Goals of Care Conversation Curriculum (GOCCC) Training

Examples of Using Curiosity and Good Listening/ Role Play

Scenario: An 82-year-old female is seeing you in follow-up for compression fractures. She was recently hospitalized for another acute compression fracture. She has significant pain.

Role Play: As the clinician, you are pressed for time since you have 2 other patients waiting and you need to leave the office early today for your child's recital.

Role Play #1: Bad Example

Doctor/Clinician: How has your pain been since your last visit?

Patient: Not good. I'm always in pain, doc.

Doctor/Clinician: Is the morphine helping?

Patient: I don't know.

Doctor/Clinician: How much morphine have you been taking?

Patient: ... I haven't actually taken any of it.

Doctor/Clinician: You have to take your medication. I know it's hard to remember to take it, but if I don't know how much you're taking, I'm not going to be able to adjust your medications and get your pain under control.

Role Play #2: Better Example

Doctor/Clinician: How much morphine have you been taking?

Patient: ...I haven't actually taken any of it.

Doctor/Clinician: Tell me more about why you haven't taken the medication. (INQUIRE)

Patient: It's not something I need.

Doctor/Clinician: Help me understand why you don't you think you need it. (INQUIRE)

Patient: My husband got morphine right before he died. I'm not there yet.

Doctor/Clinician: So you feel like morphine is given to people who are at the end of life? (PARAPHRASE)

Patient: Yeah. I'm not there yet. But you're giving me this medication...I don't know what to think anymore.

Doctor/Clinician: It sounds like you've been worried about this. What are you most worried about? (ACKNOWLEDGE, INQUIRE)

Patient: I'm scared about what it means. Am I dying? Will I be in pain forever or will I get addicted to morphine?

After the scenario, spend 5 minutes discussing as a group the 2 scenarios. Open the floor to discussion about the above role plays. Consider these questions:

- 1. What are the differences between the 2 scenarios?
- 2. What is the expected outcome for each of these scenarios?
- 3. Which scenario do you usually see? How different is this from reality?
- 4. What was an example of inquiring?
- 5. What was an example of paraphrasing?
- 6. What was an example of acknowledging?

Examples of Discussing Serious News/Role Play

Scenario: A 76-year-old male is seeing you in follow-up for lymphoma. He has had 3 courses of standard therapy without significant improvement. He has tolerated the chemotherapy without significant complications but is gradually losing weight and function.

Role Play: As the clinician, you are now reviewing the results of a CT scan after this last round of chemotherapy.

Role Play #3: Bad Example

Doctor/Clinician: So, your CT scan results came back. And it looks like the cancer didn't shrink as much as I would have liked.

Patient: So, it shrunk a little? That's good, right?

Doctor/Clinician: Yes, it's good. It didn't get bigger. But we expect a bigger response.

Patient: What do you mean? It responded a little. That must mean it's working.

Doctor/Clinician: It didn't shrink enough.

Patient: So just give me a bigger dose.

Doctor/Clinician: No, we don't do that. The chemo didn't work. A bigger dose isn't going to make a difference.

Patient: (starts to cry) There must be something else you can try then.

Doctor/Clinician: I can imagine what you're going through. Why don't I look into more clinical trials? We could always try fourth line chemo.

Role Play #4: Better Example

Doctor/Clinician: How have you been since our last visit? (ASSESS)

Patient: It's been tough. I've been pretty anxious about the test results.

Doctor/Clinician: I can't imagine how difficult it must be to wait all that time. What have you been most anxious about? (ACKNOWLEDGE, ASSESS)

Patient: I just hope the chemo worked.

Doctor/Clinician: So I do have the results of your CT scan. (Pause) How much would you like to discuss today? (NEGOTIATE)

Patient: I want to know where I stand. Is the chemo working?

Doctor/Clinician: Unfortunately, we have some serious news to discuss today. The scan showed that the cancer did not respond to the chemotherapy as we had hoped. (DISCLOSE: warning, straightforward disclosure)

Patient: (starts to cry) It's not working?

Doctor/Clinician: I can see this is really hard to hear. (ACKNOWLEDGE) Unfortunately, the chemo isn't working. I was really hoping that it would respond too. (DISCLOSE, align with patient)

Patient: What do we do now?

Doctor/Clinician: We'll need to talk about what the next steps are. We'll work together to figure out a plan that works best for your goals. (SUMMARIZE)

After the scenario, spend 5 minutes discussing as a group the 2 scenarios. Open the floor to discussion about the above role plays, *Consider these questions:*

- 1. How are the 2 scenarios different?
- 2. What was an example of assessing?
- 3. What was an example of acknowledgment?
- 4. What was an example of negotiating?
- 5. What was an example of disclosure?
- 6. What was an example of summarizing?

Examples of Discussing Prognosis/Role Play

Scenario: The same 76-year-old male is seeing you in follow-up for lymphoma. He has had 3 courses of standard therapy without significant improvement. He has tolerated the chemotherapy without significant complications but is gradually losing weight and function. You had discussed his CT scan results at the previous appointment.

Role Play: As the clinician, you are now meeting to discuss his prognosis.

Role Play #5: Bad Example

Doctor/Clinician: We talked about you CT scan at your last visit. Why don't we talk about prognosis today?

Patient: Okay, I guess.

Doctor/Clinician: The cancer has actually grown since the last scan, and we've exhausted all of our chemo options. For people in your situation, the average life expectancy is 3 months.

Patient: Isn't there anything else we can try? (Patient begins to sob)

Doctor/Clinician: I've tried everything I can. I'm sorry, but there is nothing left to do now. We really should talk about hospice. They can take care of you from now on.

Role Play #6: Better Example

Doctor/Clinician: We talked about your CT scan at your last visit, and you had mentioned that you wanted to talk more about what the results mean for you at this visit. How much do you want to talk about today? (NEGOTIATE)

Patient: Everything, I guess.

Doctor/Clinician: What do you mean by everything? (INQUIRE)

Patient: I guess, how much time I have left.

Doctor/Clinician: Are there specific concerns you have about how much time you may have left? (INQUIRE)

Patient: My daughter's wedding is in November. Will I make it?

Doctor/Clinician: What is your sense? (ASSESS)

Patient: Things have been getting worse so quickly. I'm worried I won't make it.

Doctor/Clinician: (pauses) I'm worried about that too. (DISCLOSE)

Patient: (starts crying)

Doctor/Clinician: Even though you've been thinking it, I can see it's really difficult to hear it out loud.

(ACKNOWLEDGE)

After the scenario, spend 5 minutes discussing as a group the 2 scenarios. Open the floor to discussion about the above role plays, *Consider these questions:*

- 1. How are the 2 scenarios different?
- 2. Did you identify some communications strategies in the second role play? Negotiate, assess, inquire, disclose, acknowledge.

Discussing Serious News Participant Role Play Instructions

CLINICAL SCENARIO: You've been asked to see a woman in her 70s for a Palliative Care initial inpatient consultation by the primary care team. She has Stage IV colon cancer diagnosed 1 year ago. She is s/p second line chemotherapy and her oncologist wants to offer further chemotherapy. The primary care team feels like further chemotherapy may not be in the patient's best interest and have asked you to speak to her. In reviewing her medical record, you are worried that further chemotherapy will shorten the patient's life and have discussed this with the oncologist who has said, "This is the only treatment option I have to offer. And the patient says she wants treatment." The oncologist has not discussed prognosis with the patient though the patient has asked. You assess her prognosis to be days to weeks.

INSTRUCTIONS: The group of learners can then be divided into small groups. At a minimum, there should be 2, one taking the role of patient and one taking the role of clinician. Another option is to divide into groups of 3 into the following roles: one in the role of patient, one in the role of clinician, and one in the role of observer who can provide feedback following the conversation. It is expected that the conversation will take about 30 minutes (3 components of 5 minutes of role play and 5 minutes of discussion). There are three objectives of the Discussing Bad News portion of the curriculum. Learners will:

- 1) Use curiosity and good listening skills to understand patient coping styles
- 2) Describe empathic and effective approaches to discussing serious news
- 3) Identify strategies for discussing prognosis

Learners earlier in their training, such as medical students and first year residents may not be able to move on to the next step of developing a plan of care. Those further along in their training may feel very comfortable moving onto this step.

The facilitator will instruct each dyad (or triad) to do the following 3 role play activities using the clinical scenario above. The roles of patient/clinician (and observer if a triad) can be rotated after each scenario so that each person has a chance to play each role. Specific tasks:

- a. **Prepare and assess** the person's readiness for information regarding the clinical scenario. 'How much have your doctors told you?'
- b. **Negotiate and disclose** based on their readiness to hear the news. 'How much do you want to know?'
- c. Acknowledge emotion and summarize the plan. 'I can see this is difficult'

At the end of the participant role play, reconvene the group in the final 10 minutes for a large group discussion to review the following questions with the whole group:

- 1. What do you take away from this session?
- 2. How will you identify the right family members to meet with?
- 3. How has this affected your comfort level with discussing serious news with patients?
- 4. How will your family meetings be different?

Bad Example of a GOC Discussion/Role Play

For the next part, two faculty members (preferably palliative medicine or geriatrics) will role play 2 scenarios. The first role play will demonstrate a bad example of a GOC discussion with a family member. This is followed by a large group discussion. The second example involves a similar scenario but with a better example of a GOC discussion, also followed by a large group discussion facilitated by faculty.

Scenario: This 82-year-old man with stage IV non-small cell lung cancer was admitted 2 weeks earlier for treatment of pneumonia. His co-morbidities include COPD (not oxygen dependent), CHF, diabetes mellitus and chronic kidney disease stage 3B. He had been declining at home prior to admission and has now stopped eating. No readily reversible problems have been identified for his decline. You have been asked to speak with the family to update them on his condition and discuss goals of care.

Role Play: As a clinician, you have been asked to meet with the son\daughter to have a goals- of-care conversation. The clinician will appear disorganized and unprepared, using plenty of jargon and statements like, "He's really sick".

Doctor/Clinician: The nurse asked me to come in and talk to you. What did you say your father's name is?

Son/daughter: Robert Smith

Doctor/Clinician: (shuffling through papers) Okay, well let me check a few things. Yes, he has been very sick, as you know. We've been doing everything we can for him. I see he has lung cancer. We did a

bedside echo the other day and that showed an ejection fraction of 20%. His BUN and creatinine have been rising. Output is marginal. Chest x-ray showed an increase in the size of the mass. We've been having difficulty maintaining his oxygenation. (Shuffling through papers again)

Son/daughter: Well, it has been confusing. I seem to be getting mixed messages. One of the doctors who stopped by yesterday seemed to think he wasn't doing well, but today I heard that his blood sugar was better. I'm really not sure what to think.

Doctor/Clinician: Yes, that is good news about the blood sugar.

Son/daughter: Another doctor said the lung cancer had spread and he seems so sick. Is he dying?

Doctor (clearly uncomfortable): Well I'm not GOD and I don't have a crystal ball. We never really know about these things. (Takes out cell phone and takes a minute to text message)

Son/daughter: I'm still not sure what to think.

Doctor/Clinician: Well, one thing I need to ask is, do you want us to do everything?

Son/daughter: Well, of course. We love him.

Doctor/Clinician: I have to run now. I have a lot of patients to see. The nurse is around if you need anything.

After the scenario, spend 10 minutes discussing as a group this scenario. Consider these questions:

- 1. What mistakes did the clinician make in preparing for this discussion?
- 2. What could they have done better to prepare?
- 3. How does one deal with the time constraints when having these discussions?
- 4. What strategies would have helped to relay the same information without seeming distracted or pressed for time?

Better Example of a GOC Discussion/ Role Play

Scenario: This 82-year-old man with stage IV non-small cell lung cancer was admitted 2 weeks earlier for treatment of pneumonia. His co-morbidities include COPD (not oxygen dependent), CHF, diabetes mellitus and chronic kidney disease stage 3B. He had been declining at home prior to admission and has now stopped eating. No readily reversible problems have been identified for his decline. You have been asked to speak with the family to update them on his condition and discuss goals of care.

Role Play: As a clinician, you have been asked to meet with the son\daughter to have a goals- of-care conversation. In this version, the clinician will be well prepared, and courteous. The clinician will assess the family member's understanding of the situation, will not use jargon or pauses, and will demonstrate significant empathy.

Doctor/Clinician: I am Dr._____, and I have had the opportunity to care for your father for the past few days. I want to thank you for taking the time to meet with me to discuss your father's care.

Son/daughter: No problem. I really want to know what's going on.

Doctor/Clinician: What have the doctors told you about your father's condition at this point?

Son/daughter: Well, it has been confusing. I seem to be getting mixed messages. One of the doctors who stopped by yesterday seemed to think he wasn't doing well, but today I heard that his blood sugar was better. I'm really not sure what to think.

Doctor/Clinician: What have you been told in the past about his cancer?

Son/daughter: I think his doctors said the lung cancer had spread, but he was going to get chemotherapy to control it. He seemed to be getting sicker though. He keeps having to come back into the hospital and seems to be getting weaker. I thought maybe the chemotherapy was making him weaker.

Doctor/Clinician: You are right that the cancer had spread, and in these situations, the chemotherapy is not given to cure the cancer. The hope is that the chemotherapy may help control some of the symptoms and may buy a little more time. Unfortunately, in your father's case, it is not just the cancer that is causing his problems. He has heart failure, which means that the heart muscle is not pumping as well as it should. This causes fluid to back up in the lungs, and in reviewing his record, it looks like he has had to come into the hospital twice in the past couple of months to get medication to remove this fluid. I understand he was very short of breath when this happened. Unfortunately, his kidneys are not working well, and this makes it more difficult to remove the fluid. As you may know, he also has problems with his lungs, and I see he has been on inhaler medication for this.

Son/daughter: Yes, he has been on a lot of medication, and he seems to be getting tired of taking all this medicine. Sometimes it seems like the medicine is not helping.

Doctor/Clinician: You are right. I think at this point the medicines are not as effective as they once were when his illnesses were not as severe. I am worried that we may be at a point where even with the best medical care, we are not going to be able to get him back to where he was even a few months ago.

Son/daughter: That's not good. We were all hoping you could do something to get him back where he was before this cancer thing started. He is 82, but his mother lived until she was 98, so we figured he had some time left.

Doctor/Clinician: I think if he had just one of his health problems, we would not be looking at such a serious situation. Unfortunately, it is not just the cancer, it's the heart failure, it's the kidneys not working well, it's his lungs. I think at this point, because of all of these things, we are no longer measuring in years. I am worried we may no longer be measuring in months, and it may be days or weeks at this point.

Son/daughter: Wow - that is not what I was expecting.

Pause/silence 5-10 seconds

Son/daughter: So, you don't think there is any chance he'll just bounce back from this and get back to where he was last year?

Doctor/Clinician: I wish that were possible, but unfortunately, I think his time is short.

Son/daughter: I'm not sure what to say.

Doctor/Clinician: I understand you've been very close to your father, and it must be so difficult to see him this sick.

Son/daughter: Yes. He really depends on me.

Doctor/Clinician: I really do appreciate your taking the time to speak with me today because I think it will help us determine the kind of care your father would want at this point. Did he ever talk about what he would want if he became this ill?

Son/daughter: Not exactly. He did have to stay in a nursing home before he came back to the hospital, and he said he hated it and could not live like that.

Doctor/Clinician: Can you tell me more about your father? Was he very active? Was he independent?

Son/daughter: That's why he hated being in the nursing home. He couldn't stand having people help him. A few months ago he had to stop driving, and he hated that. He was a very active man, and being sick like this has been awful for him.

Doctor/Clinician: Since I met your father a few days ago, he really hasn't been able to speak to me. I do understand that he made it clear that we should speak to you about any medical questions. Knowing his time is short, what do you think he would say if he could sit up and tell us what he wanted?

Son/daughter: I think he would say he had a good life, and it was time to say goodbye.

Doctor/Clinician: Then it sounds like he would he would not want things that would prolong his survival in this condition.

Son/daughter: No, he would think that would be torture.

Doctor/Clinician: I think there are a number of things we can do to make sure that he is comfortable, and we can stop some of the things we've been doing that I think make him uncomfortable. Given what you told me, I would suggest that when he does die, we allow him to die peacefully.

Son/daughter: I am not sure I understand.

Doctor/Clinician: Well, as it stands now, if something happens, he would be put on life support, and efforts would be made to resuscitate him, which I do not think would be helpful, but would certainly make him much more uncomfortable.

Son/daughter: There is no way he would want that.

Doctor/Clinician: Okay, I will make that clear to the doctors and nurses helping to take care of him. It sounds like you're saying his care should now focus on keeping him comfortable.

Son/daughter: That's what he would want.

Doctor/Clinician: That is what we will do then. Do you have any questions for me?

Son/daughter: Yes, what do we do next?

Doctor/Clinician: As I said, I will make sure it is clear that we will not do things that will make him uncomfortable, and his care will now focus on comfort. Are you familiar with hospice?

Son/daughter: Yes, my uncle had hospice.

Doctor/Clinician: I think it is often helpful to have them involved when care is going to focus on comfort, as they are the experts in keeping patients comfortable. I think you have a few options with hospice, and one would be to take him home with their help.

Son/daughter: I think that is what he would want.

Doctor/Clinician: If it's okay, I will have someone from hospice plan to meet with you to give you more information.

Son/daughter: That would be great.

Doctor/Clinician: Again, I want to thank you for coming in to speak with me. I think this was very important to insure that we give you father the kind of care he wanted.

After the scenario, spend 10 minutes discussing as a group the 2 scenarios. Alternatively, a large group discussion can occur after each scenario. Open the floor to analysis about the above role plays. Consider these questions:

- 1. What are the differences between the 2 scenarios?
- 2. What is the expected outcome for each of these scenarios?
- 3. Which scenario do you usually see? How different is this from reality?
- 4. If you were the family member, which would you want?

Participant Role Play Instructions

CLINICAL SCENARIO: This 82 year old male with Class IV CHF was admitted for treatment of pneumonia. His co-morbidities include COPD (not oxygen dependent), moderately severe dementia, and chronic kidney disease stage 4. He had been declining at home prior to admission and has now stopped eating. Workup did not identify any readily reversible problems for his decline. You have been asked to speak with the family to update them on his condition and discuss goals of care.

INSTRUCTIONS: The group of learners can then be divided into small groups. At a minimum, there should be 2, one taking the role of family member and one taking the role of clinician. Another and better option is to divide into groups of 3 into the following roles: family member, clinician, and observer. The conversation should take about 30 minutes (3 components for 5 minutes of role play and 5 minutes of discussion and then switch roles and redo the scenario. There are 2 main objectives for a GOC discussion that we hope all learners will accomplish during the role play:

- 1) Assessing the family member's understanding and then clarifying misunderstandings regarding clinical status and prognosis
- 2) Assessing goals and values and clarifying goals of care

Learners earlier in their training, such as medical students and first year residents may not be able to move on to the next step of developing a plan of care, and that is not necessary for this exercise. Those further along in their training may feel very comfortable moving onto the plan. The faculty facilitator will instruct each dyad (or triad) to do the following 3 role play activities. The 3 activities in order should be as follows:

- a. Initiation of a GOC discussion: What is your understanding of what your doctor has told you?
- b. **Surrogate decision making discussion**: If your family member could hear what we've discussed and the likely outcomes, what would she want?
- c. **Conclusion of the GOC discussion:** Here's what I'm hearing you say, and here is my recommendation.

At the end of the participant role play, reconvene the group in the final 10 minutes for a large group discussion to review the following questions with the whole group:

- 1. What do you take away from this session?
- 2. How will you identify the right family members to meet with?
- 3. Has this changed your comfort level with running end of life or goals of care discussions?
- 4. How do you think a goals of care discussion can impact the trajectory of patient care?
- 5. How will your family meetings be different?

Bad Example of Managing Conflict Interaction/Role Play

For the next two examples, two faculty members (preferably palliative medicine or geriatrics) will role play 2 scenarios. The first role play will demonstrate a bad example of a conversation with an angry family member. This is followed by a large group discussion. The second one involves a similar scenario but with a better example of how the clinician can manage conflict with their words and actions, also followed by a large group discussion facilitated by faculty.

Scenario: An 85-year-old female has had 3 hospitalizations in the past 2 months. She had been living at home with the assistance of family and part-time caregivers prior to the hospitalization 2 months ago. Since then, she has been in 2 different nursing homes for rehabilitation. She has a history of congestive heart failure, COPD (not oxygen dependent), diabetes mellitus, osteoarthritis, and moderately severe dementia. Her initial hospitalization was for a urinary tract infection. She was readmitted several weeks

later with *C. difficile* colitis and discharged to a nursing home again. She was readmitted a second time 2 days ago with pneumonia, and concerns have been raised about her ability to swallow.

Role Play: As the clinician, you've been notified by the nurses that son/daughter is extremely angry and demanding to speak to a doctor about their mother's care right away. In this version, you will be curt, angry, frustrated, and impatient. You will feel personally offended and become defensive, blaming the patient and family for the current situation.

Doctor/Clinician: I am Dr. ____ and the nurse told me to come in and speak to you.

Son/daughter: (angry) It's about time! I've had my fill of this place. I wouldn't want my dog treated the way my mother's been treated here. Every day more tests and more needles. This place is like a torture chamber. Nobody knows what they're doing. I am just sick and tired of....

Doctor/Clinician: (Interrupting) Ma'am/Sir, I think you need to calm down.

Son/daughter: Are you kidding me? This is calm! And who are you to tell me to calm down? You have no clue what my mother's been put through.

Doctor/Clinician: Well, I don't know what you expect. We are not miracle workers.

Son/daughter: I am not looking for a miracle, simply people who care enough to do a decent job in taking care of my mother. This is the third time she's been here, and she keeps getting sicker.

Doctor/Clinician: It looks like when she got sick the first time, you waited a couple of weeks before bringing her in. When people wait like that, it doesn't help matters.

Son/daughter: Look, I tried to get her in to see her regular doctor, but she was having trouble standing up to walk out to the car.

Doctor/Clinician: And that's another thing. She's not been in to see her regular doctor in months. She is the one who should be overseeing her care at this point.

Son/daughter: That doctor doesn't go to the nursing home, and that's not my fault. Besides, I thought the doctors here would be good. It doesn't seem you guys are able to figure anything out.

Doctor/Clinician: The doctors who have been caring for her are Board Certified. Many of the doctors who treated her are on the medical school faculty. You will not find a better group of doctors.

Son/daughter: Well, you all have not done anything to help my mother.

Doctor/Clinician: You do understand that your mother smoked for years. I think she is starting to pay the price for that at this point.

Son/daughter: You are unbelievable! I'm going to call the president of the hospital. I'm also going to call the newspaper and a TV station. A friend of mine told me to call the health department, and I will do that too. It is terrible what you have done to my mother!

Doctor/Clinician: (walking away) Well, you do what you have to do...

After the scenario, spend 10 minutes discussing as a group this scenario. Consider these questions:

- 1. Have you ever been confronted with a family member similar to this?
- 2. How difficult is it to maintain your composer when confronted this way?
- 3. How do you keep from getting angry yourself?
- 4. What words were used that might have aggravated the situation?
- 5. What non-verbal language might have contributed to the family member's anger?
- 6. Was there any benefit to bringing up outside issues related to the care whether by family or PCP?

Better Example of Managing Conflict Interaction/Role Play

Scenario: An 85-year-old female has had 3 hospitalizations in the past 2 months. She had been living at home with the assistance of family and part-time caregivers prior to the hospitalization 2 months ago. Since then she has been in 2 different nursing homes for rehabilitation. She has a history of congestive heart failure, COPD (not oxygen dependent), diabetes mellitus, osteoarthritis, and moderately severe dementia. Her initial hospitalization was for urinary tract infection. She was readmitted several weeks later with *C. difficile* colitis and discharged to a nursing home again. She was readmitted a second time 2 days ago with pneumonia, and concerns have been raised about her ability to swallow.

Role Play: As the clinician, you've been notified by the nurses that the son/daughter is extremely angry and demanding to speak to a doctor about their mother's care right away. In this version, the clinician will be well prepared, calm, patient, and courteous. The clinician will allow the family to express their frustrations, will validate their feelings, and will allow for information to be discussed in a clear and thoughtful manner.

Doctor/Clinician: I am Dr. ____ and the nurse let me know he had some questions and concerns about the care your mother's been getting.

Son/daughter: (angry) It's about time! I've had my fill of this place. I wouldn't want my dog treated the way my mother's been treated here. Every day more tests more needles. This place is like a torture chamber. Nobody knows what they're doing. I am just sick and tired of her being treated like this and I get no answers and no help from anyone.

Doctor/Clinician: I see your mother has been in the hospital several times in the past couple of months. It must be so frustrating for both of you.

Son/daughter: Are you kidding me? It has been a nightmare! She keeps getting sicker and sicker.

Doctor/Clinician: It sounds like it's been incredibly difficult for both of you.

Son/daughter: You bet it is. I am not looking for a miracle, but no one is giving me any answers. This is the third time she's been here, and she keeps getting sicker.

Doctor/Clinician: What have her doctors explained to you at this point?

Son/daughter: Doctors? I haven't talked to any doctors. I just get calls from the hospital, saying they're sending her out and calls from the nursing home, saying they're sending her in. Is that any way to treat a patient? I have absolutely no clue what is wrong with her.

Doctor/Clinician: I'm sorry this is been so frustrating for you. Would it be helpful if I spent some time reviewing her medical problems with you?

Son/daughter: Well, it's about time somebody did that.

Doctor/Clinician: Unfortunately, your mother does not have just one medical problem, she has a number of very serious health problems. She has heart failure, which means the heart muscle is not strong enough to pump the blood normally, as it should. This can cause fluid to back up in the lungs and will make it difficult for her to breathe. She also has lung disease, also called COPD, and it looks like she has been on inhalers for this. This will also make it difficult for her to breathe. I'm concerned that perhaps her most significant health problem at this point is her dementia. Sometimes, people may think of dementia is simply a problem with memory, but unfortunately, the changes in the brain that result in memory loss can also result in difficulty walking, difficulty swallowing, and make people much more prone to infections, which has been a big problem for her.

Son/daughter: Well, she definitely has been having trouble with walking, and she fell a few times at home. She also has trouble swallowing, and we had to give her baby food at home.

Doctor/Clinician: I'm worried at this point that in spite of the best medical care, she will not get better.

(Silence)

Son/daughter: That's what I was afraid of, all this stuff for nothing.

Doctor/Clinician: I think it was a good thing that you sent her to the hospital, and we have looked for things we could do to help her. I wish we had been able to get things turned around for her, but I am worried that given her underlying illnesses, that may not be possible.

Son/daughter: So, now what do we do?

Doctor/Clinician: I wanted to ask if your mother ever discussed the kind of care she would want if she became this sick. Did she ever fill out an advanced directive or designate a healthcare power of attorney?

Son/daughter: She filled out something a few years ago, and I am the person who doctors have to talk to. She did say on that that she didn't want any tubes to keep her alive.

Doctor/Clinician: Sometimes, people in your mother's condition do have feeding tubes placed into the stomach, but it does not seem to be helpful. I am concerned about her swallowing, and I think it might be helpful to have a speech therapist see her so we can get an idea if there are certain food consistencies that would be easier for her to swallow, as well as some that we should avoid. I think this might give us some helpful information and may also provide some information about prognosis for your mother.

Son/daughter: I would like to get some answers and find out where she stands.

Doctor/Clinician: Can we set up another time to meet in the next couple of days? At that point, I think we should have a little more information and should be able to get you more answers. Do you have any other questions at this point?

Son/daughter: No, I'm pretty much worn out right now.

Doctor/Clinician: Okay, but if you do think of any questions, please write them down so we can address them at our next meeting.

Son/daughter: Thank you, Doctor.

After the scenario, spend 10 minutes discussing as a group the 2 scenarios. Alternatively, a large group discussion can occur after each scenario. Open the floor to discussion about the above role plays *Consider these questions:*

- 1. What are the differences between the 2 scenarios?
- 2. What is the expected outcome for each of these scenarios?
- 3. Which scenario do you usually see? How different is this from reality?
- 4. If you were the family member, which would you want?