**National Study of Caregiving** 

Section LL [LAST MONTH OF LIFE]

Sequence: 4

LL<sub>1</sub>PRE

LL1PRE

NOT ON FILE

**QUESTION TEXT:** 

These next few questions are about the care you provided during {SP}'s last month of life.

PRESS 1 AND ENTER TO CONTINUE

LL1 cll7painhlp

C7 LL1 HELP SP MANAGE PAIN

**QUESTION TEXT:** 

During the last month of {SP}'s life, were there times when you helped {him/her} manage {his/her} pain?

CODES

1 YES 2 NO

> REFUSED DON'T KNOW

LL2 cll7brehlp

C7 LL2 HELP SP MANAGE BREATHING

**QUESTION TEXT:** 

During the last month of {SP}'s life, were there times when you helped {him/her} manage {his/her} breathing?

CODES

1 YES 2 NO

REFUSED DON'T KNOW

LL3 cll7sadhlp C7 LL3 HELP SP MANAGE SADNESS

ANXIETY

**QUESTION TEXT:** 

During the last month of  $\{SP\}$ 's life, were there times when you helped  $\{him/her\}$  with feelings of anxiety or sadness?

CODES

1 YES 2 NO

> REFUSED DON'T KNOW

BOX LL4 NOT ON FILE

If LL1=1 (YES) or LL2=1 (YES) or LL3=1 (YES), go to LL4. Otherwise, go to LL5.

LL4 cll7training C7 LL4 MED PROVIDER GIVE TRAINING LML

## **QUESTION TEXT:**

Did {SP}'s medical providers give you the training you needed to care for {him/her} in the last month of {his/her} life?

#### CODES

- 1 YES
- NO OR NOT ENOUGH
- 3 DOES NOT APPLY

REFUSED DON'T KNOW

LL<sub>5</sub>

cll7talkmed

C7 LL5 TALK TO SP ABOUT MEDICAL CARE

## **QUESTION TEXT:**

During the last month of {SP}'s life, did you talk with {him/her} about the kind of medical care that {he/she} wanted or did not want?

#### CODES

1 YES

2 NO

REFUSED DON'T KNOW

LL6

cll7makedecis

C7 LL6 MAKE MEDICAL DECISIONS FOR SP

#### **QUESTION TEXT:**

During the last month of {SP}'s life, did you make any medical decisions for {him/her}?

# **CODES**

1 YES

2 NO

REFUSED

DON'T KNOW

LL<sub>7</sub>

cll7caredecis

C7 LL7 DEC ABOUT CARE WO INPUT

# **QUESTION TEXT:**

During the last month of {SP}'s life, was there ever a decision made about {his/her} care or treatment without enough input from you?

# CODES

1 YES

2 NO

REFUSED

DON'T KNOW

LL8

cll7carenowan

C7 LL8 DEC ABOUT CARE NOT WANTED

## **QUESTION TEXT:**

During the last month of {SP}'s life, was there any decision made about care or treatment that you did not want?

## CODES

1 YES

2 NO

LL9 cll7respect C7 LL9 TREATED WITH RESPECT

# QUESTION TEXT:

During the last month of {SP}'s life, how often were you treated with respect by those who were taking care of {him/her}. Would you say always, usually, sometimes, or never?

## **CODES**

- 1 ALWAYS
- 2 USUALLY
- 3 SOMETIMES
- 4 NEVER
- 5 DOES NOT APPLY

REFUSED DON'T KNOW

LL10 C7 LL10 INFORMED ABOUT CONDITION

# **QUESTION TEXT:**

During the last month of {SP}'s life, how often were you kept informed about {his/her} conditin. Would you say always, usually, sometimes, or never?

## CODES

- 1 ALWAYS
- 2 USUALLY
- 3 SOMETIMES
- 4 NEVER
- 5 DOES NOT APPLY

REFUSED DON'T KNOW

# **PROGRAMMER INSTRUCTIONS:**

Go to Section HC – Health Care Interactions.

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