

Appendix 9.4. Semistructured Interview Guide for Family Caregivers

Goal: Discover family member perspectives about palliative and end-of-life care expectations and where care falls short of expectations.

Method: Individual interviews will be conducted with family caregivers at the nursing homes or a place preferred by the family member (eg., own home). Caregivers who can understand the purpose of the study will be identified with the assistance of the nursing home staff. Study investigators will approach the caregiver to explain the study, answer questions, and set a date and time for the interview.

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

Introduction to the Interview with the Caregiver:

Hello Mr/Mrs _____, my name is _____, thank you so much for interviewing with me today. [Caregiver'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 caregivers 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 family caregiver'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 have you been caring for a loved one in a nursing home, your loved one, how you are feeling)
2. How do you view your experience with care provided in the nursing home, in general, and with regard to meeting specific needs of your loved one at this point in their life?
 - a. Probe: What is going well
 - b. Probe: What is not going so well
 - c. Probe specifics:

1. Health care providers listening and responding
 2. Treated respectfully
 3. Getting and understanding information
 4. Symptom management
 5. Assessing and treating pain
 6. Supportive and safe environment
 7. Meaningful experiences
 8. Spiritual health and well-being
 9. Help with coping as a caregiver
3. How do you view your experience with involvement in decision-making about goals of care for your loved one?
- a. Probes: Do you serve as a Health Care Proxy?
 - b. Probe specific decisions:
 - Establishing goals of care based on loved one's values and preferences
 - Treatment preferences
 - Aggressive care/Limits on care
 - Nutrition and hydration
 - Hospitalization
 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 these 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 going well/not going so well with 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.