

Supplemental Material A

Quality of Life Seminar: Delivering Bad News

1. Teenage boy (14 years old) with progressive, metastatic, osteosarcoma is hospitalized for febrile neutropenia following intensive salvage chemotherapy. The night nurse goes to put on a flush and patient is sitting up on bed, alone in the room. He says to you “I don’t want to die.”

- Discuss possibly ways to respond *in the moment*

2. The parents of the same 14 year old with progressive, metastatic, osteosarcoma pulls the nurse out in the hallway and asks nurse and team not to mention results from recent scan as they are afraid that the patient will “lose hope”.

- How do you address this request with the family

3. Later that same shift, the teenager then asks you directly about the results from the scan with the parents in the room.

- Discuss possible ways to respond to both the patient and the parents

4. A 6 year old female with progressive, refractory NB admitted for pain control and palliative radiation. Parents refusing to give morphine for pain control, child is crying and appears very uncomfortable.

- How do you address this issue with the parents

5. You just sat in on family conference with primary team and patient (6 year old with NB) and family in which they discussed that there were no further cancer-directed therapies available at this time. The team recommended hospice enrollment and offered chance to go home or to stay at St. Jude. They gave a timeframe of days to weeks left to live. Later in the room, you overhear mom and dad talking to the child about a planned trip to Disney next summer and are worried that they do not understand/comprehend the information provided by the team.

- How do you address this issue with the parents

Discuss ways in which the interdisciplinary team may help in this situation

Study ID# _____ Pre-Seminar Palliative and End-of-Life Care Survey

Part I. Personal and Professional Background and Experience.

1. ☐ Degree (s) _____
2. What is your primary discipline? (*circle one*):

| | |
|---|-------------------------------------|
| <input type="checkbox"/> Nursing | <input type="checkbox"/> Child Life |
| <input type="checkbox"/> Physician | <input type="checkbox"/> Chaplain |
| <input type="checkbox"/> Social Worker | <input type="checkbox"/> Psychology |
| <input type="checkbox"/> Pharmacy | <input type="checkbox"/> Volunteer |
| <input type="checkbox"/> Other (<i>write in</i>): _____ | |
3. Specialty (*write in*): _____
4. Years in practice (*write in*): _____
5. Please select your gender:

| | | |
|---------------------------------|-------------------------------|---|
| <input type="checkbox"/> Female | <input type="checkbox"/> Male | <input type="checkbox"/> Prefer not to answer |
|---------------------------------|-------------------------------|---|
6. Age. Please select the range that includes your age (*check one*):

| | | | |
|---|--------------------------------|--------------------------------|--------------------------------|
| <input type="checkbox"/> 20-25 | <input type="checkbox"/> 26-30 | <input type="checkbox"/> 31-35 | <input type="checkbox"/> 36-40 |
| <input type="checkbox"/> 41-45 | <input type="checkbox"/> 46-50 | <input type="checkbox"/> 50+ | |
| <input type="checkbox"/> Prefer not to answer | | | |
7. Ethnicity. Please select your ethnicity (*check one*):

| | | |
|---|---|----------------------------------|
| <input type="checkbox"/> Hispanic | <input type="checkbox"/> NOT Hispanic or Latino | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> Prefer not to answer | | |
8. Race. Please select your race:

| | |
|--|---|
| <input type="checkbox"/> American Indian/Alaska Native | <input type="checkbox"/> White |
| <input type="checkbox"/> Asian | <input type="checkbox"/> African American |
| <input type="checkbox"/> Native Hawaiian or Other Pacific Islander | <input type="checkbox"/> Unknown / Not reported |
| <input type="checkbox"/> More than one race | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Other (<i>write in</i>): _____ | |
9. Religion. Please select:

| | | | | |
|---|-----------------------------------|-----------------------------------|-----------------------------------|------------------------------------|
| <input type="checkbox"/> Atheist | <input type="checkbox"/> Agnostic | <input type="checkbox"/> Buddhist | <input type="checkbox"/> Catholic | <input type="checkbox"/> Christian |
| <input type="checkbox"/> Jewish | <input type="checkbox"/> Hindu | <input type="checkbox"/> Lutheran | <input type="checkbox"/> Muslim | |
| <input type="checkbox"/> Prefer not to answer | | | | |
| <input type="checkbox"/> Other (<i>write in</i>): _____ | | | | |

Part II. Preparation in Palliative and End-of-Life Care

Preparation to provide Quality Palliative and EOL Care

(Fill in one circle on each line in this column)

| | <i>Not well Prepared</i> | | <i>Somewhat Prepared</i> | | <i>Very well Prepared</i> |
|--|------------------------------|-----------------------|------------------------------|-----------------------|-------------------------------|
| 1. Overall preparation: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2. Breaking bad news to a patient and family: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3. Participating in end-of-life discussions: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. Addressing pain at the end of life: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5. Addressing non-pain symptoms at the end of life: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6. Addressing patients' and families' emotional suffering at the end of life: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7. Working as a member of an interdisciplinary care team: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8. Addressing a patient and family's need for information: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9. Addressing end of life care decisions, such as a DNR decision, with a patient and family: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10. Assessing caregiver needs at end-of-life care: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 11. Addressing ethical issues that arise in caring for patients near the end of life: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12. Discussing options such as palliative care consultation, going home with hospice with patients and families: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

- | | <i><u>Not well
Prepared</u></i> | | <i><u>Somewhat
Prepared</u></i> | | <i><u>Very well
Prepared</u></i> |
|--|-------------------------------------|-----------------------|-------------------------------------|-----------------------|--------------------------------------|
| 13. Communicating with a family after their child has died: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 14. Addressing the bereavement process of family members: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 15. Addressing spiritual issues: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 16. Addressing cultural differences related to end-of-life care: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 17. Addressing age-related developmental differences in end-of-life care: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 18. Addressing the overall care of an imminently dying child and their family: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

How interested are you in obtaining additional clinical training in these areas:

- | | <i><u>Not at all
Interested</u></i> | | <i><u>Somewhat
Interested</u></i> | | <i><u>Very
Interested</u></i> |
|---|---|-----------------------|---------------------------------------|-----------------------|-----------------------------------|
| 1. Addressing the psychosocial needs of patients near the end of life and their families (e.g., breaking bad news, assessing and treating depression, helping families during bereavement)? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2. Addressing pain and other physical symptoms for patients near the end of life? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3. Working within an interdisciplinary care team? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. Helping families through the difficult process of decision-making and helping further elicit their understanding of prognosis, goals and treatment options? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Part III. Attitudes about End-of-Life Scale.

(fill in one circle on each line)

Strongly
Disagree Disagree Agree Agree
Strongly

1. There is little the physician/nurse can do to ease the suffering of grief.
☐ ☐ ☐ ☐
2. The physician/nurse has a responsibility to provide bereavement care to the patient's family members after death.
☐ ☐ ☐ ☐
3. Even at the very end, it is important to emphasize hope.
☐ ☐ ☐ ☐
4. Members of the medical team have an obligation to tell patients when death is imminent.
☐ ☐ ☐ ☐
5. It is not possible to tell patients the truth about a poor prognosis and maintain hope.
☐ ☐ ☐ ☐
6. In communicating with dying patients, it is important to protect them from information about what the process of dying is like.
☐ ☐ ☐ ☐
7. Psychological suffering can be as severe as physical suffering.
☐ ☐ ☐ ☐
8. At their request, patients at the end of life should be given whatever medications are necessary to relieve pain, even if the medications may potentially hasten death.
☐ ☐ ☐ ☐
9. Depression is normal in patients at the end of life.
☐ ☐ ☐ ☐
10. Talking about death tends to make patients with advanced illnesses more discouraged.
☐ ☐ ☐ ☐
11. Family members tend to interfere in the care of patients with advanced illnesses.
☐ ☐ ☐ ☐

Strongly
Disagree Disagree Agree *Strongly*
Agree

12. The physician's/nurse's responsibility is to the patient; other professionals should deal with the needs of the family.
- ☐ ☐ ☐ ☐
13. Physicians/nurses have a responsibility to help patients prepare for death.
- ☐ ☐ ☐ ☐
14. The physicians/nurse's role is to prolong life as long as possible.
- ☐ ☐ ☐ ☐
15. An interdisciplinary team approach to terminal illness treats patients' medical needs better than conventional care.
- ☐ ☐ ☐ ☐

Study ID# _____ Post-Seminar Palliative and End-of-Life Care Survey

Part I. Seminar and Competency Rating

Please rate your level of agreement with the following statements.

The seminar and competency-based material has improved my ability to...

| | <i>Strongly Disagree</i> | <i>Disagree</i> | <i>Agree</i> | <i>Strongly Agree</i> |
|---|------------------------------|-----------------------|-----------------------|---------------------------|
| 1. address the suffering of my patients and families | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2. implement a patient- and family-centered care plan | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3. think through an ethically challenging issue in my patient | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. work in a truly interdisciplinary manner | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5. communicate with other disciplines and across care settings | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6. address my patients' distressing symptoms | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7. address social, emotional and spiritual issues in my patients and families | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8. address issues surrounding my patients' end of life care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9. help care for a family after the death of their child | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Preparation to provide Quality Palliative and EOL Care. Please answer the pre-program questions regarding how you feel *now* about how prepared you were at the start of the session
(Fill in one circle on each line in this column)

| | <u>Not well</u> <u>Prepared</u> | | <u>Somewhat</u> <u>Prepared</u> | | <u>Very well</u> <u>Prepared</u> |
|--|------------------------------------|-----------------------|------------------------------------|-----------------------|-------------------------------------|
| 5. Overall preparation: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6. Breaking bad news to a patient and family: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3. Participating in end-of-life discussions: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. Addressing pain at the end of life: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5. Addressing non-pain symptoms at the end of life: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6. Addressing patients' and families' emotional suffering at the end of life: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7. Working as a member of an interdisciplinary care team: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8. Addressing a patient and family's need for information: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9. Addressing end of life care decisions, such as a DNR decision, with a patient and family: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10. Assessing caregiver needs in end-of-life care: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

(Fill in one circle on each line in this column)

| | <u>Not well</u> <u>Prepared</u> | | <u>Somewhat</u> <u>Prepared</u> | | <u>Very well</u> <u>Prepared</u> |
|--|------------------------------------|-----------------------|------------------------------------|-----------------------|-------------------------------------|
| 11. Addressing ethical issues that arise in caring for patients near the end of life: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12. Discussing options such as palliative care consultation and/or going home with hospice with patients and families: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 13. Communicating with a family after their child has died: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 14. Addressing the bereavement process of family members: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 15. Addressing spiritual issues: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 16. Addressing cultural differences related to end-of-life care: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 17. Addressing age-related developmental differences in end-of-life care: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 18. Addressing the overall care of an imminently dying child and their family: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

How interested are you in obtaining additional clinical training in these areas:

Not at all *Somewhat* *Very*
Interested Interested Interested

- a. Addressing the psychosocial needs of patients near the end of life and their families (e.g., breaking bad news, assessing and treating depression, helping families during bereavement)?

☐ ☐ ☐ ☐ ☐

- b. Assessing and treating pain and other physical symptoms for patients near the end of life?

☐ ☐ ☐ ☐ ☐

II. Overall Experience and Feedback

Please fill in one circle on each line:

Strongly *Strongly*
Disagree Disagree Neutral Agree Agree

1. As a result of participation in this seminar, I feel more prepared to take care of patients and families at the end of life.

☐ ☐ ☐ ☐ ☐

2. As a result of participation in this educational session, I believe that the content of my discussions with my patients and their families will be improved.

☐ ☐ ☐ ☐ ☐

3. I believe that this QOL seminar was useful in my education.

☐ ☐ ☐ ☐ ☐

4. Please tell us about your experience working with the bereaved parents at the QOL seminar today.

5. What suggestions would you provide to help improve this session for the future?

Supplemental Material B

Delivering Bad News New Fellow Orientation

Role-play Session – Facilitator Guide

Please arrive at the training 30 minutes early. We will run through the plan for the session as a group and set up the room prior to the arrival of the fellow trainees. We will have copies of the facilitator guides and communication cards available on site.

Small group facilitator pairs are as follows:

Team A – Parent + Faculty

Team B - Parent + Faculty

Team C - Parent + Faculty

Team D - Parent + Faculty

Team E - Parent + Faculty

Didactics, video, and Group intro (25 minutes; 8:00-8:25)

Faculty facilitators to give brief introduction including their current roles and review background on communication using PowerPoint. Brief introduction to communication cards.

Parent introduction (5 minutes)

Each parent will introduce themselves and tell their story including how they became involved with the hospital and the current project on communication training

- *Please emphasize that fellows should not feel pressure to “be perfect” as this is a practice session. It may also be helpful to give permission to fellows to “ask anything” and be open to suggestions and feedback.*

Group Introductions/Warm Up (5 minutes)

- Brief Introductions of clinical fellows in the group, ask fellows to include any experience they have had with delivering bad news to patients or families

Group Introduction to Role Play #1

Faculty to emphasize to group to NOT focus on details of treatment but practice phrases.

Model “What if...” statements, give example of “warning shot” for the group

Plan to focus on SPIKES and “I wish” statements

ROLE PLAY #1 (40 minutes; 8:35-9:15)

Have a fellow read the following scenario out loud to the group:

Bobby is a 14 year old male who was referred to your clinic after an Xray to evaluate for possible fracture showed a large lesion in his left femur.

The biopsy performed on the lesion in Bobby’s femur established a diagnosis of Ewing sarcoma. The initial staging evaluation showed multiple bilateral metastatic pulmonary nodules. You estimate his prognosis for long-term survival is 30%, but if the disease recurs he will have incurable disease.

- Each member of the group role play in pairs delivering this information to Bobby

If fellows become “stuck”, faculty facilitators to jump in and model/role play

Try to say in “role play” mode as much as possible, this allows more practice!

Things to highlight and have fellows practice:

- Elements of SPIKES: Perception, Invitation – *What have Bobby and his family heard? What do they want to know?*
- How to include Bobby in the discussion - *Be sure to include in this discussion how you will ask Bobby if he wants to be involved in the conversation and how much he knows and would like to know*
- Delivering the “warning shot”
- Giving the diagnosis of cancer – *Emphasize using this term during conversations*
- Giving the news simply, avoiding medical jargon
- Use of silence

- Different ways to discuss prognosis – numbers, general info, etc.
- Summary statements and follow-up
- After each learner has finished their role play, given feedback as a group. The learner should reflect on the following questions:
 - *How did that go for me?*
 - *What went well?*
 - *What could have gone better?*
- Feedback from the group on the above questions

Group Introduction to Role Play #2

Faculty to emphasize to group to NOT focus on details of treatment but practice phrases and ways of approaching the conversation.

Model “What if...” “I wish...” and “I’m worried...” statements prior to having a member of the group read the scenario aloud.

ROLE PLAY #2 (40 minutes; 9:15-9:55):

Bobby achieved a complete remission (CR) following induction chemotherapy. He had several hospitalizations for fever and neutropenia and lost about 15 pounds. Scans performed at the end of treatment confirmed a continued CR.

Six months after completion of treatment, Bobby is doing well, without pain or other symptoms. He has gained back the weight he lost and is attending school full time. Given the decrease in right lower extremity function, he can no longer participate in sports, but has developed an interest in theater and recently earned the lead role in his high school’s spring play.

Bobby’s 6 month routine surveillance scans unfortunately reveal new pulmonary nodules. He and one of his parents are in the exam room in your clinic, waiting to hear results of these scans. You must share this information; discuss prognosis and goals of care, and present therapeutic options including aggressive second-line chemotherapy or participation in a Phase 2 trial which has recently opened at your center.

- Each member of the group should role play as the physician delivering this information to Bobby and his parents
- Encourage groups to practice different phrases, using the time-out and time-in

Things for faculty to emphasize during role play:

- Be sure to have Bobby ask *“Am I going to die” and “How much time do I have?”*
- Use of a “warning shot”
- “What are you hoping for?”... “What else are you hoping for?”
- Use of THE W Statements: “I wish...” “I’m worried...” and “I wonder...”
- Invitation to discuss what happens if the tumor comes back or does not respond
- Focus on the adolescent patient during conversation

- Reframing statements- *“Given this news, it seems like a good time to talk about what to do now...”*
- What –if statements: *“We are hoping that these treatments may help. Would you like to talk about what we might consider if these treatments do not work?”*
- After each learner has finished their role play, given feedback as a group. The learner should reflect on the following questions:
 - *How did that go for me?*
 - *What went well?*
 - *What could have gone better?*
- Feedback from the group on the above questions

Break – 15 minutes (9:55-10:10)

ROLE PLAY #3 (45 minutes; 10:15-11:00):

Six weeks later, Bobby returns to the pediatric oncology clinic after having received 2 cycles of salvage or Phase 2 treatment. Both rounds of therapy were complicated by fatigue and anorexia. Bobby has attended school on a part time basis, but decided to drop out of the school play because of fatigue and the demands of coming to the hospital for treatment and transfusions.

Bobby has just undergone scan to evaluate his response to the most recent treatment. The chest CT demonstrates larger and more numerous pulmonary nodules. The PET scan shows an area of increased uptake in the L2 vertebral body.

Bobby and one of his parents are again waiting in your clinic exam room to hear the results of these scans. You will discuss prognosis and goals of care and present further treatment options including a Phase 1 or Phase 2 clinical trial, palliative chemotherapy and/or radiation therapy, and comfort measures alone.

- Each member of the group should role play as the physician delivering this information to Bobby and his parent

Things for faculty to emphasize during role play:

- Assess understanding
- Mirroring language used by patient and family
- NURSE Statements for empathy
- The use of silence
- “What are you hoping for?” ... “What else are you hoping for?”
- Use of THE W Statements: “I wish...” “I’m worried...” and “I wonder...” *“I wish there was more that we could do that would halt the progress of this disease, but none of the treatments we have are able to do this...”*
- Discussion of involvement of palliative care and hospice
- Willingness to give recommendations based on patient and families goals of care

Large group wrap-up – 15 minutes

- One thing I learned...
- One thing I struggled with...
- One thing I might do differently now...

Groups can spend about 5 minutes as a small group answering these questions.

Justin will then go around to each table to have them share their 3 points.

Parent panel – 30 minutes; 11:15-11:45

Parents will be asked to give trainees key pointers about communicating with patients and families. Open forum for questions from fellows.

Several questions for parents to consider (Faculty will ask if no questions from audience):

1. What would you recommend for caregivers to do if they don't have the "right words?" What if they say something that they wish they hadn't?
2. What was the most helpful thing that a physician told you during the course of your child's treatment and/or after their death?
3. What is the one piece of advice that you would give to our new fellows?
4. How was your child included in difficult conversations? How did your child's medical team include them in the discussion and how would you recommend this be done?

Encourage participants to complete the post-session survey prior to end of session. Thank you!!

Facilitator Debrief – 30 minutes; 12:00-12:30

Study ID# _____ Pre-Session Survey on Communication

Part I. Professional Background and Experience.

1. Please select your gender:

- ☐ Female ☐ Male ☐ Prefer not to answer

3. Age. Please select the range that includes your age (*check one*):

- ☐ 20-25 ☐ 26-30 ☐ 31-35
☐ 41-45 ☐ 46-50 ☐ 50+
☐ Prefer not to answer

4. Ethnicity. Please select your ethnicity (*check one*):

- ☐ Hispanic ☐ NOT Hispanic or Latino ☐ Unknown
☐ Prefer not to answer

5. Race. Please select your race:

- ☐ American Indian/Alaska Native ☐ White
☐ Asian ☐ African American
☐ Native Hawaiian or Other Pacific Islander ☐ Unknown / Not reported
☐ More than one race ☐ Prefer not to answer

6. Religion. Please select:

- ☐ Atheist ☐ Agnostic ☐ Buddhist ☐ Catholic ☐ Christian
☐ Jewish ☐ Hindu ☐ Lutheran ☐ Muslim ☐ Other
☐ Prefer not to answer

6. Please write your current Degree (s) _____

7. PGY year (as of July 2016):

- ☐ First-year fellow ☐ Second-year fellow ☐ Third year fellow
☐ Fourth-year fellow or beyond

8. What is your primary fellowship discipline? (*check one*):

- ☐ Pediatric Hematology/Oncology ☐ Infectious Disease
☐ Hospice and Palliative Medicine ☐ Surgery
☐ Neuro-Oncology ☐ Bone Marrow Transplantation
☐ Survivorship ☐ Other (*write in*) _____

9. How many times have you been the primary person to deliver bad news?

- | <u>None</u> | <u>1-2</u> | <u>3-10</u> | <u>11-20</u> | <u>>20</u> |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

10. How many times have you received teaching or feedback from a more senior physician regarding your delivery of bad news?

- | <u>None</u> | <u>1-2</u> | <u>3-10</u> | <u>11-20</u> | <u>>20</u> |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

11. How many formal didactic seminars/teaching sessions have you received on general communication skills (i.e., SPIKES model)?

- | <u>None</u> | <u>1-2</u> | <u>3-10</u> | <u>11-20</u> | <u>>20</u> |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

12. How many of these seminars included role playing or simulation?

| | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <u>None</u> | <u>1-2</u> | <u>3-10</u> | <u>11-20</u> | <u>>20</u> |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

13. How many formal didactic seminars/teaching sessions have you received specifically on delivering bad news?

| | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <u>None</u> | <u>1-2</u> | <u>3-10</u> | <u>11-20</u> | <u>>20</u> |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

14. How many seminars on delivering bad news included role playing or simulation?

| | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <u>None</u> | <u>1-2</u> | <u>3-10</u> | <u>11-20</u> | <u>>20</u> |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

15. How would you describe the quality of your formal training in the principles of delivering bad news?

| | | |
|-----------------------|-----------------------|-------------------------|
| <u>Not Sufficient</u> | <u>Adequate</u> | <u>More than Enough</u> |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

16. How would you describe the quality of the feedback you have received (formal or informal) on delivering bad news?

| | | |
|-----------------------|-----------------------|-------------------------|
| <u>Not Sufficient</u> | <u>Adequate</u> | <u>More than Enough</u> |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Part II. Preparation in Giving Bad News

Preparation to communicate effectively and empathetically with patients and families prior to this training session.

(Fill in one circle on each line in this column)

| | <i>Not well</i> | | <i>Somewhat</i> | | <i>Very well</i> |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| | <u>Prepared</u> | | <u>Prepared</u> | | <u>Prepared</u> |
| 7. Overall preparation: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8. Breaking bad news to a patient and family: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9. Participating in end-of-life care discussions: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10. Leading end-of-life care discussions: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 11. Working as a member of an interdisciplinary care team: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12. Addressing a patient's and family's need for information: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 13. Addressing patients' and families' emotional suffering at the end of life: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 14. Addressing if/when the patient should be included in the discussion: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 15. Including the patient in the discussion (adolescent and young adult): | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

16. Including the patient in the discussion (young children <13 years):
☐ ☐ ☐ ☐ ☐
17. Addressing end of life care decisions, such a decision regarding resuscitation status (DNR or POST) with a patient and family:
☐ ☐ ☐ ☐ ☐
18. Making a recommendation for no further intensive or cure-directed therapy.
☐ ☐ ☐ ☐ ☐
19. Making a recommendation to discontinue artificial life-sustaining measures such as mechanical ventilation:
☐ ☐ ☐ ☐ ☐
Not well *Somewhat* *Very well*
Prepared Prepared Prepared
20. Discussing options such as transfer to inpatient hospice or going home with hospice:
☐ ☐ ☐ ☐ ☐
21. Addressing cultural differences related to communication:
☐ ☐ ☐ ☐ ☐
22. Addressing age-related and/or developmental differences in communication:
☐ ☐ ☐ ☐ ☐
23. Communicating with a family after their child has died:
☐ ☐ ☐ ☐ ☐

Part III. Attitudes about Communication at the End of Life

Fill in one circle on each line

Strongly

Strongly

Disagree *Disagree* *Agree* *Agree*

8. Even at the very end of life, it is important to emphasize hope.
☐ ☐ ☐ ☐
9. Physicians have an obligation to tell patients when death is imminent.
☐ ☐ ☐ ☐
10. It is not possible to tell patients the truth about a terminal prognosis and maintain hope.
☐ ☐ ☐ ☐
11. In communicating with dying patients, it is important to protect them from information about what the process of dying is like.
☐ ☐ ☐ ☐
5. Talking about death tends to make patients with terminal illnesses more discouraged.
☐ ☐ ☐ ☐
6. The physicians' role is to prolong life as long as possible.
☐ ☐ ☐ ☐
7. An interdisciplinary team approach to end-of-life care treats patients' medical needs better than conventional care.
☐ ☐ ☐ ☐

Study ID# _____

Post-Seminar Palliative and End-of-Life Care Survey

I. Preparation in Palliative and End-of-Life Care.

Preparation to communicate effectively and empathetically with patients and families prior to this training session. Please answer the pre-program questions regarding how you feel *now* about how prepared you were at the *start* of the session

(Fill in one circle on each line in this column)

| | Not well | | Somewhat | | Very well |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| | <u>Prepared</u> | | <u>Prepared</u> | | <u>Prepared</u> |
| 24. Overall preparation: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 25. Breaking bad news to a patient and family: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3. Participating in end-of-life care discussions: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. Leading end-of-life care discussions: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Post-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5. Sharing prognostic information with patients and families: | | | | | |
| a. Pre-program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

b. Post-program ☐ ☐ ☐ ☐ ☐

6. Working as a member of an interdisciplinary care team:

a. Pre-program ☐ ☐ ☐ ☐ ☐

b. Post-program ☐ ☐ ☐ ☐ ☐

7. Addressing a patient's and family's need for information:

a. Pre-program ☐ ☐ ☐ ☐ ☐

b. Post-program ☐ ☐ ☐ ☐ ☐

8. Addressing patients' and families' emotional suffering at the end of life:

a. Pre-program ☐ ☐ ☐ ☐ ☐

b. Post-program ☐ ☐ ☐ ☐ ☐

9. Addressing if/when the patient should be included in the discussion:

a. Pre-program ☐ ☐ ☐ ☐ ☐

b. Post-program ☐ ☐ ☐ ☐ ☐

Preparation to communicate effectively and empathetically with patients and families prior to this training session. Please answer the pre-program questions regarding how you feel *now* about how prepared you were at the *start* of the session

(Fill in one circle on each line in this column)

Not well

Somewhat

Very well

Prepared

Prepared

Prepared

10. Including the patient in the discussion (adolescent and young adult):

- a. Pre-program ☐ ☐ ☐ ☐ ☐
- b. Post-program ☐ ☐ ☐ ☐ ☐

11. Including the patient in the discussion (young children <13 years):

- a. Pre-program ☐ ☐ ☐ ☐ ☐
- b. Post-program ☐ ☐ ☐ ☐ ☐

12. Addressing end of life care decisions, such a decisions regarding resuscitation status (DNR or POST) with a patient and family:

- a. Pre-program ☐ ☐ ☐ ☐ ☐
- b. Post-program ☐ ☐ ☐ ☐ ☐

13. Making a recommendation for no further intensive or cure-directed therapy:

- a. Pre-program ☐ ☐ ☐ ☐ ☐
- b. Post-program ☐ ☐ ☐ ☐ ☐

14. Making a recommendation to discontinue artificial life-sustaining measures such as mechanical ventilation:

- a. Pre-program ☐ ☐ ☐ ☐ ☐
- b. Post-program ☐ ☐ ☐ ☐ ☐

15. Discussing options such as transfer to inpatient hospice or going home with hospice services:

- a. Pre-program ☐ ☐ ☐ ☐ ☐
- b. Post-program ☐ ☐ ☐ ☐ ☐

16. Addressing cultural differences related to communication:

- a. Pre-program ☐ ☐ ☐ ☐ ☐
- b. Post-program ☐ ☐ ☐ ☐ ☐

17. Addressing age-related and/or developmental differences in communication:

- a. Pre-program ☐ ☐ ☐ ☐ ☐
- b. Post-program ☐ ☐ ☐ ☐ ☐

18. Communicating with a family after their child has died:

- a. Pre-program ☐ ☐ ☐ ☐ ☐
- b. Post-program ☐ ☐ ☐ ☐ ☐

II. Overall Experience and Feedback

Please fill in one circle on each line:

Strongly

Strongly

DisagreeDisagreeNeutral

Agree

Agree

4. As a result of participation in this educational session, I feel more prepared to have difficult conversations with my patients and their families.

○ ○ ○ ○ ○

5. As a result of participation in this educational session, I believe that the content of my discussions with my patients and their families will be improved.

○ ○ ○ ○ ○

6. I believe that this communication session was useful in my education.

○ ○ ○ ○ ○

4. Please tell us about your experience working with the bereaved parent educators.

5. Please tell us about your experience with case-based learning approach and role playing at this session today.

6. What suggestions would you provide to help improve this session for future trainees?