HOPE AND INFORMATION PROJECT
INTERVIEWER GUIDE: FAMILY MEMBER RESPONDENTS

Introduction

We would like to learn how people talk with their doctors and nurses about the health of their family members, especially around 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 family member's 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 family member's illness, the ups and downs of what he/she has been 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 family member's illness, what gives you hope?**

    - What are the sorts of things you are wishing for, or hope will happen?…things that you are hopeful for – could be about disease itself, about treatment or separate from your family member's illness?
    - Are there things that take away your hope in the face of your family member's illness? *(Use examples from narrative as prompts if needed.)*

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 your family member became ill?**

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

CLINICIANS: Abandonment vs. Reassurance

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

4. **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?
    - Probe in relation to sentinel events.

5. **How much attention does your doctor pay or give to your hope and the hope of your family member?**

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

FAMILY VIEWPOINT/MATCH-MISMATCH:

I'm going to ask you a few questions about your family member and how similar your feelings are to his/her feelings.

7. **How hopeful would you say your loved one has been about his/her illness?**

8. **Are you and your loved one similar in how hopeful you are?**
    - How can you tell this? Probe cues, would others know this.
    - Probe value of similarity (good/bad).

9. **How does this affect you and your relationship with your loved one or the care you are providing?**
    - Probe easier/harder.

INFORMATION: Avoidance of Truth vs. Full Disclosure

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

Some people say:

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

10. **In your conversations with the doctor(s), how much information do you want to hear about your family member's illness?** *Clarify response for placement in one of three categories*.
    - Probe: 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).

11. **Have you talked to your family member's doctor about how much information you would like?**

12. **What about your family member's doctor? Where would he/she be on this line?** *(Remind of responses)*

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

14. **Has the amount of information you want to know about your family member's illness changed over time?**
    - Can you give an example of how what you wanted to know about your family member's illness has changed over time? If yes, in what ways?

15. **Have you ever talked with your family member's doctor by yourself, without your loved one present?**
    - Tell me about a time that you did this.

17. **Does the doctor give you and your family member different amounts of information about your family member's illness?**

  - Is what the doctor says/how he/she interacts with you versus your family member different?
  - If so, how do you feel about the difference in information?

18. **How satisfied are you with the amount of information you have gotten from your doctor about your family member's illness?**

Now we'd like to ask you about your feelings about how treatment decisions are made. When we talk to family members of patients, some people say, in an ideal world:

- *The doctor would make all the decisions about my family member's illness.*
- *My family member would make the final decision about their treatment.*
- *The doctor and my family member would share the responsibility for deciding which treatments are best for my family member.*

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

20. **Have you and your family member's doctor talked about how you would like decisions to be made?**

21. **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 people get from doctors about their family members' illnesses. Think of a time when you received some bad or discouraging news from your family member's doctor.

22. **How did the doctor handle this?**
    (Want specifics)

    - Can you take me through what happened?
    - What did he/she do?
    - Was this any different from when you have received good news?
    - What was it like to receive that news? (Probe emotional and cognitive responses.)

23. **Can you tell me of a time in your family member's illness that was particularly tough for you (feelings of hopelessness)?**

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

24. Was your family member's 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 attended a doctor's appointment during that tough time, what would you have wanted your doctor to do to be helpful?

- If **yes**, probe for circumstances.
  - How did the doctor show they were aware of this tough time?
  - How did this awareness affect you?
  - Do you wish they had done anything differently? What?

25. Was there ever a time when you went with your family member to see the doctor and you felt better afterward?

- What did you talk about or what did the doctor do?

26. Did the doctor ever tell you something that made you feel worse?

Ask only if appropriate

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

BALANCING HOPE AND INFORMATION vs. CONFLICT/IMBALANCE:

We were just talking about communication with your family member's 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.

27. How is it for you?

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

28. What could your family member's doctor and nurses do to help you balance [manage] having hope and getting information?

29. How important is it to you that your family member's doctor supports your hopes?

30. How well does your family member's doctor support your hopes?

31. **Has your family member's doctor ever talked to you about how you are doing with your family member's illness?**
    - *(if so)* How did he/she respond when you told him/her?
    - *(if not)* Do you wish that he/she would talk to you about how you are doing?

32. **What kind of support would you like to see doctors and nurses give family members concerning their loved one's illness?**

33. **From the doctor's perspective, we sometimes hear that when they care for patients with serious illnesses, they sometimes have a conflict. They want to be completely honest with patients and their families but they don't want to destroy their patients' or family members' hope. These doctors find that conflict difficult.**
    - What do you think about that?
    - What do you think that doctors who feel that conflict should do?
    - What would be most helpful to family members?

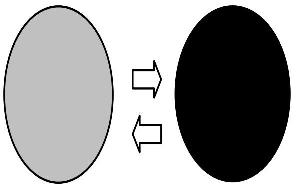
SPIRITUALITY: OPTIMISM

34. **Do you think your personal beliefs, your spiritual belief, or faith play a role in your hope about your family member's illness *(or attitude, way of dealing with your illness)*?**

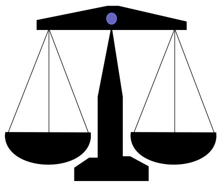
DIAGRAMS (optional):

I'm going to show you four figures, with stories from family members who explain how they deal with their loved one's illness. I'd like to get your reactions to these.

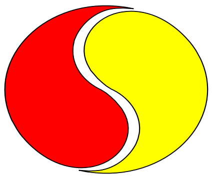
Alternate existence of hope and truth



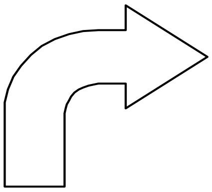
Balance of hope and truth



Harmonious integration of hope and truth



Redirection of hope



A. Look at this figure. [Back and forth] This relates to a situation in which a close relative of a patient with a very serious illness said,

"It's been hard since I heard the bad news about my spouse's disease. Sometimes I feel very hopeful and think positively about the future. Other times I feel fearful and sad because I know how serious their illness is. I seem to go back and forth between those two feelings."

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

B. Look at this figure. [Yin and yang] This relates to the son of a man who has a very serious, possibly terminal illness. The son said,

"I seem to be able to hear bad news about my dad's illness and yet hold onto my hope—both at the same time. I know that his illness is very serious, and yet I also know that I must maintain my hope that he will be okay, 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 you've felt at any point?
- If yes, what would be helpful for a doctor or nurse to do when you felt that way?

C. Look at figure. [Scales] A woman whose daughter had a very serious illness said,

"I have to keep things balanced. I wanted information about my daughter's 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 that 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?

D. Look at this figure. [Arrow] A spouse of a person with a very serious illness said,

"I used to hope for a cure for my wife but now what's important to me has changed. Now I hope for other things."

- Does that 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?
