you see him with all these tubes, you have to separate your pain as parents from his physical pain as a patient.

**Nurse Aquino:**

But that's what I was going to say. Sometimes parents identify so much with their children that their own suffering, they think that because they are suffering their children are suffering too. And that's not the case here.

**Ethics consultant:**

I think you can be comfortable that, despite the terrible level of anguish and pain that you two have, he will not experience physical pain. So, are you comfortable on that point?

**Mr. Abruzzi:**

Yes.

**Mrs. Abruzzi:**

That was very helpful.

**Ethics consultant:**

OK. That's a very important point. So now let's come back because I think there is a very important issue here. Let me state to you what I know here. Frankie's a fighter. Every time he reached a juncture where he could make a decision to go ahead and be treated, he did. That's a really important thing. If we want to try to make the decision

for him now that he would make, that's very powerful evidence. Dr. Heinstein is saying that's his sense of Frankie also. So, let me try to break up these three decisions in the order in which they seem to make sense. One is to go ahead in treating the leukemia. But let me tell you what I hear. I hear from the two of you that if Frankie could make the decision, he might make the decision to go ahead. But that's pretty important. I would argue to you now that if that's the decision that he would make, maybe that's the decision we should make.

**Mrs. Abrizzo:**

Oh sure. We're OK with that.

**Ethics consultant:**

OK. So we're moving along. Dr. Heinstein. Dr. Schwartz, are you comfortable with that?

**Dr. Schwartz:**

I am. I think that I am here to try to represent Frankie's needs. I think we all are, and it's important that we get at them.

**Ethics consultant:**

OK. So I think we're moving. As I said to you, my goal doesn't always work. I've had some spectacular failures, but my role is always to try to get everyone to be comfortable with the decision because then nobody feels the burden exclusively. So let's say that we're going to go ahead with treating the leukemia. Dr. Heinstein, let me argue with you a little bit. The parents would like the leukemia treated, and my guess is that if you asked them, they would probably do it. But it's pretty problematic. Even you would agree that this is a very sick patient. Treating the leukemia may not work. The patient is already intubated, so if there is a pulmonary event, if something happens in his lungs, he is not really going to go into arrest. So the question is, if under the assault of everything that's happening in his body, if his heart stops, what should we do? I think that you might agree that if that happens and there is yet one more layer, that maybe it's appropriate to recognize that we and Frankie have lost this battle. I really ask you to reconsider. The parents are saying they would like you to treat the leukemia. Let's give it one more chance, but if he should arrest, let's be ready to accept that judgment. Could you live with that?

**Dr. Heinstein:**

I would accept it (the DNR) then, but I'm not entirely comfortable with that, again given my tradition that we should at least try to restart his heart.

**Ethics consultant:**

But your tradition is if there is any chance at all, you take it. Maybe the parents and Frankie come from a different tradition which is less powerful, and in a situation of so much uncertainty and anguish, it would not be unreasonable for them to make the decision that a cardiac arrest really was the end of this. The end of the life of their child.

**Mr. Abruzzi:**

If my wife and I could just talk to each other for a moment. I appreciate you all being here because this has been very helpful. I was just wondering if we could just talk for a moment.

**Ethics consultant:**

Absolutely. Would you like some coffee. There is a coffee machine at the nurses' station. It makes the worst coffee in history, but I'm sure they'd be willing to share it with you. Do you want to go and get a cup of coffee and talk, and then you can come back and we'll talk some more.

(The parents leave the room. Once they do, the battle becomes much more confrontational.)

**Ethics consultant:**

Hey, what's bugging you about this case? I think we're moving nicely. The family is going to agree with treating the leukemia. Dr. Heinstein is going to agree.

**Dr. Schwartz:**

We don't know why they wanted it.

**Ethics consultant:**

They want it because their son is dying.

**Dr. Schwartz:**

You haven't heard from them why they want it.

**Ethics consultant:**

You said you could live with treating the cancer.

**Dr. Schwartz:**

Well, I heard you say that you would only accept the DNR order if you couldn't do anything at all to help the patient.

**Dr. Heinstein:**

So it sounds like you're backing away from that.

**Dr. Schwartz:**

What are you trying to save? You know, if you resuscitate this guy, the chances of him regaining consciousness are .01 percent. He has a million other problems that are going on. This guy is not getting out of the hospital if he has another arrest. You're treating his bone marrow. You're not treating him.

**Ethics consultant:**

I think, Dr. Heinstein, that in the business of compromising on medical decisions and where we're going and what's happening, you've won this one. Give them a break.

You've won it. You're going to go ahead. They're very uncertain, but they're with you. Give them a break on the DNR. We haven't come to that yet.

**Mrs. Abruzzi:**

We were just listening to you before we went out to talk. The pain has really been my only concern. That's why I signed the DNR order. I didn't want him to be in pain. My husband has always not wanted to do that, but I have one more question about the DNR. If you do something and you resuscitate him, will he be in more pain? Will he hurt? Are you going to do things to him that will make things worse off?

**Ethics consultant:**

If his heart stops and we resuscitate him, or if we try – It's not clear that that will work, but if we try, would that add to his pain? Let's assume that he stays at the baseline that he is now. Could that cause additional pain?

**Dr. Schwartz:**

It's possible, but again, not unmanageably. It could prolong it though. More than additional pain, it could take us longer and longer in an area of greater uncertainty.

**Mrs. Abruzzi:**

But the act of resuscitating him wouldn't make him hurt a lot more?

**Dr. Heinstein:**

He is unconscious already. If his heart stops and the blood ceases to flow to his brain, he is not going to feel any more pain. Yes, the resuscitation might not work.

**Mrs. Abruzzi:**

The only thing we are worried about is his pain. If you're telling me that he's not going to be in more pain, then we're prepared to tear the DNR up for now.

**Ethics consultant:**

Dr. Heinstein, Dr. Schwartz, are we agreed that even if we try to resuscitate the patient, given his present medical condition, giving the alertness of the medical and nursing staff, that he will not experience more pain?

**Dr. Schwartz:**

I don't think we can say it for sure. I think the thing is, after he's resuscitated, if he lives, we may be back to where we were, but we may be into a situation we've got other medical options that we have to try.

**Ethics consultant:**

But why would that increase his pain?

**Dr. Schwartz:**

Because every time you have a new thing going on, it makes it harder to control the pain. That doesn't mean we wouldn't make every effort, and in most instances we're successful.

**Ethics consultant:**

This is hard for his parents to hear.

**Mr. Abruzzi:**

But isn't he unconscious? Isn't that what Dr. Heinstein said?

**Dr. Schwartz:**

But there are levels of pain that can be experienced even when the patient is unconscious.

**Ethics consultant:**

So deep pain. Can you leave an order for morphine that would be sufficient to control that eventuality?

**Dr. Schwartz:**

Yes.

**Ethics consultant:**

OK. If your single concern is the pain issue, the Dr. Schwartz says he can leave an order that is sufficiently strong for pain medication. We can't promise you 100 percent in a package wrapped in gold. Medicine isn't that way. But we can promise you our best efforts. What I hear from you is that if we can do that then you would like to go ahead with the leukemia treatment for now. Remember, the decision we reached today we can all get back together and change tomorrow. But for today, where we are now, you would like Dr. Heinstein to continue with treating the leukemia, and you would like for the moment to suspend the DNR. Is that comfortable for you now?

**Mrs. Abruzzi:**

Yes.

**Mr. Abruzzi:**

Yes.

**Ethics consultant:**

Are we all in agreement? OK. I think we can end for now, although you have to understand, as we all do, that things change all the time, and we're available for you if you'd like to come back into the conversation. My guess is that everyone is on board; that we're going to try this. If this doesn't "work," if the leukemia doesn't get better, then I think Dr. Heinstein and you will be more comfortable knowing everything was tried, and then it will be a different discussion. But for now, are we all in agreement? OK. Thank you. Thank you very much for coming. I know this was a very hard decision, but

I think you were very courageous to face it, and we think you're good advocates for your son.

**Mrs. Abruzzi:**

Thank you.

## **Further Discussion of HIV and Postsurgical Complications in the ICU: A Role Play Transcript**

The ethics consultant entered this case with the working hypothesis that a DNR order was appropriate – a view that she still had at the end of the mediation. Because she was able to put her preconceptions aside, make sure that all the relevant facts were on the table, and listen to the participants, she avoided imposing her views and allowed the mediation process to lead to an outcome that was very different from the one she anticipated.

Some observers of this mediation were troubled by the decision to continue treatment because they viewed this as a futility case. (In New York State the definition of futility is either the treatment will not work – for example, using an antibiotic to treat a virus – or the patient will go into cardiac arrest repeatedly in a short period.) The observers in the mediation for Frankie's case thought that a DNR based on futility should have been written and that it was unethical to take up an ICU bed and continue to expose nurses to the risks of treating an HIV patient. The ethics consultant's view was that these parents knew their son was dying but were not quite ready to face that fact. They needed to feel they had done everything they could for their son. Since the proposed treatment was not going to harm Frankie, the ethics consultant did not see continued treatment as unethical. She anticipated that the resuscitation was not going to work but saw this treatment as being for the benefit of the parents, not the patient. She stated that when she is sure the patient is beyond pain, she sometimes thinks it is helpful to treat the family because doing so lets them live more comfortably afterward with the consequences of the decision.

Had any of the participants raised futility issue the ethics consultant would have explored it. The fact that no one on the treatment team saw the case that way determined the direction of the discussion. When one of the doctors or the nurses in a mediation says, "This resuscitation effort will be futile," the ethics consultant will argue that it is the team's ethical obligation to write a futility order of DNR to avoid exposing staff unnecessarily to HIV infection.

Other observers were concerned that the ethics consultant did not ask the parents whether they understood what the process of resuscitation entails. When the parents returned to the room they had decided on resuscitation and no one explained how violent resuscitation can be, that it might result in broken ribs, information that might be important for the parents, especially given the mother's concern about pain. The ethics consultant explained that once the parents made the decision, she did not go further with the discussion. She assumed that if this patient's heart stopped, the staff would respond with a resuscitation attempt, and that no one was going to pursue this attempt over a long time. Her assumption was that if Frankie's heart stopped, the staff would make an attempt and they would be able to see pretty quickly whether it was successful and if it was not they would stop.

## **Postscript**

In January 1999, two years after the actual mediation, the ethics consultant spoke with the oncologist in the real case on which this role play was based to get an update. The patient recovered enough to go on dialysis until he was able to leave the hospital without needing it. When asked, the patient made it clear that he would want everything done again if necessary. He was never told that his parents had initially signed a DNR order. At the time of the conversation between the ethics consultant and the oncologist, the patient was still being treated for AIDS and it was under good control. He was working and still receiving interferon for his chronic leukemia, which was also under good control. The patient's mother has since died of cancer.