

HOPE AND INFORMATION PROJECT

INTERVIEWER GUIDE: NURSE RESPONDENTS

INTRODUCTION:

We would like to learn about how nurses and doctors work with patients in their need for hope, on the one hand, and information about their illness, on the other. As you know, [patient name] has enrolled in this project and suggested that we talk to you. We'd like to ask you about hope and information in your clinical work with them.

But before we start talking about [patient name], 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 nurses are challenged by the need to provide patients with accurate information, on the one hand, while maintaining patient hope on the other hand.

- What do you think about 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?

2. Now let's talk first about [patient name].

- Can you tell me about your relationship with this patient?
- Tell me briefly how his/her illness has gone.

HOPE:

3. 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?

4. Do you know if this patient has talked with his/her doctor about his/her hopes?

- *If yes*, can you tell me more about that?
- *If no*, do you think this patient would like to talk with his/her doctor about his/her hopes? Why or why not?

DEATH & DYING CONCERNS:

5. Has this patient talked about his/her prognosis with you?

- If so, how did the topic come up?
- What did you say and how did he/she respond?

6. Do you know if this patient has talked about his/her prognosis with his/her doctor?

- *If yes*, how did the patient feel about that conversation?
- *If no*, do you get the sense he/she would like to have that conversation?

7. Does this patient want to know that his/her illness may be terminal?

- What led you to that conclusion?

8. 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?

9. In your estimation, how concerned is this patient about dying?

- How does he/she express his/her concern?
- How do you respond?

ABANDONMENT VS REASSURANCE:

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

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

- How were you able to do that?

AVOIDANCE OF TRUTH VS FULL DISCLOSURE:

12. 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.*

13. How did you figure that out for this patient?

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

14. How important do you think receiving information—including prognosis and any bad news—is to this patient?

15. How much information have you given this patient about his/her illness?

- What is the nature of the information you have given the patient?
- Probe types of information: diagnosis, prognosis, treatment

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

17. Do you think this patient has received as much information about his/her illness and prognosis as he/she wants?

- Can you give me a situation or example of information sharing with this patient?
- Ask about situation that is different than the one described.
 - *If talks about positive situation*, ask about any that haven't gone as smoothly.
 - *If talks about difficult situation*, ask about one that went more smoothly.

18. Have you ever been hesitant to give bad news to this patient?

- What were your concerns/perceived risks of giving information?
- Probe fears of destroying patient's hope.
- How did that affect what you did and said with this patient?

19. Do you think that other health care providers have been hesitant to give bad news to this patient?

- Tell me more about that.

20. 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.

21. Now that we've talked about this 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:

At the beginning of this conversation, you talked about managing hope and information with patients with life threatening illnesses. Now thinking about this patient ...

22. 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?

23. Throughout this patient's medical care—whether from you, his/her physicians, or anyone else—do you think that the patient's need for hope, information, or a balance of the two has been handled well?

- What could have been done better?

24. 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?

FAMILY MEMBERS:

25. How has this patient's family been involved in his/her care?

- How important has this patient's family been in his/her care?
- What role has the family played in his/her care?

26. Do the patient and his/her family seem to be on the same page about their need for hope and information?

- Tell me more about that.
- What tells you that they are/are not on the same page?

27. Have you talked with the family about the patient?

- *If yes*, have you talked about the family's hopes for the patient?
- *If yes*, have you given the family information about the patient's illness and prognosis?

28. With this family, do you feel a tension between the need to provide hope, on the one hand, and realistic information about the patient's illness on the other?

- *If yes*, how have you handled that tension with this family?
- How have other health care providers who work with the family handled that tension?

GENERAL QUESTIONS:

(Probe examples and specific situations)

29. Based on your experiences working with patients with terminal illnesses, do you have an approach you use to address dying patients' need for hope, on the one hand, and full information about their illness and prognosis, on the other hand?

30. In general, how important would you say *nurses* are in sustaining patients' hope?

31. How important are *nurses* in providing patients with information about their illness?

32. If you were asked to give some suggestions for *nurses* in helping patients with terminal illnesses cope with the need for hopeful and realistic information, what would you be sure to include?

33. If you were asked to give some suggestions for *doctors* in helping patients with terminal illnesses cope with the need for hope and realistic information, what would you include?

34. How could systems or clinical teams work better around handling hope and information with patients with life-threatening illnesses?

35. When it comes to patient's need for hope and information, what do *nurses* tend to do well and what could they do better?

36. What are the barriers to communicating hope and information to patients with life-threatening illness?

- Probe: time constraints, poor communication with MD, system issues.

37. How could systems or clinical teams work better around handling hope and information with patients with life-threatening illnesses?

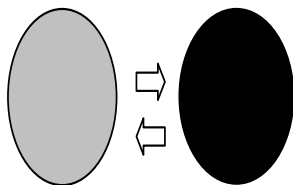
38. Do you have a philosophy or belief system that influences the way you provide care to people with life-threatening illnesses?

39. Is there anything else that you feel we should know about your experience in balancing hope and information with patients with life threatening illnesses?

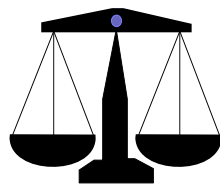
DIAGRAMS:

I'm going to show you three 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.

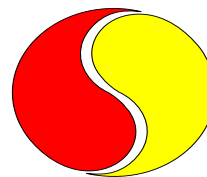
Alternate existence of hope and truth



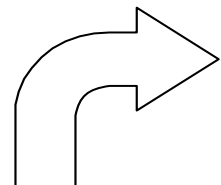
Balance of hope and truth



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 name].

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