

NATURAL COURSE OF AGING WITH DISABILITY

INTERVIEW SCHEDULE

Introduce self and thank informant for participation.

Set up audio/video equipment.

Explain we will be asking for consent to participate on videotape

Ask if any questions.

Reminder: If I ask any questions you'd rather not answer, just let me know.

If you get tired, and would like a break, just tell me.

Begin interview.

A. LIFE DOMAIN

1. Tell me a little bit about yourself.

(Prompts: age, where from originally, family of origin, married, children, work)

2. What kind of person would you say you are? How would a close friend or family member describe you?

3. How do you feel about your overall quality of life?

4. What memorable life events have you experienced? *(is the most memorable)*

(Prompts: Graduation from school, marriage, birth of children, travel; divorce, deaths, financial problems)

5. Describe a typical day in your life.

B. DISABILITY DOMAIN

1. Tell me a bit about your disability. How did you become disabled?

2a. Child-onset disability: What was it like growing up with name of disability?

(Prompts: best/worst memories of that time; reaction of family of origin; school experiences; adolescence; other medical problems)

2b. Adult-onset disability: What was your life like before name of disability? How did it change when you developed/had name of disability?

(Prompts: work, relationships, daily life; what goals did you have for yourself; effect on significant others, friends, work/school, daily routine, where you lived; other medical problems)

3. What has life been like for you over the past ____ years, living with this disability?

(Prompts: What makes you feel that way?)

4. What physical changes have you noticed over the past ____ years?

(Prompts: more difficult to get around, more fatigue, weakness; what are examples of things you can't do now that you could do ____ years ago?)

*relationships
work
kids*

5. What about positive changes? Has anything improved for you in terms of your physical health? What about in terms of your ability to cope with health problems?
6. Have you experienced any changes in your equipment needs? If so, has it been easy or difficult to make these changes (and why)?
7. What about psychological or emotional changes?
8. How have these changes affected your family? Your work? Your daily life?
9. What things worry or frighten you about your current health situation? What are your concerns about the future?
(Prompts: independent living vs. dependency; who will be available to assist you?)
10. What kind of support do you have available on a regular basis?
(Prompts: informal [family, friends]; organizational [support groups, volunteers]; professional [assistants, social workers, physicians, clergy]; emotional vs. instrumental)
11. How do you cope on a daily basis? What keeps you going? *

C. MEDICAL DOMAIN.

1. What ^{at home} ~~current~~ health problems do you have?
(Prompts: pain, fatigue, weight, cholesterol, high blood pressure, heart problems, cancer; current medications; surgeries, hospitalizations)
2. How would you say your mood is generally?
3. How do your health problems affect your overall quality of life, or your overall satisfaction with life in general?
4. Do your health problems affect your relationships with family and friends, your work, your daily life? If so, how?
5. Do you have someone you consider to be your primary care physician/provider?
6. Who is the doctor who mainly takes care of you?
7. How would you describe your relationship with your current physician?
8. How has your relationship with doctors changed over the past ____ years, since you developed name of disability?
(Prompts: better/worse; more/less contact; more/less time)
9. Do you have any problems getting routine health care?

(Prompts: health screenings, immunizations, colds, flu)

10. How about logistical problems with medical care?

(Prompts: Transportation to and from doctor's office; getting wheelchair into rooms; getting on and off exam table)

11. What do you need to do in order to prepare for and go to the doctor? How long does it take you to do that? (Prompts: how long does it take to get dressed, to get in/out of the car, to get from the parking lot to the doctor's office, etc)

12. In your experience, what are common mistakes physicians make in caring for someone with disabilities?

13. What do you want your doctors to know about you as a person?

14. What do you want your doctors to be aware of about your particular medical condition?

15. How do you want to be treated by doctors?

(Prompts: Tell me more about what you mean; in what way; give me an example)

Is there anything I should have asked or that you'd want to add about having a disability over time or about the best way doctors can care for someone with your type of disability over time?