

Family Member Interview After Death Instrument for Simultaneous Case Study

Patient's Last Name, First Name, Middle Name

Surrogate's / Primary Caregiver's Relationship to Patient

Hello, Is this (Surrogate)? My name is (Interviewer Name) and I am part of the [Institution] research team who asked (Patient's Name) questions about (his/her) illness and experiences during the last weeks. Our research includes trying to understand how the medical care system can do better in serving seriously ill persons and their families. We are doing this by speaking, to individuals such as yourself who can provide important information about the dying experience of a loved one. I realize that this might be a difficult topic for you, but I wonder if I might ask you some questions. Your answers will help us help other families in the future. Your participation is very important for the success of this research. I will be asking questions about (Patient's) health/medical care during (his/her) illness. You are free to decide not to be involved at all, refuse to answer any question, or you may stop at any time. Your answers will be kept strictly confidential and will be used only to help us improve care.

1. We'd like to know how things were while (Patient) was receiving investigational chemotherapy. During this time, did he/she ... (Circle Answer)

a. experience pain?	Yes	No	Don't Know	Refused
b. have shortness of breath?	Yes	No	Don't Know	Refused
c. have unconsciousness or coma?	Yes	No	Don't Know	Refused
d. have depression?	Yes	No	Don't Know	Refused
e. have anxiety?	Yes	No	Don't Know	Refused
f. continue to make (his/her)own decisions?	Yes	No	Don't Know	Refused
g. have a resuscitation attempt? (CPR?)	Yes	No	Don't Know	Refused
h. use a respirator or ventilator?	Yes	No	Don't Know	Refused
i. have feedings through a tube?	Yes	No	Don't Know	Refused

2. What symptoms really bothered (Patient)?

3. How difficult was it for (Patient) to tolerate the physical symptoms he/she experienced? (Read All Options)

Not at all	Slightly difficult
Moderately difficult	Quite difficult
Extremely difficult	Don't know
Refused	

The next questions refer to (Patient's) medical care during his/her investigational chemotherapy

4. Did the doctors and nurses talk to you or (Patient) in a way you could understand, about (Circle Answer)

a. (Patient's) choices for treatment?	Yes	No	Don't Know	Refused
b. the chances that (Patient) would survive?	Yes	No	Don't Know	Refused
c. how pain/other symptoms would be treated?	Yes	No	Don't Know	Refused
d. the possible use of hospice?	Yes	No	Don't Know	Refused
e. (Patient's) wishes for treatment?	Yes	No	Don't Know	Refused

5. Were there any changes in caregivers during (Patient's) investigational treatment?

No
 Yes If Yes, what happened?
 Don't know
 Refused

6. Was hospice involved in (Patient's) care after investigational treatment?

No
 Yes If Yes, for how long?
 Don't know
 Refused

7. Do you remember ever having a problem with a doctor or nurse not doing everything they could to help control (Patient's) symptoms?

No
 Yes, physician
 Yes, nursing staff
 Yes, both
 Don't know
 Refused

8. Did (Patient) ever have to wait too long for a pain medication?

No
 Yes If yes, for how long? Minutes Hours
 Don't know If yes, what happened?
 Refused

9. Did you feel that the doctors, nurses, and other health professionals really understood what you and your family were going through?

No

Yes
Don't Know
Refused

10. Did someone talk with you and/or (Patient) about your religious or spiritual beliefs in a supportive and sensitive manner?

No
Yes
Don't Know
Refused

11. Did a doctor really listen to you and (Patient) about your hopes, fears, and beliefs as much as you wanted?

No
Yes
Don't Know
Refused

12. Did the nurses really listen to you and (Patient) about your hopes, fears, and beliefs as much as you wanted?

No
Yes
Don't Know
Refused