

F-6.
Prompts. INT
11-20-90
cc: Bethel
Tobin

THE EXPERIENCE OF CAREGIVING
INTERVIEW QUESTIONS AND PROMPTS

I. DEMOGRAPHICS

I'd like to begin by asking a few simple questions about you and your family.

- A. How many people are in your family?
 - 1. Their relationships to you...
 - 2. And their ages are...And your age...and your spouse's age...
 - 3. Do they live with you or close by?

- B. What grade did you complete in school?
 - 1. What grade did your spouse complete?
 - 2. How about your children?

- C. Are you currently working outside the home?
 - 1. If yes, what type of work do you do?
 - 2. Were you working prior to (pt's) accident?
 - a) Did you have to give up your job to care for child/spouse?
 - b) What type of job?
 - 3. Is your spouse currently working?
 - a) If yes, what type of work does he do? or
 - b) What was his last job?

- D. What type of transportation do you normally use?

- E. Do you have a specific religious affiliation?
 - 1. If yes, what?
 - 2. About how many time have you attended church in the past 3 months?

- F. How long ago did (stroke, accident) occur?

- G. What types of treatment is (the patient) currently receiving?

II. NATURE OF THE CAREGIVING EXPERIENCE

Now I'd like to ask you some questions about (your husband's stroke, your child's accident). I'm sure this has been a very difficult experience for you.

- A. Most difficult aspects
What aspects have been most difficult for you personally?

PROMPTS: Grief (shock, anger, depression); loss of valued activities; guilt and blame; burden and helplessness; social isolation; resentment, feeling cheated; overprotectiveness; conflict with professionals; conflict with family members; loss of work; financial impact; lack of appreciation; physical - exhaustion, back-ache; fears

for future (long term care); reconsidering plans for the future; daily hassles - reorganization of daily activities

Do you feel more tired since pt's accident/stroke?
Had you ever thought something like this might happen to you?

B. Most positive aspects

Have there been any aspects of this experience which you would consider positive? If so, what are they?

PROMPTS: Goals and expectations; personal satisfactions; hopes for the future; unexpected support from some friends and family/making new friends; lessons learned/personal growth

C. Changes in caregiving experience over time

What was your immediate reaction to (patient's) stroke, accident?
How has this reaction changed over time?
While patient was in hospital, what did you think it would be like to take care of patient?
Has the reality turned out to be easier/harder? In what ways?

D. Most difficult specific caregiving problems

Can you tell me most difficult problem you have in taking care of patient?

PROMPTS: I'm talking about self-care (bathing, feeding); instrumental (shopping, paying bills); inappropriate social behavior (excessive demands for companionship)

Have you ever considered turning over the major caregiving responsibilities for (pt) to someone else? Why or why not?
How would you be spending the time if you were not caring for (pt)?

PROMPTS: work, hobbies, social activities, family

At the end of the day, what kind of job do you normally feel you've done in terms of caring for (pt.)?

PROMPTS: Behaviors, thoughts, feelings

III. INFORMATION

I'd like to ask a few questions about what kind of information you've received about (pt.s) condition

- A. Sources of information
From what sources have you received information about (pt's) condition?
In what ways has this information been helpful to you?
Was there any information that was not helpful?
- B. Seeking information
Have you tried to get more information about (pt's) condition on your own? From where? Has this been helpful? In what ways?

IV. NATURE OF THE SOCIAL SUPPORT SYSTEM

I'd like to talk a little with you about the kinds of help you receive from others.

- A. Quality and use of informal support (family, relatives, friends, neighbors)
- Before this experience, who did you count on most for support and help?
- What kind of support and help did you receive from these people?
- About how often did you receive help?
- How satisfied were you with the usefulness of the help you received?
- What kind of help do you give in return?
- How has this experience changed the type of support you receive?
- When you've been in crisis have you called anyone? Who? Did it help? How does this person help?

PROMPTS: What has been the impact of this experience on marital/family relationships? How much do you feel you can count on (social support system) for help? How often do you request help? What kind of help do they provide? In what areas are they most helpful? In what areas do problems arise? Are former friends of pt. helpful for either emotional or instrumental support?

B. Quality and use of formal support

Are there agencies or services from which you currently receive help? (day-care programs, home/public health nursing, family support groups, rehab programs, Meals on Wheels)

PROMPTS: What supportive services are available to patient? How did you find out about these services?

What influenced your decision to participate/not participate in them? How helpful have they been? In what ways have they been a disappointment? What kind of financial support are you receiving?

Do you employ anyone to help you with pt. tasks?

V. PRESENT AND PRIOR RELATIONSHIP WITH PATIENT/SEVERITY OF IMPAIRMENT

Now I'd like to focus on changes you may have noticed in your relationship with (patient)

A. Changes in pt.

What was patient like before? How has s/he changed? What is his/her current level of independent functioning (autonomy issues)?

PROMPT: Physical, cognitive, behavioral, social/emotional impairments; personality changes

B. Changes in relationship

How would you compare your past and present relationship with (patient)?

PROMPTS: Loss of emotional closeness, companionship; changes in sexual relationship; social inappropriateness; loss of mutuality; issues of caregiver abuse

Who are you turning to to make up for relationship losses with (patient)?

VI. MEANING

Next, I'd like to ask you some of the hardest questions, the questions with no answers that we all ask: Why me? Why him/her?

How do you answer the Why me? question?

Does this experience have any meaning for you, or was it a purposeless, random event?

What have you learned from this experience?

VII. CARE OF THE CAREGIVER

What have you done to reduce burden and stress on yourself?

What things have been most helpful to you? What things have you experienced which have not been helpful?

VIII. OTHER STRESSORS

Is there anything else that's happening this year that's made caregiving even harder for you?

What other stressors have you been experiencing over the past year?

PROMPTS: Health problems; family problems; financial problems; problems at work; losses, deaths, moves, unexpected positive or negative changes

IX. ANYTHING ELSE YOU WOULD LIKE TO SHARE WITH ME?