

HOPE AND INFORMATION PROJECT

INTERVIEWER GUIDE: PATIENT RESPONDENTS

Introduction

We would like to learn how people talk with their doctors and nurses about their health especially around their hope and how they receive the information they want.

I'd like to start this interview by hearing about your experiences since you were told about your condition. Remember that you are the expert here, and I want to learn from you.

Would you mind telling me about the story of your illness, the ups and downs of what you have been through and are going through?

HOPE: Beliefs: Illness

1. Thinking broadly, or in a more general way, can you tell me what comes to mind when I say the word, “hope”? What does that mean for you personally?

- When someone says something like “I have a lot of hope.” What does that mean?
- Can you tell me what things come to mind when I just say the word “hope”?
(If respondent doesn't embrace the term “hope”, use his/her language – can skip to #3.)

2. In terms of your illness, what gives you hope?

- What are the sorts of things you are wishing for, or hope will happen?
- Are there things that take away your hope in the face of your illness?

3. For some people, their hope (or attitude, way of dealing with their illness) changes over time with what's going on in their lives. Would you say that your hope has changed since you became ill?

- If your hope has changed, how has it changed?
- Probe sentinel events – when you were diagnosed how would describe your hope; now how is hope?
- Probe response of physicians to changing hope.

Ask about fears as the flip-side of hope.

What are your fears around your illness?

Have your fears changed over time?

How has your MD affected your fears?

SPIRITUALITY: OPTIMISM

- 4. Do you think your personal beliefs, your spiritual belief, or faith play a role in your hope (or attitude, way of dealing with your illness)?**

CLINICIANS:

For the next questions, I'd like you to think about a doctor who is taking care of you now. Consider what he or she has done to affect your hope and how you deal with your illness.

- 5. Can you think of specific things or give an example of something that your doctor did or said - something that gives you hope – or takes away hope?**
 - Think of a time when your doctor gave you hope. What did he/she do to give you hope?
 - Similarly, think of a time when a doctor took away your hope. What did he/she do to make you feel without hope?

What has your doctor done to affect your fears?

What has your doctor done to help you “keep going”?

- 6. How much attention does your doctor pay or give to your hope?**

- 7. Is there a nurse or another member of your health care team who is important to you?**
(Refer back to this person as appropriate)

INFORMATION: Avoidance of Truth vs. Full Disclosure: Physician's Role

Next, we'd like to talk about the information doctors share with their patients. We know from our work in this area that patients vary as to how much information they want from their doctors regarding their disease and the seriousness of their illness.

Some people say:

- *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.*

8. In your conversations with your doctor(s), how much information do you want to hear about your illness?

(Clarify response for placement in one of three categories.)

- What kinds of information do you want? (e.g., about treatment, prognosis, medication, how the illness will affect life/functioning, diagnosis, symptoms, and death/dying).

9. Have you talked to your doctor about how much information you would like?

10. What about your doctor? Where would he/she be on this line?

11. What cues did you get from your doctor that told you this?

12. Has the amount of information you want to know about your illness changed over time?

13. How satisfied are you with the amount of information you have gotten from your doctor about your illness?

Now that we've talked about how much information you want from your doctor, we'd like to ask you about your feelings about how treatment decisions are made.

When we talk to patients, some people say:

- *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.*

14. Where would you place yourself in regards to how you prefer that treatment decisions are made?

15. Have you talked with your doctor about how you would like decisions to be made?

16. Have your feelings around how treatment decisions are made changed over time?

BAD NEWS/TOUGH TIMES:

Now I'd like to ask you about some specific types of information patients get from doctors about their illness. Think of a time when you received some bad or discouraging news from your doctor.

17. How did your doctor handle this?

(Want specifics)

- Can you take me through what happened?

18. Was there ever a time when you went to see the doctor and you felt better afterward?

- What did you talk about or what did the doctor do?
- Have you ever felt better even if the news was discouraging or not so good?

19. Can you tell me of a time that was particularly tough for you (feelings of hopelessness)?

- What decision or changes did you make as a result of that experience?

20. Was your doctor aware that that time was very difficult for you?

- If **no**, probe for circumstances and whether patient would have wanted doctor to have been aware.
 - If you had a doctor's appointment scheduled during that tough time, what would you have wanted your doctor to do to be helpful?
- If **yes**, probe for circumstances.
 - How did your doctor show they were aware of this tough time?
 - How did this awareness affect you?
 - Do you wish they had done anything differently? What?

21. Have you ever had doctors who were afraid to talk about serious illness or to give you the full picture?

- What sort of difference did that make for you if any?

22. Have you ever had nurses who were afraid to talk about serious illness or to give you the full picture?

- What sort of difference did that make for you if any?

Ask only if appropriate

- Have you ever wondered about your doctor giving up on you?

BALANCING HOPE AND INFORMATION vs. Conflict, Imbalance:

We were just talking about communication with your doctor and getting bad news. For some people, keeping up hope in the face of bad news is a challenge and for others it is not.

23. How is it for you?

- Probe sentinel bad news events described earlier. Probe other experiences with discouraging news. Focus on hope.
- Have you ever experienced this as a conflict or does this feel like just part of the way things are?

24. What could your doctor and nurses do to help you balance [manage] having hope and getting information?

FAMILY MEMBERS:

Now I'd like to ask a few questions about your family.

25. What place do you feel your family plays in feelings around these topics?

26. How hopeful would you say they have been about your illness?

27. Do you think your feelings about your illness are the same as your family's feelings?

- *(If conflict)* **How does this affect you and your relationship with them, or the care you are receiving?**
- Probe for match or mismatch and what sorts of behaviors illustrate this and try to elicit what sorts of behaviors would be helpful.

HOPE: General: Direct Question

Some doctors and nurses tell us that when they care for patients with serious illnesses, they sometimes find it difficult to provide information and provide hope. They want to be completely honest with these patients about their illness but they also don't want to destroy their patients' hope.

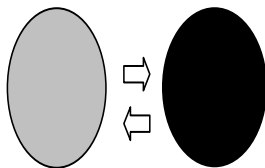
28. What do you think about that?

- What do you think that doctors and nurses who feel that conflict should do?
- What would be most helpful to patients?

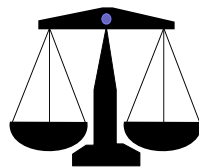
DIAGRAMS:

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

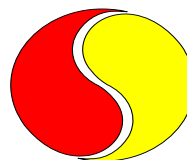
Alternate existence of hope and truth



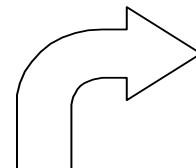
Balance of hope and truth



Harmonious integration of hope and truth



Redirection of hope



A. Look at this figure. (Circles) This relates to a patient with a serious illness who said,

“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.”

- Does this make sense to you?
- Does this describe an experience that you have had?
- (If yes) What would be helpful for a doctor or nurse to do to help you work through these different reactions?”

B. Look at this figure.(Scales) This relates to a patient who said,

“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.”

- Does this make sense to you?
- Does this describe a way that you have felt at any point?
- What would be helpful for a doctor or nurse to do when you felt this way?

C. Look at this diagram. (Yin-yang) This relates to a patient who said,

“I seem to be able to hear bad news about my illness and yet hold onto my 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.”

- Does this make sense to you?
- Does this describe a way that you have felt at any time?
- (if yes) what would be helpful for a doctor or nurse to do when you felt this way?

D. Look at this diagram. (Arrow) This relates to a patient who said,

“I used to hope for a cure but now what’s important to me has changed. Now I hope for other things.”

- Does this make sense to you?
- Does it describe a way that you have felt at any time?
- If yes, what would be helpful for a doctor or nurse to do when you felt that way?

29. What else would you like us to know about your interactions with your doctors and nurses around getting information you need and your hopes?
