

# TOOLKIT OF INSTRUMENTS TO MEASURE END OF LIFE CARE

## AFTER-DEATH BEREAVED FAMILY MEMBER INTERVIEW

### Hospice Version

August 2000

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## FAQs (FREQUENTLY ASKED QUESTIONS)

**What can a hospice gain from administering this survey?** Assessing quality of care is essential for quality improvement, and a family member's perspective is important for judging quality of care. This survey allows hospice staff to collect that perspective with a state of the art measurement tool geared specifically toward hospice care.

**Is this a valid and reliable instrument?** Yes. We have tested the instrument with a population of bereaved family members whose loved ones died in a hospital, nursing home, or while under hospice care. For these settings, the instrument is both reliable (i.e., it produces the same results when repeated and the items within each domain are correlated) and valid (i.e., it measures what it intends to measure). More information will be available in an upcoming article.

**How should I administer the survey?** An interviewer should administer the survey either over the telephone or in-person. (See "Instructions for Interviewers" below.) The survey is not intended to be self-administered by the respondent (e.g., mail-back surveys).

**Why are the questions numbered out of sequence?** The hospice version is based on a longer instrument and has been tailored to reflect hospice services. As a result, some questions from the longer instrument have been deleted and other questions have been moved. To maintain consistency across versions, we have retained the numbering from the original instrument – which means that the numbering for the hospice version appears out of sequence.

**What do the colored circles around some of the questions mean?** The instrument provides information on seven different aspects (or domains) of quality of care. We have color-coded the domains so that the questions pertaining to a specific domain all share the same color. (See "Instructions for Scoring" below.)

**Do all of the questions in the main survey have to be asked, or can the survey be shortened?** You can choose to focus on one or more specific domains. If you choose to limit your domains of interest, you should ask only those questions pertaining to your domains of interest (plus the questions included in "Introduction and Screening" and "Checking the Facts"). It is important to the validity and reliability of your results, though, that you include all of the questions within each domain of interest.

If you choose to limit the domains of interest, we suggest that a useful survey would include the following four domains: 1) physical comfort and emotional support, 2) promote shared decision making, 3) focus on individual, and 4) attend to the emotional and spiritual needs of the family. In this case, the interviewer would ask only those questions pertaining to the domains color-coded in blue, green, purple, and yellow (plus the questions included in "Introduction and Screening" and "Checking the Facts").

*Note:* Even if you limit your domains of interest, all respondents should answer the questions included in the "Introduction and Screening" and "Checking the Facts" sections. In addition, if the

domains of interest are limited, then the numbers of the “skip to” questions may change.

**Can I re-arrange the order of the questions?** No. To maintain the validity and reliability of the instrument, the questions need to be asked in the order that they appear in the instrument (even when you are deleting the questions pertaining to domains in which you are not interested).

**When should I use the optional questions and the last month of life module?** This is your choice, depending on what information you need or want. The optional questions and the last month of life module are not included in the problem scores or overall ratings.

**How should I analyze the results?** The instrument is intended to identify opportunities to improve, so the data for the questions in the 7 domains are summarized as “problem scores”. Each domain has its own problem score. In addition, an overall rating is derived from the ratings questions. For more information, please see Chapter 4 of the Resource Guide.

**Should the survey be used for individual patients or groups of patients?** The survey was designed to be used with groups of people, but it can be used to assess the quality of care received by an individual patient. If the survey is used with a bereaved family member of a single patient and some of the questions do not apply to that patient/family member, then corresponding problem scores to the “skipped” questions will not be able to be computed. “Skipped” questions for some respondents is not a problem when groups of people are interviewed.

**Is there a benchmark to which my scores can be compared?** A current study will produce norms for the U.S., which will be available in Spring, 2002. Problem scores should be compared to norms, rather than to each other.

**Who can I contact if I have questions?**

By email, [Joan\\_Teno@Brown.edu](mailto:Joan_Teno@Brown.edu) ; by phone, Jeff Edmonds at (401) 863-9630.

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## INSTRUCTIONS FOR THE INTERVIEWER

- When conducting this interview (starting with the section titled “Introduction and Screening”), read all lowercase text aloud to the respondent.
- Instructions for interviewers are provided throughout the questionnaire in capital letters. Words appearing in capital letters are meant to guide the interviewer and should not be read aloud.
- Read instructions written in lowercase letters aloud to the respondent to guide him/her in answering.
- It is important to read questions in their entirety, exactly as written.
- Many of the questions are followed by ellipsis (...), which indicate that the interviewer should read the answer choices aloud to the respondent. Read *all* of the answer choices before pausing for a response. For yes/no questions, the answer categories should *not* be read aloud. These questions will not be followed by ellipsis, and the answer categories will appear in uppercase letters.
- The interviewer will often be expected to fill in personal information into survey questions. For example, the patient’s name often is inserted into questions. The interviewer will know to substitute specific information when a word written in capital letters is enclosed in parentheses.

EXAMPLE: Was [PATIENT] able to make decisions in the last week of life?

READ AS: Was *Mr. Smith* able to make decisions in the last week of life?

At times, the name of the hospice at which the patient died or the date on which the patient died should be inserted. The interviewer should be prepared with this information before beginning the interview.

- When lower case words appear in parentheses, the interviewer should choose the appropriate word.

EXAMPLE: Was [PATIENT] unconscious or in a coma all of the time during the last week of (his/her) life?

READ AS: Was Mrs. Jones unconscious or in a coma all of the time during the last week of *her* life?

- Words that are underlined should be emphasized when read aloud. It is important to the meaning of the question that these words are read with emphasis.

- At times, optional words or phrases are provided in parentheses after a question. These words or phrases should be read only if the respondent requests further clarification. In all other cases, questions should be read as written, and the interviewer should *not* provide a definition or clarification to the respondent.
- Circle the number corresponding to the answer chosen by the respondent. For fill-in or open text answers, write in the appropriate information as stated by the respondent.
- Based on the answers to certain questions, it is sometimes logical to skip subsequent questions. For example, a surrogate who reports no pain should not then be asked about pain severity. Instruction for skips is generally provided within parentheses after a specific answer choice. If this answer is selected, move on to the question number indicated after that answer choice.

EXAMPLE: Do you think this is where [PATIENT] would have most wanted to die?  
[ ] YES (SKIP TO 5)  
[ ] NO

ACTION: If the respondent chooses YES, then skip to question 5.

- Be familiar with the instrument before conducting interviews. At times, for example, it is necessary to refer back to previous answers to determine if a question or a group of questions should be skipped.

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## INSTRUCTIONS FOR SCORING

The purpose of this tool is to aid hospice staff in assessing and improving quality of care in 7 different aspects (or domains) of care. For 6 of the domains, the questions are summarized as “problem scores,” with a higher number signifying more opportunity to improve. For the self-efficacy domain, key questions are summarized on a 3-point scale rather than as a problem score. In addition to the domains, the instrument produces an overall rating scale for patient focused, family centered care.

Each of the domains (listed below) is coded with a different color and symbol. Throughout the survey, all of the questions contributing to a domain’s overall score are marked with that area’s color. A question color-coded for a particular domain but not included in the list of “key questions” is necessary for obtaining an answer to a “key question” but is not itself included in the score.

### Problem Scores



Physical comfort and emotional support

*Key questions for problem score-* D12a, D15, D15a, D16b, D17b



Inform and promote shared decision making

*Key questions for problem score-* C1a, C1b, C1c, D19, D26a, D27a, D28a, E1



Encourage advance care planning

*Key questions for problem score-* D2, D3, D4



Focus on individual

*Key questions for problem score-* D21, D22, D23, D24, D25, E2



Attend to the emotional and spiritual needs of the family

*Key questions for problem score-* E5, E5a, E5b, E6, E7, E8



Provide coordination of care

*Key questions for problem score-* C1d, C2/C2a, D15a, D18

### Scale scores



<sup>D</sup>c

Support the self-efficacy of the family

*Key questions for scale-* D26b, D27b, D28b, D29b



Overall Rating Scale for patient focused, family centered care

*Key questions for scale-* F1, F2, F3, F4, F5

**Computing Domain Problem Scores and Scale Scores-** Upon receipt of your registration form, Dr. Teno will send you a Scoring Packet. This Packet includes two items: 1) a pre-formatted Microsoft Excel spreadsheet for data entry and analysis, and 2) a Scoring Guide with information about using Excel as well as necessary codes for data entry.

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**COVERSHEET**

\_\_\_\_\_  
**Date of Interview**

\_\_\_\_\_  
**Interviewer ID**

\_\_\_\_\_  
**Surrogate ID**

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
**Patient Date of Birth**

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
**Patient Date of Death**

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
**Date of Admit to Hospice Service**

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
**Date of Discharge**  
(if different than date of death)

**Was patient under care of hospice during all of the last 7 days of life?** \_\_\_\_\_

**Patient Diagnosis:** \_\_\_\_\_  
\_\_\_\_\_

**Patient Karnofsky Score:** \_\_\_\_\_

**Patient Marital Status:** Married Widowed Divorced Single, never married

**Patient Sex:** M F

**Patient Religious Preference:** \_\_\_\_\_

**Surrogate Name (First Last):** \_\_\_\_\_

**Surrogate Sex** M F

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## INTRODUCTION & SCREENING

Hello, may I speak to [SURROGATE FIRST NAME]?

My name is [YOUR NAME] and I am working on a study of patients of [HOSPICE]. I am sorry to hear of the loss of [PATIENT]. We are working on a program to help seriously ill patients and families make the best possible medical decisions. 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 is a difficult time for you, [SURROGATE'S FIRST NAME], but I wonder if I might ask you some questions. Is this a good time for us to talk?

<input type="checkbox"/> YES →	(CONTINUE WITH INTERVIEW – GO TO QUESTION 1)
<input type="checkbox"/> NO →	We will call you another time. When is usually a good time for you to talk? _____ [CONFIRM THAT SURROGATE WILL BE CALLED AGAIN, AND TERMINATE INTERVIEW]

1. Can you tell me how you were related to [PATIENT NAME]?

SPOUSE  
PARTNER

CHILD  
DAUGHTER-IN-LAW/SON-IN-LAW  
PARENT  
SIBLING  
OTHER RELATIVE

FRIEND  
OTHER (SPECIFY: \_\_\_\_\_)

2. Would you say you are one of the people who knows the most about how [PATIENT] was doing during (his/her) last few weeks of life?

YES (GO TO INFORMED CONSENT STATEMENT)  
 NO

3. Who would know more about [PATIENT NAME] in (his/her) last few weeks of life than you?

\_\_\_\_\_ (ALTERNATIVE PERSON)



3a. What is this person's relationship to [PATIENT NAME]?

SPOUSE  
PARTNER

CHILD  
DAUGHTER/SON-IN-LAW  
PARENT  
SIBLING  
OTHER RELATIVE  
FRIEND  
OTHER (SPECIFY: \_\_\_\_\_)

3b. We may want to interview [ALTERNATIVE PERSON], do you happen to have (his/her) full name, address and telephone number nearby.

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

CITY: \_\_\_\_\_ STATE: \_\_\_\_\_ ZIP CODE: \_\_\_\_\_

PHONE NUMBER: \_\_\_\_\_

INTERVIEWER: CONFIRM THAT THE REFERRAL PERSON KNOWS MORE THAN THE RESPONDENT ABOUT THE PATIENT'S LAST FEW WEEKS.

\*\*\*\*\* THANK RESPONDENT AND TERMINATE INTERVIEW \*\*\*\*\*

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## INFORMED CONSENT

INTERVIEWER OR ADMINISTRATOR: IF NECESSARY MODIFY THIS INFORMED CONSENT STATEMENT BASED ON YOUR OWN INSTITUTION'S IRB.

To make sure you have all the information about the study, I am going to read you a few sentences.

Your participation in this interview is, of course, voluntary. If you decide not to participate, it will not affect you in any way.

Your answers will be kept completely confidential to the extent of the law. The information from this study will not be presented or published in any way that would allow the identification of any respondent. Your answers will be combined with the answers of other people for statistical analysis.

It is important that your answers be accurate. Take your time and be sure to ask me if you are not sure what a question means or what kind of answer is wanted. It is very important that you answer as

honestly and as accurately as you can. If there is any question you would rather not to answer, just tell me and I will skip it.

Finally, I have to tell you that my supervisor may monitor parts of the interview for quality control purposes.

Do you have any questions about who is doing the study or anything else pertaining to the study?

May we proceed with the interview?

- YES (CONTINUE THE INTERVIEW -- GO TO QUESTION A)  
 NO (THANK RESPONDENT AND TERMINATE INTERVIEW)
- 

### CHECKING THE FACTS

A. Where did [PATIENT'S] death take place? [INTERVIEWER- IF NECESSARY, PROMPT UNTIL SITE IS IDENTIFIED]

<input type="checkbox"/> AT HOME →	Was that in the patient's own home [ ], or in your home [ ], or in someone else's home [ ]?
<input type="checkbox"/> IN A HOSPITAL →	Was that in the Intensive Care Unit, <input type="checkbox"/> YES <input type="checkbox"/> NO → Was that in a palliative care or inpatient hospice unit? <input type="checkbox"/> YES [ ] NO
<input type="checkbox"/> NURSING HOME OR OTHER LONG-TERM CARE FACILITY →	Was that an inpatient hospice unit? <input type="checkbox"/> YES [ ] NO
<input type="checkbox"/> HOSPICE →	Do you mean an inpatient hospice unit? <input type="checkbox"/> YES [ ] NO  Do you mean residential housing provided by hospice? <input type="checkbox"/> YES [ ] NO
<input type="checkbox"/> IN TRANSIT TO A MEDICAL FACILITY	
<input type="checkbox"/> SOMEWHERE ELSE →	SPECIFY:
<input type="checkbox"/> DON'T KNOW	

A1. And our information is that [PATIENT] died in [DATE OF DEATH]. Is this correct?

- YES  
 NO → In what month and year did (he/she) die? \_\_\_\_\_/\_\_\_\_\_

A5. We're interested in finding out where [PATIENT] spent the last 30 days of (his/her) life. Let's start with where (he/she) was 30 days before (he/she) died. Where was (he/she)? For how many days was (he/she) there?

PLACE (30 DAYS BEFORE): \_\_\_\_\_ NUMBER OF DAYS: \_\_\_\_\_

[AS NEEDED: Did (he/she) go anywhere after that? Where was that? How long was (he/she) there? CONTINUE THROUGH THE DAY OF DEATH]

PLACE: \_\_\_\_\_ NUMBER OF DAYS: \_\_\_\_\_

PLACE: \_\_\_\_\_ NUMBER OF DAYS: \_\_\_\_\_

LAST PLACE: \_\_\_\_\_ NUMBER OF DAYS: \_\_\_\_\_

INTERVIEWER CHECK RE: (IN THAT LAST WEEK/WHILE UNDER CARE OF HOSPICE) DETERMINE FROM THE COVER SHEET WHETHER PATIENT WAS UNDER CARE OF HOSPICE DURING THE LAST 7 DAYS OF HIS/HER LIFE.

IF YES → CHOOSE "IN THAT LAST WEEK"

IF NO → CHOOSE "WHILE UNDER CARE OF HOSPICE"

NOTE: LAST WEEK = 7 DAYS

## DOMAIN QUESTIONS

These next questions are about [PATIENT'S] experience (during (his/her) last week/while under care of hospice).

**C1.** (In [PATIENT'S] last week/While [PATIENT] was under care of hospice), did you talk with any of [PATIENT'S] doctors yourself?

YES  
 NO (SKIP TO C2)

**C1a.** (In that last week/ While under care of hospice), was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?

YES  
 NO

**C1b.** (In that last week/ While under care of hospice), did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?

YES  
 NO  
 HAD NO CONCERNS

C1c. (In that last week/ While under care of hospice), how much information did the doctors provide you about [PATIENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?

- LESS THAN WAS NEEDED
- JUST THE RIGHT AMOUNT
- MORE THAN WAS NEEDED

C1d. (In that last week/ While under care of hospice), how often did any doctor give confusing or contradictory information about [PATIENT'S] medical treatment - always, usually, sometimes, or never?

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

C2. (In that last week/ While under care of hospice), was there always a doctor in charge of [PATIENT]'s care?

- YES
- NO

C2a. (In that last week/While under care of hospice), was it always clear to you which doctor was in charge of (his/her) care?

- YES
- NO

D1. Did [PATIENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?

- YES
- NO (SKIP TO D5)
- DON'T KNOW (SKIP TO D5)

D2. To the best of your knowledge, did [PATIENT]'s doctor or the medical staff who cared for (him/her) while under care of hospice speak to (him/her) or you about (his/her) wishes about medical treatment?

- YES
- NO

D3. Did (his/her) doctor or the medical staff who cared for (him/her) while under care of hospice speak to (him/her) or you about making sure (his/her) care was consistent with (his/her) wishes?

- YES
- NO

D4. (In that last week/ While under care of hospice), was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her) previously stated wishes?

[ ] YES  
 [ ] NO

D5. Did [PATIENT] have a signed Durable Power of Attorney for Health Care naming someone to make decisions about medical treatment if (he/she) could not speak for (him/her) self?

[ ] YES  
 [ ] NO  
 [ ] DON'T KNOW

D6. Did [PATIENT] have a signed Living Will giving directions for the kind of medical treatment (he/she) would want if (he/she) could not speak for (him/her) self?

[ ] YES  
 [ ] NO  
 [ ] DON'T KNOW

INTERVIEWER CHECK: DOES D5= YES OR D6 =YES?




[ ] YES  
 [ ] NO (SKIP TO A8)

D7. Had you or [PATIENT] discussed (his/her) Living Will or Durable Power of Attorney for Health Care with a doctor caring for (him/her) while under care of hospice?

[ ] YES  
 [ ] NO

Now I want to ask some specific questions about when [PATIENT]'s health started to get worse and (his/her) symptoms while (he/she) was under the care of hospice.

A8. About how many days or weeks before (he/she) died did [PATIENT] lose consciousness?

   \_\_\_\_\_ DAYS OR \_\_\_\_\_ WEEKS

[ ] NEVER LOST CONSCIOUSNESS

INTERVIEWER CHECK: IS A8 GREATER THAN OR EQUAL TO ONE WEEK OR, IF LESS THAN ONE WEEK, LONGER THAN THE TIME THE PATIENT WAS UNDER THE CARE OF HOSPICE?

YES (SKIP TO D18)

NO

D12. (In that last week/ While under care of hospice), was [PATIENT] on medicines to treat (his/her) pain?



YES

NO (SKIP TO D15)

DON'T KNOW (SKIP TO D15)

D12a. (In that last week/ While under care of hospice), did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?



YES

NO

D15. (In that last week/ While under care of hospice), did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain?



TOO MUCH

TOO LITTLE

RIGHT AMOUNT

D15a. (In that last week/ While under care of hospice), was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?



YES

NO

D16. (In that last week/ While under care of hospice), did (he/she) have trouble breathing?



YES

NO (SKIP TO D17)

DON'T KNOW (SKIP TO D17)

D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?



LESS THAN WAS NEEDED

RIGHT AMOUNT

D17. (In that last week/ While under care of hospice), did (he/she) have any feelings of anxiety or sadness?



- YES
- NO (SKIP TO D18)
- DON'T KNOW (SKIP TO D18)

D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?



- LESS THAN WAS NEEDED
- RIGHT AMOUNT

D18. (In that last week/ While under care of hospice), was there any problem with doctors or nurses not knowing enough about [PATIENT'S] medical history to provide the best possible care?



- YES
- NO

D19. (In that last week/ While under care of hospice), was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?



- YES
- NO

D21. (In that last week/ While under care of hospice), how often were [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?



- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

D22. (In that last week/ While under care of hospice), how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?



- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

D23. (In that last week/ While under care of hospice), how often was [PATIENT] treated with kindness by those who were taking care of (him/her) - always, usually, sometimes, or never?



- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

D24. (In that last week/ While under care of hospice), was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

①

YES  
 NO

D25. (In that last week/ While under care of hospice), was there enough help with medications and getting dressings changed?

①

YES  
 NO

D26. At any time while [PATIENT] was involved with hospice did you or your family receive any information about what to expect while (he/she) was dying?

🗨️

YES  
 NO

D26a. Would you have wanted (some/more) information about that?

🗨️

YES  
 NO

D26b. How confident were you that you knew what to expect while [PATIENT] was dying - very confident, fairly confident, or not confident?

<sup>Dc</sup>

VERY CONFIDENT  
 FAIRLY CONFIDENT  
 NOT CONFIDENT

D27. At any time while [PATIENT] was involved with hospice did you or your family receive any information about what to do at the time of (his/her) death?

🗨️

YES  
 NO

D27a. Would you have wanted (some/more) information about that?

🗨️

YES  
 NO

D27b. How confident were you that you knew what to do at the time of death - very confident, fairly confident, or not confident?

<sup>Dc</sup>

VERY CONFIDENT  
 FAIRLY CONFIDENT  
 NOT CONFIDENT



D28. At any time while [PATIENT] was involved with hospice did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

- YES
- NO

D28a. Would you have wanted (some/more) information about the medicines?

- YES
- NO

D28b. How confident were you that you understood about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms - very confident, fairly confident, or not confident?

D<sub>C</sub>

- VERY CONFIDENT
- FAIRLY CONFIDENT
- NOT CONFIDENT

INTERVIEWER CHECK: DID PATIENT DIE AT HOME, SURROGATE'S HOME, OR SOMEONE ELSE'S HOME?

- YES
- NO (SKIP TO E1)

D29b. How confident did you feel about taking care of [PATIENT] at home - very confident, fairly confident, or not confident?

D<sub>C</sub>

- VERY CONFIDENT
- FAIRLY CONFIDENT
- NOT CONFIDENT

These next questions are about your experience (during [PATIENT'S] last week/while under care of hospice).

E1. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how often were you or other family members kept informed about [PATIENT'S] condition – always, usually, sometimes, or never?

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

E2. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how often did you have concerns about [PATIENT'S] personal care needs – such as bathing, dressing, and changing bedding- being met when you were not there - always, usually, sometimes, or never?

①

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

E5. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did someone from hospice talk with you about your religious or spiritual beliefs?



- YES
- NO (SKIP TO E6)

E5a. Was this done in a sensitive manner?



- YES
- NO

E5b. Did you have as much contact of that kind as you wanted (in [PATIENT'S] last week/ while [PATIENT] was under care of hospice)?



- YES
- NO

E6. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how much support in dealing with your feelings about [PATIENT]'s death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?



- LESS THAN WAS NEEDED
- RIGHT AMOUNT

E7. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death?



<input type="checkbox"/> YES	→	Was it done in a sensitive manner?
		<input type="checkbox"/> YES <input type="checkbox"/> NO
<input type="checkbox"/> NO	→	Would you have wanted them to?
		<input type="checkbox"/> YES <input type="checkbox"/> NO

E8. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone you could turn to for help if you were feeling stressed?



YES  
 NO

## RATINGS

Now we would like you to rate some aspects of the care [PATIENT] received (in that last week/ while [PATIENT] was under care of hospice). For each of the following questions, I'm going to ask you to use a scale from 0 to 10, where 0 means the worst care possible and 10 means the best care possible.

F1. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how well did the doctors, nurses, and other professional staff who cared for [PATIENT] communicate with (him/her) and the family about the illness and the likely outcomes of care?

**R**

[ 0 1 2 3 4 5 6 7 8 9 10 ]

F2. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how would you rate how well those taking care of [PATIENT] provided medical care that respected (his/her) wishes?

**R**

[ 0 1 2 3 4 5 6 7 8 9 10 ]

F3. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how well did those taking care of [PATIENT] make sure (his/her) symptoms were controlled to a degree that was acceptable to (him/her)?

R

[ 0 1 2 3 4 5 6 7 8 9 10 ]

F4. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how well did those taking care of [PATIENT] make sure that [PATIENT] died with dignity - that is, died on (his/her) own terms?

R

[ 0 1 2 3 4 5 6 7 8 9 10 ]

F5. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how well did those taking care of [PATIENT] do at providing emotional support for you and [PATIENT]'s family and friends?

R

[ 0 1 2 3 4 5 6 7 8 9 10 ]

And now an overall rating...

F6. On a scale of 0 to 10, where 0 means the worst care possible and 10 means the best care possible, what number would you give the overall care that [PATIENT] received in [PATIENT'S] last week of life/ while [PATIENT] was under care of hospice)?

[ 0 1 2 3 4 5 6 7 8 9 10 ]

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## OPTIONAL SETS OF QUESTIONS

### SOCIAL BACKGROUND

Now I have a few background questions about [PATIENT].

H1. At the time of (his/her) death, was [PATIENT] married, widowed, divorced, separated, or had he/she never been married?

- MARRIED
- WIDOWED
- DIVORCED
- SEPARATED
- NEVER MARRIED
- DON'T KNOW

H2. Was (he/she) living alone?

- YES
- NO
- DON'T KNOW

H3. What was the highest level of schooling [PATIENT] completed?

- LESS THAN HIGH SCHOOL
- HIGH SCHOOL GRADUATE
- TECHNICAL SCHOOL OR AA DEGREE
- COLLEGE GRADUATE
- ADVANCED DEGREE
- DON'T KNOW

H4. What was [PATIENT'S] religious preference - Protestant, Catholic, Jewish, or something else?

<input type="checkbox"/> PROTESTANT → What denomination is that? _____
<input type="checkbox"/> CATHOLIC
<input type="checkbox"/> JEWISH → Is that Orthodox, Conservative, Reformed or something else? <input type="checkbox"/> ORTHODOX <input type="checkbox"/> CONSERVATIVE <input type="checkbox"/> REFORM <input type="checkbox"/> OTHER

- SOMETHING ELSE (SPECIFY) → \_\_\_\_\_
- NONE/ATHEIST
- DON'T KNOW

H5. Was [PATIENT] Hispanic or Latino?

- YES
- NO

H6. (In addition to being Hispanic or Latino), Was [PATIENT] White, Black, Asian, or something else?

- WHITE
- BLACK
- ASIAN
- SOMETHING ELSE (SPECIFY: \_\_\_\_\_)
- DON'T KNOW

H7. What is your best guess of [PATIENT'S] household income in 1999 from all sources before taxes were taken out? Was it

- under \$11,000
- \$11,000-25,000
- \$25,000-50,000
- more than \$50,000
  
- DON'T KNOW
- REFUSED TO ANSWER

## RESPONDENT DEMOGRAPHIC CHARACTERISTICS

Now I have a few last questions about you.

J1. How old were you on your last birthday?

\_\_\_\_\_ YEARS OLD

J2. What is the highest level of schooling you have completed?

- LESS THAN HIGH SCHOOL
- HIGH SCHOOL GRADUATE
- TECHNICAL SCHOOL OR AA DEGREE
- COLLEGE GRADUATE
- ADVANCED DEGREE
  
- DON'T KNOW

J3. How would you rate your health? Would you say excellent, very good, good, fair, or poor?

- EXCELLENT
- VERY GOOD
- GOOD
- FAIR
- POOR

J4. Is there anything else you'd like to share about [PATIENT]'s medical care in the last few days of life?

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J5. Is there anything else that you would like to share about how the medical care could have been improved for (PATIENT)?

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\*\*\*\*\* THANK RESPONDENT AND TERMINATE INTERVIEW \*\*\*\*\*

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## MODULE: LAST MONTH OF LIFE QUESTIONS

Now I want to ask about the care [PATIENT] received during (his/her) last month of life.

INTERVIEWER CHECK: IS THE ANSWER TO A8 [IN DOMAIN QUESTIONS SECTION] GREATER THAN OR EQUAL TO 30 DAYS (1 MONTH)?

- YES (SKIP TO B4)
- NO

B1. During the last month of [PATIENT'S] life, were there times when (he/she) experienced pain?

- YES
- NO (SKIP TO B2)
- DON'T KNOW (SKIP TO B2)

B1a. Did (he/she) get any help in dealing with (his/her) pain?

- YES
- NO (SKIP TO B2)

B1b. How much help in dealing with (his/her) pain did [PATIENT] receive - less than was needed or about the right amount?

- LESS THAN WAS NEEDED
- RIGHT AMOUNT

B2. During the last month of [PATIENT'S] life, were there times when (he/she) had trouble breathing?

- YES
- NO (SKIP TO B3)
- DON'T KNOW (SKIP TO B3)

B2a. Did (he/she) get any help in dealing with (his/her) trouble breathing?

- YES
- NO (SKIP TO B3)

B2b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed or about the right amount?

- LESS THAN WAS NEEDED
- RIGHT AMOUNT



B3. During the last month of life, did [PATIENT] have any feelings of anxiety or sadness?

- YES
- NO (SKIP TO B4)
- DON'T KNOW (SKIP TO B4)

B3a. Did (he/she) get any help in dealing with (his/her) feelings of anxiety or sadness?

- YES
- NO (SKIP TO B4)

B3b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

- LESS THAN WAS NEEDED
- RIGHT AMOUNT

B4. During the last month of life, was there ever a decision made about [PATIENT'S] care or treatment without enough input from (him/her) or (his/her) family?

- YES
- NO

B5. During the last month of life, was there any decision made about care or treatment that [PATIENT] would not have wanted?

- YES
- NO

B6. During the last month of [PATIENT'S] life, how often were (his/her) personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - always, usually, sometimes, or never?

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

B7. During the last month of life, how often was [PATIENT] treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

B8. During the last month of life, how often were you or other family members kept informed about [PATIENT'S] condition - always, usually, sometimes, or never?

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

B9. During the last month of life, was there always a doctor in charge of [PATIENT]'s care?

- YES
- NO (SKIP TO B10)

B9a. During the last month of life, was it always clear to you which doctor was in charge of [PATIENT'S] care?

- YES
- NO

INTERVIEWER CHECK: IS A8 [IN DOMAIN QUESTIONS SECTION] GREATER THAN OR EQUAL TO 30 DAYS (1 MONTH)?

- YES (SKIP TO B11)
- NO

B10. During the last month of life, do you think [PATIENT] had any interest in seeing or talking with a priest, rabbi, minister, or other religious person?

- YES
- NO (SKIP TO B11)

B10a. During the last month of life, do you think (he/she) had as much contact of this kind as (he/she) wanted?

- YES
- NO

B11. Now, on a scale of 0 to 10, where 0 means as badly as possible and 10 means as well as possible, overall, how would you rate the way things went for [PATIENT] in the last month of life?

[ 0 1 2 3 4 5 6 7 8 9 10 ]

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## EXAMPLE SURVEY INCLUDING 4 DOMAINS

- Physical comfort and emotional support
- Inform and promote shared decision making
- Focus on individual
- Attend to the emotional and spiritual needs of the family

INTRODUCTION AND SCREENING  
INFORMED CONSENT  
CHECKING THE FACTS

→ These sections remain intact.

## DOMAIN QUESTIONS

These next questions are about [PATIENT'S] experience (during (his/her) last week/while under care of hospice).

C1. (In [PATIENT'S] last week/While [PATIENT] was under care of hospice), did you talk with any of [PATIENT'S] doctors yourself?

- YES  
 NO (SKIP TO D1)

C1a. (In that last week/ While under care of hospice), was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?

- YES  
 NO

C1b. (In that last week/ While under care of hospice), did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?

- YES  
 NO  
 HAD NO CONCERNS

C1c. (In that last week/ While under care of hospice), how much information did the doctors provide you about [PATIENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?

- LESS THAN WAS NEEDED  
 JUST THE RIGHT AMOUNT  
 MORE THAN WAS NEEDED

Now I want to ask some specific questions about when [PATIENT]'s health started to get worse and (his/her) symptoms while (he/she) was under the care of hospice.

A8.

About how many days or weeks before (he/she) died did [PATIENT] lose consciousness?



\_\_\_\_\_ DAYS OR \_\_\_\_\_ WEEKS

[ ] NEVER LOST CONSCIOUSNESS

INTERVIEWER CHECK: IS A8 GREATER THAN OR EQUAL TO ONE WEEK OR, IF LESS THAN ONE WEEK, LONGER THAN THE TIME THE PATIENT WAS UNDER THE CARE OF HOSPICE?

[ ] YES (SKIP TO D19)

[ ] NO

D12. (In that last week/ While under care of hospice), was [PATIENT] on medicines to treat (his/her) pain?



[ ] YES

[ ] NO (SKIP TO D15)

[ ] DON'T KNOW (SKIP TO D15)

D12a. (In that last week/ While under care of hospice), did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that



you could understand?

[ ] YES

[ ] NO

D15. (In that last week/ While under care of hospice), did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain?



[ ] TOO MUCH

[ ] TOO LITTLE

[ ] RIGHT AMOUNT

D15a. (In that last week/ While under care of hospice), was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?



[ ] YES

[ ] NO

D16. (In that last week/ While under care of hospice), did (he/she) have trouble breathing?



- YES
- NO (SKIP TO D17)
- DON'T KNOW (SKIP TO D17)

D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?



- LESS THAN WAS NEEDED
- RIGHT AMOUNT

D17. (In that last week/ While under care of hospice), did (he/she) have any feelings of anxiety or sadness?



- YES
- NO (SKIP TO D18)
- DON'T KNOW (SKIP TO D18)

D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?



- LESS THAN WAS NEEDED
- RIGHT AMOUNT

D19. (In that last week/ While under care of hospice), was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?



- YES
- NO

D21. (In that last week/ While under care of hospice), how often were [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?



- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

D22. (In that last week/ While under care of hospice), how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?



- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

D23. (In that last week/ While under care of hospice), how often was [PATIENT] treated with kindness by those who were taking care of (him/her) – always, usually, sometimes, or never?

①

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

D24. (In that last week/ While under care of hospice), was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

①

- YES
- NO

D25. (In that last week/ While under care of hospice), was there enough help with medications and getting dressings changed?

①

- YES
- NO

D26. At any time while [PATIENT] was involved with hospice did you or your family receive any information about what to expect while (he/she) was dying?

🗨️

- YES

D26a. Would you have wanted (some/more) information about that?

🗨️

- YES
- NO

D27. At any time while [PATIENT] was involved with hospice did you or your family receive any information about what to do at the time of (his/her) death?

🗨️

- YES
- NO

D27a. Would you have wanted (some/more) information about that?

🗨️

- YES
- NO

D28. At any time while [PATIENT] was involved with hospice did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?


🗨️

- YES
- NO


 D28a. Would you have wanted (some/more) information about the medicines?

- YES
- NO

These next questions are about your experience (during [PATIENT'S] last week/while under care of hospice).


 E1. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how often were you or other family members kept informed about [PATIENT'S] condition – always, usually, sometimes, or never?

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

 E2. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how often did you have concerns about [PATIENT'S] personal care needs – such as bathing, dressing, and changing bedding- being met when you were not there - always, usually, sometimes, or never?


①

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

 E5. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did someone from hospice talk with you about your religious or spiritual beliefs?




- YES
- NO (SKIP TO E6)

 E5a. Was this done in a sensitive manner?



- YES
- NO

 E5b. Did you have as much contact of that kind as you wanted (in [PATIENT'S] last week/ while [PATIENT] was under care of hospice)?



- YES
- NO

E6. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how much support in dealing with your feelings about [PATIENT]'s death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?



- LESS THAN WAS NEEDED  
 RIGHT AMOUNT

E7. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death?



<input type="checkbox"/> YES	—————▶	Was it done in a sensitive manner?
		<input type="checkbox"/> YES <input type="checkbox"/> NO
<input type="checkbox"/> NO	—————▶	Would you have wanted them to?
		<input type="checkbox"/> YES <input type="checkbox"/> NO

E8. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone you could turn to for help if you were feeling stressed?



- YES  
 NO

\*\*\*\*\* THANK RESPONDENT AND TERMINATE INTERVIEW \*\*\*\*\*

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