

HOPE AND INFORMATION PROJECT

INTERVIEWER GUIDE: PHYSICIAN RESPONDENTS

INTRODUCTION:

We would like to learn about how doctors and nurses work with patients in their need for hope, on the one hand, and information about their illness, on the other. As you know, your patient(s) [name1] and [name2] have enrolled in this project, so we'd like to talk to you about hope and information in your clinical work with them.

But before we start talking about patient [name1] we'd like to find out what you think generally about the balance of hope and information in clinical work with patients with a life-threatening illness.

1. Medical literature suggests that many doctors are challenged by the need to provide patients with accurate information, on the one hand, while maintaining patient hope on the other hand.

- What is your reaction to this statement?
- Have you experienced a challenge or tension in providing both hope and information to your patients?
- How much do you find that tension concerns you?
- How do you deal with it?

FIRST PATIENT

2a. Now let's talk about [patient name1].

- How long have you cared for (patient name)?
- Tell me how his/her illness has gone.

HOPE:

3a. Is hope important to this patient?

- What does he/she hope for?
- How have you approached this patient's need for hope?
- Has this patient's hope changed over time? [if so, how?]
- Is hope a good thing for this patient to have?

DEATH AND DYING CONCERNS

4a. Have you discussed prognosis with this patient?

- *If yes...* Tell me about the first conversation with this patient around prognosis.
- What did you tell him/her?
- How did he/she respond?
- What did it do to his/her hope?
- Did the patient seem to feel the conversation went well?
- How did you feel about this discussion?

5a. Have you ever given this patient very bad news other than prognostic information?

- *If yes...* Tell me about that situation.
- How did you provide the bad news?
- How did he/she respond?
- What did this do to his/her hope?
- How did you feel about this information sharing?
- Is there anything you would have done differently?

6a. Have you talked about death and dying with this patient?

- If NO, why not?
- How concerned is this patient with dying? How do you know?
- How does he/she express his/her concern?
- How did you respond?
- How does this affect your communication/information sharing with the patient?
- Do you think talking about death and dying has affected this patient? How?

ABANDONMENT VS REASSURANCE:

7a. Has this patient expressed to you things that are important to him/her, such as family, maintaining hope, reaching some milestone, or anything else?

8a. Have you been able to offer this patient emotional support?

- How were you able to do that?

AVOIDANCE OF TRUTH VS FULL DISCLOSURE

9a. If you had to characterize this patient's need for information on the following continuum, where would you put him/her?

- I prefer to have all the information about my illness.
- I prefer that the doctor decide how much information to give me about my illness.
- I prefer that the doctor and I decide together how much information I will have about my illness.

10a. How did you figure that out for this patient?

- What cues did you use? (Probe affective and cognitive cues)

11a. How have you approached this patient's need for information?

12a. Have you ever been hesitant to give bad news because it might affect the patient's hope?

- How did that affect what you did and said with this patient?

13a. Have you ever found yourself being more optimistic than is warranted with this patient?

- What led you to be overly optimistic with this patient?
- Probe how related to hope.

14a. Thinking about the information continuum again, can you think of patients you've worked with whose need for information was different from [patient name1]?

- How would you approach those patients' need for information? Would it differ from [patient name1]?
- Would your role change?

15a. Now that we've talked about your patient's information needs, I'd like to ask you about how treatment decisions are made. If you had to characterize this patient's preference around treatment decisions on the following continuum, where would you put him/her?

- I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.
 - I prefer that my doctor makes the final decision about my treatment, but seriously considers my opinion.
 - I prefer that my doctor and I share responsibility for deciding which treatments are best for me.
- How did you figure that out for this patient?
 - What cues did you use? (Probe affective and cognitive cues)

BALANCE HOPE/INFORMATION VS TENSION

16a. With this patient, do you feel a tension between the need to provide hope on the one hand, and realistic information on the other?

- How have you handled that tension with this patient?
- How do you balance hope and information with this patient?

17a. Do you think you have done a good job with this patient in managing hope and information? Why or why not?

- What is a “good job”?
- How do you know you’ve done a good job?

18a. If you could start over with this patient, what might you do differently?

SECOND PATIENT

2b. Now let’s talk about [patient name2].

- How long have you cared for (patient name)?
- Tell me how his/her illness has gone.

HOPE:

3b. Is hope important to this patient?

- What does he/she hope for?
- How have you approached this patient’s need for hope?
- Has this patient’s hope changed over time? [if so, how?]
- Is hope a good thing for this patient to have?

DEATH AND DYING CONCERNS:

4b. Have you discussed prognosis with this patient?

- *If yes...* Tell me about the first conversation with this patient around prognosis.
- What did you tell him/her?
- How did he/she respond?
- What did it do to his/her hope?
- Did the patient seem to feel the conversation went well?
- How did you feel about this discussion?

5b. Have you ever given this patient very bad news other than prognostic information?

- *If yes...* Tell me about that situation.
- How did you provide the bad news?
- How did he/she respond?
- What did this do to his/her hope?
- How did you feel about this information sharing?
- Is there anything you would have done differently?

6b. Have you talked about death and dying with this patient?

- If NO, why not?
- How concerned is this patient with dying? How do you know?
- How does he/she express his/her concern?
- How did you respond?
- How does this affect your communication/information sharing with the patient?
- Do you think talking about death and dying has affected this patient? How?

ABANDONMENT VS REASSURANCE:

7b. Has this patient expressed to you things that are important to him/her, such as family, maintaining hope, reaching some milestone, or anything else?

8b. Have you been able to offer this patient emotional support?

- How were you able to do that?

AVOIDANCE OF TRUTH VS. FULL DISCLOSURE:

9b. If you had to characterize this patient's need for information on the following continuum, where would you put him/her?

- I prefer to have all the information about my illness.
- I prefer that the doctor decide how much information to give me about my illness.
- I prefer that the doctor and I decide together how much information I will have about my illness.

10b. How did you figure that out for this patient?

- What cues did you use? (Probe affective and cognitive cues)

11b. How have you approached this patient's need for information?

12b. Have you ever been hesitant to give bad news because it might affect the patient's hope?

- How did that affect what you did and said with this patient?

13b. Have you ever found yourself being more optimistic than is warranted with this patient?

- What led you to be overly optimistic with this patient?
- Probe how related to hope.

14b. Thinking about the information continuum again, can you think of patients you've worked with whose need for information was different from [patient name2]?

- How would you approach those patients' need for information? Would it differ from [patient name2]?
- Would your role change?

15b. Now that we've talked about your patient's information needs, I'd like to ask you about how treatment decisions are made. If you had to characterize this patient's preference around treatment decisions on the following continuum, where would you put him/her?

- I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.
 - I prefer that my doctor makes the final decision about my treatment, but seriously considers my opinion.
 - I prefer that my doctor and I share responsibility for deciding which treatments are best for me.
- How did you figure that out for this patient?
 - What cues did you use? (Probe affective and cognitive cues)

BALANCE HOPE/INFORMATION VS TENSION

16b. With this patient, do you feel a tension between the need to provide hope on the one hand, and realistic information on the other?

- How have you handled that tension with this patient?
- How do you balance hope and information with this patient?

17b. Do you think you have done a good job with this patient in managing hope and information? Why or why not?

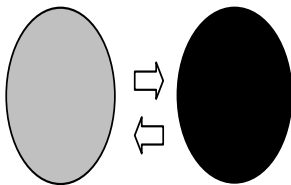
- What is a “good job”?
- How do you know you’ve done a good job?

18b. If you could start over with this patient, what might you do differently?

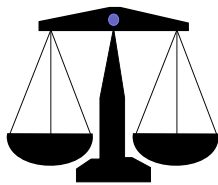
DIAGRAMS:

I'm going to show you four figures, with stories from patients who explain how they deal with their illness. I'd like to get your reactions to these. Look at these diagrams and quotes.

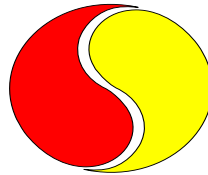
Alternate existence of hope and truth



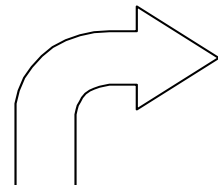
Balance of hope and truth



Harmonious integration of hope and truth



Redirection of hope



Quotes:

- 1) *It's been hard since I heard the bad news about my disease. Sometimes I feel very hopeful and think positively about the future. Other times, I feel fearful and sad because I know how serious my illness is. I seem to go back and forth between those two feelings.*
- 2) *I have to keep things balanced. I want information about my illness, but too much information makes me depressed. Also, I want to be hopeful but I know that I can't be too hopeful because that's not realistic. So I kind of maintain a balance between the two.*
- 3) *I seem to be able to hear bad news about my illness and yet hold onto hope – both at the same time. I know that my illness is very serious, and yet I also know that I must maintain my hope, and somehow I'm able to do both of those. They're both there at the same time.*
- 4) *I used to hope for survival but now what's important to me has changed. Now I hope for other things.*

Now I'd like to talk about [patient 1].

- Which of these do you feel best describes the experience that [patient 1] has had?
- What would be helpful for a doctor to do to with a patient who felt this way?
- What would be helpful for a nurse to do to with a patient who felt this way?
- How have you addressed this reaction with [patient 1]?

Now I'd like to talk about [patient 2].

- Which of these do you feel best describes the experience that [patient 2] has had?
- What would be helpful for a doctor to do to with a patient who felt this way?
- What would be helpful for a nurse to do to with a patient who felt this way?
- How have you addressed this reaction with [patient 2]?

GENERAL QUESTIONS:

(To be asked after you have talked about both patients)

19. Do you think that your approach has changed over time? How?

20. Let's say that you were invited to Grand Rounds to talk about how to share information with patients with life threatening illnesses. What suggestions would you be sure to include for new doctors?

- 21. Are some doctors too optimistic or too pessimistic when sharing information with patients?**
- How does this affect care and decisions made?
- 22. Have you ever been in a position where you someone became deeply depressed because you gave them full information?**
- What happened?
 - What do you do to help patients maintain a balance of hope and information?

Now, I'd like to switch gears a little bit. As you know, we are interested in the experiences of doctors from different practice types. Some doctors say that their practice setting affects how they communicate with their patients.

- 23. Are there characteristics of how your practice works or runs that affects how you handle information and hope with this patient?"**
- 24. Is there anything else that you feel we should know about your experience in balancing hope and information with terminally ill patients?**
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