

Appendix 9.3. Semistructured Interview Guide for Nursing Home Residents

Goal: Discover nursing home residents' expectations for high quality palliative care experiences and to identify areas for improvement in care delivery processes and outcomes.

Facilitators: Tobie Olsan, PhD, RN with assistance from Susan Ladwig, MPH, Project Coordinator to help with scheduling.

Introduction to the Interview with the Resident:

Hello Mr/Mrs _____, my name is _____, thank you so much for interviewing with me today. [Resident's understanding of the interview is reviewed before continuing].

I am working with researchers at the University of Rochester on a study to better understand how residents view their experience with care in nursing homes. Seeing the health care system through your eyes will help improve the ability of health care professionals to provide care in nursing homes. In this interview you are my teacher about what you expect from high quality care and to identify areas for improvement in care. I want to understand what matters to you and how to address challenges in terms of what could be done differently. Do you have any questions about the purpose of the interview?

I would like to talk with you for about 45 minutes to an hour, but if you are not able to talk that long please let me know when you are ready to end the interview. If you are still interested in talking with me after this first meeting, we can schedule a second session for an interview. I would like to tape record the interview so I can concentrate on our conversation and better remember what you said. Do you have any objections to me tape recording our interview?

Questions

NOTE: Interviewer will follow-up on details of the resident's experience using the Probe Questions, with timing and wording dictated by interview content, dynamics, and conversation flow.

1. Tell me about yourself (how old, how long in the nursing home, your family, how you are feeling)
 - a. Probe: What does it mean to you to be a nursing home resident at this time in your life?
 - b. Probe: Do you feel differently about yourself now than when you were younger?
 2. What do you need from the health care system to be well cared for at this stage of your life?
 - a. Probe: Are these needs different from the past? How?
 - b. Probe: What has changed?
 3. How do you view your experience with care, in general, and with regard to meeting your needs?
 - a. Probe: Are you able to get your needs met?
 - b. Probe: Which needs? How well are they met?
 - c. Probe specific needs and experiences:
 1. Involvement in decision making
 - a. Establishing goals of care based on your values and preferences
 - b. Treatment preferences

- c. Aggressive care/Limits on care
- d. Nutrition and hydration
- e. Hospitalization
- f. End-of-life care

- 2. Health care providers listening and responding
- 3. Treated respectfully
- 4. Getting and understanding information
- 5. Symptom management
- 6. Assessing and treating pain
- 7. Supportive and safe environment
- 8. Meaningful experiences
- 9. Spiritual health and well-being
- 10. Interactions with loved ones
- 11. Help for your family to cope with your illness, death

- 4. Are there any important needs (expectations, outcomes of care) that are not being met?
 - a. Probe: What are you particularly worried about or afraid of?
 - b. Probe: How can health care providers help with meeting your needs?
- 5. Are you familiar with the term palliative care? Comfort care? End-of-Life care?
 - a. What does the term mean to you?
- 6. In closing, do you have any other suggestions or wisdom that you can share with us about what is good/not good about your experience with care? What could be done differently?

Thank you again for taking the time to meet with me and provide feedback about the study.