

Inquiry Process: Focus Groups - Family Members

- What does the word hospice mean to you? In general?
For you and your family?
- What would make it likely for you or a member of your family to choose hospice care?
- What would prevent you or a member of your family from choosing hospice care?
- What did the physician tell you about your family member's illness?
Options regarding continuing care?

Probes: What would you have liked to have been told?

Please give us any comments you have about those interactions.

- How would you prefer to be told your illness is now terminal or not curable?
- During your family member's illness, what was your experience/your family member's experience with the following?

Pain/symptom management. In addition to health care professionals' treatment of pain as described by the patient, this includes shortness of breath, fatigue, nausea or vomiting, confusion, skin breakdown, and any other physical symptoms that affected your family member's quality of life/comfort.

Advance care planning. Including documenting and honoring the patient's preferences and circumstances, prior to a crisis, regarding level and kind of medical intervention/care.

Probes: Did the physician speak to your family member about the type of care he or she would like to receive? Did this happen at an appropriate time and in a way he or she could understand? Did your physician speak to the appropriate family member about care of your loved one? If your family member had a living will, was it honored?

Provider continuity and skill. This refers to a continuous, long-term relationship with health care professionals who were skilled in communication, psychological support, and pain and symptom control.

Probes: Did you and your family member trust the health care professionals (doctors, nurses, and others) who were taking care of him or her? Did you feel you could talk to the professionals taking care of your family member? Did you always know who to speak with if you had concerns or questions about your family member's care or condition?

Emotional symptoms. This includes anxiety, depression, sadness, fear and any other emotional symptoms that affected your family member's quality of life.

Grief bereavement. Assistance to you or your family before and after the patient's death with your grief.

Probe: How did the health care professionals help you in your time of grief?

What is the appropriate time to offer bereavement counseling?

Family burden/care giver strain (economic demands). Serious financial or emotional effects from the costs of care and the challenges of direct care giving.

Probes: While your family member was ill, was any attention paid to the economic and emotional concerns of you and your family? How did the health care given to your family member address those concerns?

Quality of life. Patient's overall sense of well being.

Patient and family satisfaction with the quality of the end-of life experience. Satisfaction with the care and comfort given.

Probes: What were your feelings about the decision-making process, the care given, the extent to which opportunities were provided for your family member to complete life in a meaningful way? Did you and your family member have peace of mind about his or her care and comfort?

Spirituality. Attention to the spiritual/religious needs of the patient and family. Peace of mind.

Prolongation of dying. Kinds of medical interventions that occurred during the last month (phase) of life.

Patient control and autonomy. Personal dignity and self-respect; patient control over decisions about care.