

8. Health Related Quality of Life (HRQOL)

Archive Note: All HRQOL data collected by the University of Pittsburgh Central Quality of Life Center during the course of the FHN Trials and Extension Studies will be destroyed in December, 2014.

Only participant response data, identified by FHN study id (unique 6-digit FHN number/alphacode), was transmitted securely to the DCC. Data received from the Central Quality of Life Interview Center was downloaded into individual HRQOL instrument data collection tables.

8.1 Introduction to Health-Related Quality of Life: A Critical Outcome for the FHN Study

What is health-related quality of life (HRQOL)?

The current definition of HRQOL reflects the World Health Organization's definition of health as "a complete state of physical, mental, and social well-being and not merely the absence of disease and infirmity". Health-related quality of life refers to a subset of quality of life endpoints related to the health of the patient[1]. Most HRQOL instruments used in dialysis patients are multi-dimensional instruments that assess physical, mental, and social domains. If the treatment options for ESRD are potentially similar, such as the decision regarding using HD or PD, nephrologists may wish to discuss HRQOL issues as a part of the decision-making process. In FHN, HRQOL is a co-primary outcome and the collection of this data is crucial to the success of the trial. The collection of the HRQOL data will allow the investigators to examine differences in physical well-being due to the study interventions and describe the experiences of the study participants.

Why health related quality of life is important to FHN

HRQOL measurements are based on a patient's "subjective" sense of well-being and are commonly used as an important clinical measure for beneficial extent of medical treatments for patients undergoing maintenance hemodialysis [2-4]. While the questionnaires are subjective and represent the patients own perspective, they are highly reproducible and the reliability of HRQOL domains used in FHN compare favorably with the reliability of blood pressure measurements. Furthermore, among those with ESRD, HRQOL has been shown to change over the first several months of dialysis, to improve with erythropoietin therapy[5-7] and exercise[8-11], and to be an independent predictor of survival[12-14]. However, recent investigation has revealed that HRQOL is not effected by hemodialysis dose or flux[15]. The value of HRQOL measurement as a tool to improve clinical care has been recognized by many in the research community [12, 18-21] and both the National Kidney Foundation and the Centers for Medicare and Medicaid Services (CMS).

THE FHN conceptualization of HRQOL

In the FHN trial, the study group will examine HRQOL as a multi-dimensional concept. The study co-primary outcome is physical-well being as measured by an SF-36 RAND summary score (Physical Health Component). The FHN study will also focus on symptoms of depression,

mental health, health utility, sleep problems, self-perceived burden of care and sexual function. These aspects of health-related quality of life are thought to comprise domains that may be impacted by the study intervention and are valued by patients with ESRD.

Telephone administered QOL surveys

Because self-administered questionnaires may be more difficult to complete for the elderly, minority groups, and those with high comorbidity from trial participation [Unruh, 2003], all questionnaires will be administered by trained interviewers using computer-assisted telephone interviewing (CATI). HRQOL will be assessed at baseline, 4 months and 12 months after randomization in the daily study and at baseline, 5 months and 14 months after randomization in the nocturnal study. The telephone interviewers will be blinded to treatment allocation and will conduct the interviews through a central telephone service by the University Center for Social and Urban Research at the University of Pittsburgh.

8.2 Protocol for Transfer of Information To and From HRQOL Central Interviewing Center

1. The patient is recruited as a potential study participant at dialysis clinic.
2. The study coordinator at the dialysis clinic completes and submits the web-based Direct Patient Contact Form. The form includes the following fields:
 - a. patient study ID #,
 - b. current date,
 - c. patient's last name,
 - d. patient's first name and middle initial,
 - e. patient's state or province of residence,
 - f. patient's phone number (including area code and country code if patient is Canadian) and best time to reach patient at given number (x 3),
 - g. patient age indicator (minor (less than 18 years of age) or adult indicator)
 - h. trial indicator (Nocturnal or In-Center Daily),
 - i. language preference indicator (English or Spanish), and
 - j. site indicator.

Data from the form are appended to the HRQOL Central Interviewing Center's HRQOL Patient Tracking Database.

3. The study coordinator at the dialysis clinic notifies the Data Coordinating Center (DCC) that the patient has been recruited.
4. Study personnel complete the Core and Participating Site Data Form (Form 600). Data from the form are appended to the HRQOL Central Interviewing Center's HRQOL Patient Tracking Database.

5. The baseline HRQOL Interview is conducted as soon as possible after the nephrologist contact information has been obtained by the HRQOL Central Interviewing Center. The nephrologist's contact information is needed to ensure that if certain questions (e.g., suicidal thoughts) are answered in the affirmative by the patient, that the patient's physician can be notified promptly.
6. The participant will be contacted during a best time to call. The telephone administered HRQOL survey should take approximately 45 minutes to complete. The interview will include the following survey instruments, which are described in detail below:
 - a. SF-36
 - b. Health Utilities Index
 - c. Beck Depression Inventory
 - d. The Medical Outcomes Study (MOS) Sleep Problems Index (SPI)
 - e. Caregiver Burden
 - f. Dialysis specific questions
7. If the patient endorses suicide during administration of the Beck's Depression Inventory (Beck Item 13 responses: I would like to kill myself or I would kill myself if I had the chance), the FHN HRQOL Central Interviewing Center will alert the responsible investigators identified in Form 600.
8. HRQOL Central Interviewing Center's HRQOL Patient Tracking Database is updated with date of Baseline HRQOL Interview completion and projected dates for follow-up HRQOL interviews.
9. Baseline HRQOL Interview data are transferred within 24 hours of interview completion to the DCC. An adequate response rate as defined as a Physical Health Composite Score will be required for randomization.
10. The DCC computes scores based on HRQOL interview data and determines if the patient is eligible to participate in trial. If eligible, patient is randomized.
11. The DCC notifies the HRQOL Central Interviewing Center as to whether the patient has been randomized or not. The HRQOL Central Interviewing Center's HRQOL Patient Tracking Database is updated with randomization status (i.e., randomized, not randomized).
12. Two weeks prior to the scheduled date for HRQOL Interview Follow-up 1, the HRQOL Central Interviewing Center sends a standardized email to the study coordinator at the dialysis clinic to remind him/her to complete the web-based HRQOL Interview Follow-up Contact Form which includes the following fields:
 - a. patient ID #,
 - b. status (i.e., still participating in trial, withdrew from trial but interview, withdrew from trial and don't interview, deceased), and
 - c. contact information.

13. Two weeks prior to the scheduled date for HRQOL Interview Follow-up 2, the HRQOL Central Interviewing Center sends a standardized email to the study coordinator at the dialysis clinic to remind him/her to complete the web-based HRQOL Interview Follow-up Contact Form as described above.

FHN Project - Form 107



Core Consortium #0 Test
Test Center

Frequent Hemodialysis Network
"Patient Contact Form"

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[Logout](#)

Patient Contact Form 107

Patient ID:	12345	Find Patient Form
Alpha Code:		
Last Name:		
First Name & Middle Initial:		
Trial:	<input type="radio"/> Daily Study <input type="radio"/> Nocturnal Study	
Visit:	<input type="radio"/> Baseline <input type="radio"/> First Follow-up (F4 or F5) <input type="radio"/> Final Follow-up (F12 or F14)	
Status:	<input type="radio"/> Baseline <input type="radio"/> Still in Trial <input type="radio"/> Withdrew from Trial, agreed to be contacted for QOL interview <input type="radio"/> Withdrew from Trial, do not contact for QOL interview <input type="radio"/> Deceased	
Age:	<input type="radio"/> Adult 18 years old and over <input type="radio"/> 17 years old and younger	
Preferred Interview Language:	<input type="radio"/> English <input type="radio"/> Spanish	
Best Times to Call:	Phone 1:	<input style="width: 100%;" type="text"/>
	Time 1:	
	Phone 2:	<input style="width: 100%;" type="text"/>
	Time 2:	
	Phone 3:	<input style="width: 100%;" type="text"/>
	Time 3:	
<input type="button" value="Save"/> <input type="button" value="Reset"/>		«Delete»

University of Pittsburgh
 University Center for Social and Urban Research
 Technical Questions: survey@pitt.edu
<https://surveyweb2.ucsur.pitt.edu/DialysisQOL/patient.php>

10/12/2005

8.3 HRQOL Measures in FHN

SF-36 [Archive note: This instrument was completed in English and Spanish. It required a licensing agreement because of the Spanish component]

The World Health Organization characterizes health as a state of mental, physical and social well-being. Consistent with this construct of health, the SF36, a short-form HRQOL scoring system with 36 items, is a self-administered questionnaire that was constructed to fill the gap between much more lengthy surveys and relatively coarse single-item measures of the HRQOL [2, 12, 20]. It consists of 36 questions, 35 of which form into eight multi-item scales:

- (1) Physical functioning is a ten-question scale that captures abilities to deal with the physical requirement of life, such as attending to personal needs, walking, and flexibility;
- (2) Role-physical is a four-item scale that evaluates the extent to which physical capabilities limit activity;
- (3) Bodily pain is a two-item scale that evaluates the perceived amount of pain experienced during the previous 4 wk and the extent to which that pain interfered with normal work activities;
- (4) General health is a five-item scale that evaluates general health in terms of personal perception;
- (5) Vitality is a four-item scale that evaluates feelings of pep, energy, and fatigue;
- (6) Social functioning (SF) is a two-item scale that evaluates the extent and amount of time, if any, that physical health or emotional problems interfered with family, friends, and other social interactions during the previous 4 wk;
- (7) Role-emotional (RE) is a three-item scale that evaluates the extent, if any, to which emotional factors interfere with work or other activities; and
- (8) Mental health is a five-item scale that evaluates feelings principally of anxiety and depression.

The RAND Physical Health Composite (PHC) from the SF-36 will be used to define the second of the two co-primary outcomes for the trial. The short-form 36 (SF-36) is one of the most commonly used instruments to measure patient-reported health related quality of life in the world, and its 36 items making 8 subscales and 2 summary scales (physical and mental components) have been tested extensively for reliability, validity, and responsiveness in HD patients. [Allen, 2002;Beusterien, 1996;Cagney, 2000;DeOreo, 1997;Diaz-Buxo, 2000;Edgell, 1996;Levin, 1993;Merkus, 1997;Meyer, 1994;Rettig, 1997] The survey is well accepted by HD patients, taking only 5 to 10 minutes to complete. [Kurtin, 1992;Rettig, 1997]. Studies in nocturnal hemodialysis patients have shown an improvement in both PCS and MCS scores from baseline [Brissenden, 1998;Kooistra, 1998;Lockridge, 1999;McPhatter, 1999;Mohr, 1999]. The minimal clinically important difference for a change in each of these scores has been suggested to be 3 to 5 points. [Hays, 2001;Samsa, 1999]

The RAND PHC score is used as a component of a co-primary outcome rather than one of the SF-36 summary scales (PCS, MCS) because the PCS and MCS can in some cases produce

distorted results. [Simon, 1998] In one study, for example, the MCS failed to detect major clinical differences associated with disease progression, despite significant differences in its component subscales. [Norvedt, 2000] The RAND PHC is based on the same SF-36 scales as the PCS score (physical function, role-physical, pain, general health perceptions). Unlike the PCS, however, the scoring algorithm used to calculate the PHC is based on non-orthogonal factor rotation. [Hays, 1998] This allows the PHC to correlate with mental health, unlike the PCS.

Health Utilities Index (HUI) [Archive note: *This instrument was completed in English and Spanish. It required a licensing agreement.*]

The Health Utilities Index, Mark 3 (HUI3) is a 21-item generic health instrument for determining the overall utility associated with particular health states. The HUI questionnaire is composed of eight attributes of high importance to members of the general population: vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain. A preference-based scoring function, based on multi-attribute utility theory, allows one to convert questionnaire responses into a measure of overall health utility, which can then be used to calculate quality-adjusted life years (QALYs) in clinical trials. In the London study, the HUI showed differential responsiveness to change in nocturnal versus conventional HD patients during longitudinal follow-up. Test-retest reliability at 4 weeks was a 0.77. HUI scores will be used for quality-adjustment of survival time in the economic evaluation of this trial. [Archive note: *'HUI scores will be used for quality-adjustment of survival time in the economic evaluation of this trial' was not done during the course of the trials.*]

Beck Depression Inventory [Archive note: *This instrument required a licensing agreement and the data collection form was not permitted to be displayed on the FHN website. This instrument was completed in English and Spanish.*]

The Beck Depression Index (BDI), a 21-question validated survey presented in multiple-choice format, measures the presence and degree of depression in adults. Each of the answers is scored on a 0 to 3 scale, and inventory items correspond to a specific category of depressive symptom and/or attitude. BDI results are highly correlated with psychiatrists' ratings using the Hamilton Rating Scale (0.75-0.80). Based on a pooled analysis of studies in primary care, the sensitivity and specificity of the BDI in detecting moderate-severe depression are approximately 90 and 56%, respectively. Depressive symptoms are frequently encountered in patients with ESRD. The BDI has been frequently used to assess depression in patients with ESRD [14, 31-33]. High scores on the BDI are associated with mortality in this patient population.

The Medical Outcomes Study (MOS) Sleep Problems Index (SPI)

The Medical Outcomes Study (MOS) Sleep Problems Index (SPI) is a 12-item measure that includes items on sleep initiation and maintenance, sleep adequacy, daytime somnolence, and respiratory disturbance; 10 items of the SPI are summed to obtain an overall sleep score [34]. Subjects are instructed to relate responses to sleep habits over the previous month. The SPI showed good internal consistency reliability (Cronbach's alpha = 0.70) and discriminative validity, with lower (worse) overall sleep scores in HD patients versus patients without known kidney disease [34].

Caregiver Burden

The self-perceived burden scale is a measure to identify patients in emotional distress due to feelings of being a burden on others, and as an outcome measure in intervention studies. The conceptual framework and scale items were derived from previous literature and from qualitative interviews with patients and health professionals. This survey was administered in a construct validation to 100 outpatients undergoing hemodialysis. A 10-item abbreviation of the survey had an alpha = 0.85 [Cousineau, 2003] and this abbreviated version will be used in the FHN study.

Dialysis Specific Questions

There will be eight items specifically related to the frequent dialysis outcomes including time to recovery after dialysis, preference for dialysis modality, global quality of life, and three of the items regarding sexual function. The questions on sexual function will not be administered to minors enrolled in the study.

8.4 Script For the Telephone Administration Of The FHN HRQOL Survey

Hi, my name is ____ and I'm calling you from the University of Pittsburgh. I am calling on behalf of the Frequent Hemodialysis Study to conduct an interview with you. As you may recall, you recently agreed to participate in a randomized clinical trial evaluating the quality of life of dialysis patients. The survey will take about 40 minutes and your answers will be kept completely confidential. It's important that you answer as honestly and as accurately as possible.

1. YES
2. CALL BACK
3. TERMINATE CALL

Q:GENINTR

The following questions ask your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

If you are unsure about how to answer a question, please give the best answer you can. You may feel that some of these questions do not apply to you, but it is important that we ask the same questions of everyone. Also, a few questions are similar; please excuse the apparent overlap and answer each question independently.

All information you provide is confidential. There are no right or wrong answers; what we want is your opinion about your abilities and feelings.

Q:SFINTRO

These first questions are about your health now and your current daily activities. Please try to answer every question as accurately as you can.

Q:SF5

In general, would you say your health is....?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor
8. DON'T KNOW
9. REFUSED

Q:SF6

Compared to one year ago, how would you rate your health in general now? Would you say it is:

1. Much better now than one year ago
2. Somewhat better now than one year ago
3. About the same as one year ago
4. Somewhat worse now than one year ago
5. Much worse than one year ago
8. DON'T KNOW
9. REFUSED

Q:SF7a

Now I'm going to read a list of activities that you might do during a typical day. As I read each item, please tell me if your health now limits you a lot, limits you a little, or does not limit you at all in these activities.

First, vigorous activities such as running, lifting heavy objects, or participating in strenuous sports. Does your health now limit you a lot, limit you a little, or not limit you at all?

[INTERVIEWER: IF RESPONDENT SAYS S/HE DOES NOT DO ACTIVITY, PROBE:

"Is that because of your health?"]

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all
8. DON'T KNOW
9. REFUSED

Q:SF7b

. moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf? Does your health now limit you a lot, limit you a little, or not limit you at all?

[INTERVIEWER: IF RESPONDENT SAYS S/HE DOES NOT DO ACTIVITY, PROBE:

"Is that because of your health?"]

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all
8. DON'T KNOW
9. REFUSED

Q:SF7c

. lifting or carrying groceries? Does your health now limit you a lot, limit you a little, or not limit you at all?

[INTERVIEWER: IF RESPONDENT SAYS S/HE DOES NOT DO ACTIVITY, PROBE:

"Is that because of your health?"]

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all
8. DON'T KNOW
9. REFUSED

Q:SF7d

. climbing several flights of stairs? Does your health now limit you a lot, limit you a little, or not limit you at all?

[INTERVIEWER: IF RESPONDENT SAYS S/HE DOES NOT DO ACTIVITY, PROBE:

"Is that because of your health?"]

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all
8. DON'T KNOW
9. REFUSED

Q:SF7e

. climbing one flight of stairs? Does your health now limit you a lot, limit you a little, or not limit you at all?

[INTERVIEWER: IF RESPONDENT SAYS S/HE DOES NOT DO ACTIVITY, PROBE:

"Is that because of your health?"]

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all
8. DON'T KNOW
9. REFUSED

Q:SF7f

. bending, kneeling, or stooping? Does your health now limit you a lot, limit you a little, or not limit you at all?

[INTERVIEWER: IF RESPONDENT SAYS S/HE DOES NOT DO ACTIVITY, PROBE:

"Is that because of your health?"]

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all
8. DON'T KNOW
9. REFUSED

Q:SF7g

. walking more than a mile? Does your health now limit you a lot, limit you a little, or not limit you at all?

[INTERVIEWER: IF RESPONDENT SAYS S/HE DOES NOT DO ACTIVITY, PROBE:

"Is that because of your health?"]

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all
8. DON'T KNOW
9. REFUSED

Q:SF7h

. walking several blocks? Does your health now limit you a lot, limit you a little, or not limit you at all?

[INTERVIEWER: IF RESPONDENT SAYS S/HE DOES NOT DO ACTIVITY, PROBE:
"Is that because of your health?"]

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all
8. DON'T KNOW
9. REFUSED

Q:SF7i

. walking one block? Does your health now limit you a lot, limit you a little, or not limit you at all?

[INTERVIEWER: IF RESPONDENT SAYS S/HE DOES NOT DO ACTIVITY, PROBE:
"Is that because of your health?"]

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all
8. DON'T KNOW
9. REFUSED

Q:SF7j

. bathing or dressing yourself? Does your health now limit you a lot, limit you a little, or not limit you at all?

[INTERVIEWER: IF RESPONDENT SAYS S/HE DOES NOT DO ACTIVITY, PROBE:
"Is that because of your health?"]

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all
8. DON'T KNOW
9. REFUSED

Q:SF8a

The following four questions ask about your physical health and your daily activities.

During the past 4 weeks, have you had to cut down on the amount of time you spent on work or other activities as a result of your physical health?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:SF8b

During the past 4 weeks, have you accomplished less than you would like as a result of your physical health?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:SF8c

During the past 4 weeks, were you limited in the kind of work or other regular daily activities you do as a result of your physical health?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:SF8d

During the past 4 weeks, have you had difficulty performing work or other regular daily activities, as a result of your physical health? For example, it took extra effort?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:SF9a

The following three questions ask about your emotions and your daily activities.

During the past 4 weeks, have you had to cut down the amount of time you spent on work or other activities as a result of any emotional problems, such as feeling depressed or anxious?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:SF9b

During the past 4 weeks, have you accomplished less than you would like as a result of any emotional problems, such as feeling depressed or anxious?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:SF9c

During the past 4 weeks, did you not do work or other regular daily activities as carefully as usual as a result of any emotional problems, such as feeling depressed or anxious?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:SF10

During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Has it interfered...

1. Not at all
2. Slightly
3. Moderately
4. Quite a bit
5. Extremely
8. DON'T KNOW
9. REFUSED

Q:SF11

How much bodily pain have you had during the past 4 weeks? Have you had...

1. None
2. Very Mild
3. Mild
4. Moderate
5. Severe
6. Very Severe
8. DON'T KNOW
9. REFUSED

Q:SF12

During the past 4 weeks, how much did pain interfere with your normal work, including both work outside the home and housework?

1. Not at all
2. Slightly
3. Moderately
4. Quite a bit
5. Extremely
8. DON'T KNOW
9. REFUSED

Q:SF13INT

The next questions are about how you feel and how things have been with you during the past 4 weeks.

As I read each statement, please give the one answer that comes closest to the way you have been feeling; is it all of the time, most of the time, a good bit of the time, some of the time, a little bit of the time, or none of the time?

Q:SF13a

How much of the time during the past 4 weeks ... did you feel full of pep?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SF13b

How much of the time during the past 4 weeks ... have you been a very nervous person?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SF13c

How much of the time during the past 4 weeks ... have you felt so down in the dumps that nothing could cheer you up?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SF13d

How much of the time during the past 4 weeks ... have you felt calm and peaceful?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SF13e

How much of the time during the past 4 weeks ... did you have a lot of energy?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SF13f

How much of the time during the past 4 weeks ... have you felt downhearted and blue?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SF13g

How much of the time during the past 4 weeks ... did you feel worn out?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SF13h

How much of the time during the past 4 weeks ... have you been a happy person?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SF13i

How much of the time during the past 4 weeks ... did you feel tired?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SF14

These next questions are about your health and health-related matters.

During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities, like visiting with friends, relatives, etc.?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time
8. DON'T KNOW
9. REFUSED

Q:SF15a

Now I'm going to read a list of statements. After each one, please tell me if it is definitely true, mostly true, mostly false, or definitely false. If you don't know, just tell me.

I seem to get sick a little easier than other people. Would you say that's ...

1. Definitely True
2. Mostly True
3. Don't Know
4. Mostly False
5. Definitely False
9. REFUSED

Q:SF15b

I am as healthy as anybody I know. Would you say that's...

1. Definitely True
2. Mostly True
3. Don't Know
4. Mostly False
5. Definitely False
9. REFUSED

Q:SF15c

I expect my health to get worse. Would you say that's...

1. Definitely True
2. Mostly True
3. Don't Know
4. Mostly False
5. Definitely False
9. REFUSED

Q:SF15d

My health is excellent. Would you say that's

1. Definitely True
2. Mostly True
3. Don't Know
4. Mostly False
5. Definitely False
9. REFUSED

Q:HUINTRO

The next set of questions asks about various aspects of your health. When answering these questions we would like you to think about your health and your ability to do things on a day-to-day basis, during the past week. To define the past week period, please think about what the date was 7 days ago and recall the major events that you have experienced during this period. Please focus your answers on your abilities, disabilities and how you have felt during the past week. You may feel that some of these questions do not apply to you, but it is important that we ask the same questions of everyone. Also, a few questions are similar; please excuse the apparent overlap and answer each question independently.

Q:HU5

During the past week, have you been able to see well enough to read ordinary newspaper WITHOUT glasses or contact lenses?

1. YES – SKIP TO HU8
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU6

Have you been able to see well enough to read ordinary newsprint WITH glasses or contact lenses?

1. YES – SKIP TO HU8
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU7

During the past week, have you been able to see at all?

1. YES
2. NO - SKIP TO HU10
8. DON'T KNOW
9. REFUSED

Q:HU8

During the past week, have you been able to see well enough to recognize a friend on the other side of the street WITHOUT glasses or contact lenses?

1. YES - SKIP TO HU10
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU9

Have you been able to see well enough to recognize a friend on the other side of the street WITH glasses or contact lenses?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU10

During the past week, have you been able to hear what is said in a group conversation with at least three other people WITHOUT a hearing aid?

1. YES – SKIP TO HU15
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU11

Have you been able to hear what is said in a group conversation with at least three other people WITH a hearing aid?

1. YES – SKIP TO HU13
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU12

During the past week, have you been able to hear at all?

1. YES
2. NO – SKIP TO HU15
8. DON'T KNOW
9. REFUSED

Q:HU13

During the past week, have you been able to hear what is said in a conversation with one other person in a quiet room WITHOUT a hearing aid?

1. YES – SKIP TO HU15
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU14

Have you been able to hear what is said in a conversation with one other person in a quiet room WITH a hearing aid?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU15

During the past week, have you been able to be understood COMPLETELY when speaking your own language with people who do not know you?

1. YES – SKIP TO HU20
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU16

Have you been able to be understood PARTIALLY when speaking with people who do not know you?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU17

During the past week, have you been able to be understood COMPLETELY when speaking with people who know you well?

1. YES – SKIP TO HU20
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU18

Have you been able to be understood PARTIALLY when speaking with people who know you well?

1. YES – SKIP TO HU20
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU19

During the past week, have you been able to speak at all?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU20

During the past week, have you been able to bend, lift, jump and run WITHOUT DIFFICULTY and WITHOUT HELP OR EQUIPMENT of any kind?

1. YES – SKIP TO HU28
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU21

Have you been able to walk around the neighborhood WITHOUT DIFFICULTY and WITHOUT HELP OR EQUIPMENT of any kind?

1. YES – SKIP TO HU28
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU22

Have you been able to walk around the neighborhood WITH DIFFICULTY but WITHOUT HELP OR EQUIPMENT of any kind?

1. YES – SKIP TO HU28
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU23

During the past week, have you been able to walk at all?

1. YES - SKIP TO HU26
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU24

Have you needed mechanical support, such as braces or a cane or crutches, to be able to walk around the neighborhood?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU25

Have you needed the help of another person to walk?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU26

Have you needed a wheelchair to get around the neighborhood?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU27

Have you needed the help of another person to get around in the wheelchair?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU28

During the past week, have you had the FULL USE of both hands and ten fingers?

1. YES – SKIP TO HU32
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU29

Have you needed the help of another person because of limitations in the use of your hands or fingers?

1. YES
2. NO - SKIP TO HU31
8. DON'T KNOW
9. REFUSED

Q:HU30

Have you needed the help of another person with some tasks, most tasks, or all tasks?

1. SOME TASKS
2. MOST TASKS
3. ALL TASKS
8. DON'T KNOW
9. REFUSED

Q:HU31

Have you needed special equipment, for example special tools to help with dressing or eating, because of limitations in the use of your hands or fingers?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU32

During the past week, have you been able to eat, bathe, dress and use the toilet without difficulty?

1. YES – SKIP TO HU35
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU33

Have you needed the help of another person to eat, bathe, dress or use the toilet?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU34

Have you needed special equipment or tools to eat, bathe, dress or use the toilet?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU35

During the past week, have you been feeling happy or unhappy?

1. HAPPY
2. UNHAPPY – SKIP TO HU37
8. DON'T KNOW
9. REFUSED

Q:HU36

Would you describe yourself as having felt:

1. Happy and interested in life, or - SKIP TO HU38
2. Somewhat happy? – SKIP TO HU38
8. DON'T KNOW
9. REFUSED

Q:HU37

Would you describe yourself as having felt:

1. Somewhat unhappy
2. Very unhappy
3. So unhappy that life was not worthwhile
8. DON'T KNOW
9. REFUSED

Q:HU38

During the past week, did you ever feel fretful, angry, irritable, anxious or depressed?

1. YES
2. NO – SKIP TO HU41
8. DON'T KNOW
9. REFUSED

Q:HU39

How often did you feel fretful, angry, irritable, anxious or depressed?

1. Rarely
2. Occasionally
3. Often
4. Almost always
8. DON'T KNOW
9. REFUSED

Q:HU40

During the past week did you feel EXTREMELY fretful, angry, irritable, anxious or depressed; to the point of needing professional help?

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:HU41

How would you describe your ability to remember things, during the past week:

1. Able to remember most things
2. Somewhat forgetful
3. Very forgetful
4. Unable to remember anything at all
8. DON'T KNOW
9. REFUSED

Q:HU42

How would you describe your ability to think and solve day to day problems, during the past week:

1. Able to think clearly and solve problems
2. Had a little difficulty
3. Had some difficulty
4. Had a great deal of difficulty
5. Unable to think or solve problems?
8. DON'T KNOW
9. REFUSED

Q:HU43

Have you had any trouble with pain or discomfort, during the past week?

1. YES
2. NO – SKIP TO HU45
8. DON'T KNOW
9. REFUSED

Q:HU44

How many of your activities, during the past week, were limited by pain or discomfort:

1. None
2. A few
3. Some
4. Most
5. All
8. DON'T KNOW
9. REFUSED

Q:HU45

Overall, how would you rate your health during the past week?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor
8. DON'T KNOW
9. REFUSED

Q:BDINTRO

The following questions consists of 21 groups of statements. Please listen to each group of statements carefully, and then pick out the one statement in each group that BEST describes the way YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.

Q:BD5

Here is the first group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I do not feel sad.
2. I feel sad.
3. I am sad all the time and I can't snap out of it.
4. I am so sad or unhappy that I can't stand it.
8. DON'T KNOW
9. REFUSED

Q:BD6

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I am not particularly discouraged about the future.
2. I feel discouraged about the future.
3. I feel I have nothing to look forward to.
4. I feel that the future is hopeless and that things can't improve.
8. DON'T KNOW
9. REFUSED

Q:BD7

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I do not feel like a failure.
2. I feel I have failed more than the average person.
3. As I look back on my life, all I see is a lot of failures.
4. I feel I am a complete failure as a person.
8. DON'T KNOW
9. REFUSED

Q:BD8

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I get as much satisfaction out of things as I used to.
2. I don't enjoy things the way I used to.
3. I don't get real satisfaction out of anything anymore.
4. I am dissatisfied or bored with everything.
8. DON'T KNOW
9. REFUSED

Q:BD9

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I don't feel particularly guilty.
2. I feel guilty a good part of the time.
3. I feel guilty most of the time.
4. I feel guilty all of the time.
8. DON'T KNOW
9. REFUSED

Q:BD10

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I don't feel I am being punished.
2. I feel I may be punished.
3. I expect to be punished.
4. I feel I am being punished.
8. DON'T KNOW
9. REFUSED

Q:BD11

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I don't feel disappointed in myself.
2. I am disappointed in myself.
3. I am disgusted with myself.
4. I hate myself.
8. DON'T KNOW
9. REFUSED

Q:BD12

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I don't feel I am any worse than anybody else.
2. I am critical of myself for my weaknesses or mistakes.
3. I blame myself all the time for my faults.
4. I blame myself for everything bad that happens.
8. DON'T KNOW
9. REFUSED

Q:BD13

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I don't have any thought of killing myself.
2. I have thoughts of killing myself, I would not carry them out.
3. I would like to kill myself.
4. I would kill myself if I had the chance.
8. DON'T KNOW
9. REFUSED

Q:BD14

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I don't cry anymore than usual.
2. I cry more now than I used to.
3. I cry all the time now.
4. I used to be able to cry, but now I can't cry even though I want to.
8. DON'T KNOW
9. REFUSED

Q:BD15

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I am no more irritated now than I ever am.
2. I get annoyed or irritated more easily than I used to.
3. I feel irritated all the time now.
4. I don't get irritated at all by the things that used to irritate me..
8. DON'T KNOW
9. REFUSED

Q:BD16

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I have not lost interest in other people.
2. I am less interested in other people than I used to be.
3. I have lost most of my interest in other people.
4. I have lost all of my interest in other people.
8. DON'T KNOW
9. REFUSED

Q:BD17

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I make decisions about as well as I ever could.
2. I put off making decisions more than I used to.
3. I have greater difficulty in making decisions than before.
4. I can't make decisions at all anymore.
8. DON'T KNOW
9. REFUSED

Q:BD18

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I don't feel I look any worse than I used to.
2. I am worried that I am looking old or unattractive.
3. I feel that there are permanent changes in my appearance that make me look unattractive.
4. I believe that I look ugly.
8. DON'T KNOW
9. REFUSED

Q:BD19

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I can work about as well as before.
2. It takes an extra effort to get started at doing something.
3. I have to push myself very hard to do anything.
4. I can't do any work at all.
8. DON'T KNOW
9. REFUSED

Q:BD20

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I can sleep as well as usual.
2. I don't sleep as well as I used to.
3. I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
4. I wake up several hours earlier than I used to and cannot get back to sleep.
8. DON'T KNOW
9. REFUSED

Q:BD21

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I don't get more tired than usual.
2. I get tired more easily than I used to.
3. I get tired from doing almost anything.
4. I am too tired to do anything.
8. DON'T KNOW
9. REFUSED

Q:BD22

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. My appetite is no worse than usual.
2. My appetite is not as good as it used to be.
3. My appetite is much worse now.
4. I have no appetite at all anymore.
8. DON'T KNOW
9. REFUSED

Q:BD23A

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I haven't lost much weight, if any, lately.
2. I have lost more than 5 pounds.
3. I have lost more than 10 pounds.
4. I have lost more than 15 pounds.
8. DON'T KNOW
9. REFUSED

Q:BD23B

I am purposely trying to lose weight by eating less:

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:BD24

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I am no more worried about my health than usual.
2. I am worried about physical problems such as aches and pains; or upset stomach; or constipation.
3. I am very worried about physical problems and it's hard to think of much else.
4. I am so worried about my physical problems that I can't think about much else.
8. DON'T KNOW
9. REFUSED

Q:BD25

Here is the next group of statements:

[PLEASE LISTEN TO EACH GROUP OF STATEMENTS CAREFULLY, AND THEN PICK OUT THE ONE STATEMENT THAT BEST DESCRIBES THE WAY YOU HAVE BEEN FEELING DURING THE PAST WEEK, INCLUDING TODAY.]

1. I have not noticed any recent change in my interest in sex.
2. I am less interested in sex than I used to be.
3. I am much less interested in sex.
4. I have lost interest in sex completely.
8. DON'T KNOW
9. REFUSED

Q:SD5

And now I have a few questions about your sleep during the past 4 weeks.

How long did it usually take for you to fall asleep during the past 4 weeks? Include both work and leisure time.

1. 0 - 15 minutes
2. 16 - 30 minutes
3. 31 - 45 minutes
4. 46 - 60 minutes
5. More than 60 minutes
8. DON'T KNOW
9. REFUSED

Q:SD6

On the average, how many hours did you sleep EACH NIGHT during the past 4 weeks?

INTERVIEWER: WRITE DOWN # OF HOURS PER NIGHT

PLEASE WRITE 88 FOR DON'T KNOW AND 99 FOR REFUSED

Q:SD7

How often during the past 4 weeks did you feel that your sleep was not quiet? For example where you experienced moving restlessly, feeling tense, speaking, etc., while sleeping.

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SD8

How often during the past 4 weeks did you feel that you had enough sleep to feel rested upon waking in the morning?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SD9

How often during the past 4 weeks did you awaken short of breath or with a headache?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SD10

How often during the past 4 weeks did you feel drowsy or sleepy during the day?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SD11

How often during the past 4 weeks did you have trouble falling asleep?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SD12

How often during the past 4 weeks did you awaken during your sleep time and have trouble falling asleep again?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SD13

How often during the past 4 weeks did you have trouble staying awake during the day?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SD14

How often during the past 4 weeks did you snore during your sleep?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SD15

How often during the past 4 weeks did you take naps (5 minutes or longer) during the day?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q:SD16

How often during the past 4 weeks did you get the amount of sleep you needed?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little bit of the time
6. None of the time
8. DON'T KNOW
9. REFUSED

Q: BSINTRO

OK, that's all of the sleep questions. Now I will ask you some other types of questions.

We are interested in how you feel about the relationship that you have with the person or people who help you out with your day-to-day activities. You may need a little bit of help with things like shoveling snow and carrying groceries, or a lot of help, like driving you to dialysis or preparing meals. The person who helps you may be a friend, neighbor, or a member of your family – someone who is NOT paid to help you. We will refer to this person as your caregiver.

For each of the statements that I read, please tell me how often you feel this way. Is it none of the time, a little of the time, some of the time, most of the time, or all of the time?

Q:BS5

I worry that the health of my caregiver could suffer as a result of caring for me.

1. None of the time
2. A little of the time
3. Some of the time
4. Most of the time
5. All of the time
8. DON'T KNOW
9. REFUSED

Q:BS6

I worry that my caregiver is overextending him/herself in helping me.

1. None of the time
2. A little of the time
3. Some of the time
4. Most of the time
5. All of the time
8. DON'T KNOW
9. REFUSED

Q:BS7

I am concerned that it costs my caregiver a lot of money to care for me.

1. None of the time
2. A little of the time
3. Some of the time
4. Most of the time
5. All of the time
8. DON'T KNOW
9. REFUSED

Q:BS8

I feel guilty about the demands that I make on my caregiver.

1. None of the time
2. A little of the time
3. Some of the time
4. Most of the time
5. All of the time
8. DON'T KNOW
9. REFUSED

Q:BS9

I am concerned that my caregiver is helping me beyond their capacity.

1. None of the time
2. A little of the time
3. Some of the time
4. Most of the time
5. All of the time
8. DON'T KNOW
9. REFUSED

Q:BS10

I am concerned that I am "too much trouble" to my caregiver.

1. None of the time
2. A little of the time
3. Some of the time
4. Most of the time
5. All of the time
8. DON'T KNOW
9. REFUSED

Q:BS11

I am concerned that because of my illness, my caregiver is trying to do too many things at once.

1. None of the time
2. A little of the time
3. Some of the time
4. Most of the time
5. All of the time
8. DON'T KNOW
9. REFUSED

Q:BS12

I am confident that my caregiver can handle the demands of caring for me.

1. None of the time
2. A little of the time
3. Some of the time
4. Most of the time
5. All of the time
8. DON'T KNOW
9. REFUSED

Q:BS13

I think that I make things hard on my caregiver.

1. None of the time
2. A little of the time
3. Some of the time
4. Most of the time
5. All of the time
8. DON'T KNOW
9. REFUSED

Q:BS14

I feel that I am a burden to my caregiver.

1. None of the time
2. A little of the time
3. Some of the time
4. Most of the time
5. All of the time
8. DON'T KNOW
9. REFUSED

Q:SS5A

Okay, we have one last set of questions to go.

First of all, how long does it take you to recover from a dialysis session and resume your normal, usual activities?

INTERVIEWER: RECORD QUANTITY HERE AND UNITS ON NEXT SCREEN.

ENTER 88 FOR DON'T KNOW AND 99 FOR REFUSED.

IF (88 OR 99) SKIP TO SS6

Q:SS5B

Units of measure in previous question:

1. MINUTES
2. HOURS
3. DAYS

Q:SS6

On a scale from 0 to 100, with 0 being “no inconvenience” and 100 being “extreme inconvenience,” how inconvenient do you find dialysis?

Q:SS7A

Have you missed any pills in the past week?

1. YES
2. NO – SKIP TO SS8
8. DON'T KNOW – SKIP TO SS8
9. REFUSED – SKIP TO SS8

Q:SS7B

EXCEPT for your phosphate binders, have you missed any pills in the last week?

INTERVIEWER NOTE: PHOSPHATE BINDERS INCLUDE, BUT ARE NOT LIMITED TO: TUMS, OSCAL, CALCIUM CARBONATE, CALCIUM ACETATE (PHOS-LO), RENAGEL, LANTHANUM CARBONATE, ETC. THESE PILLS ARE TAKEN WITH EACH MEAL TO BIND TO THE PHOSPHORUS.

1. YES
2. NO
8. DON'T KNOW
9. REFUSED

Q:SS8

The next three questions are personal and relate to your sexual activity, but your answers are important in understanding how kidney disease impacts on people's lives.

Have you had any sexual activity in the past 4 weeks?

1. YES
2. NO – SKIP TO SS11A IF FOLLOWUP2; END OF SURVEY IF BASELINE OR FOLLOWUP1
8. DON'T KNOW – SKIP TO SS11A IF FOLLOWUP2; END OF SURVEY IF BASELINE OR FOLLOWUP1
9. REFUSED – SKIP TO SS11A IF FOLLOWUP2; END OF SURVEY IF BASELINE OR FOLLOWUP1

Q:SS9

How much of a problem was each of the following in the past 4 weeks?

Enjoying sex?

1. Not a problem
2. A little problem
3. Somewhat of a problem
4. Very much a problem
5. Severe problem
8. DON'T KNOW
9. REFUSED

Q:SS10

[HOW MUCH OF A PROBLEM WAS EACH OF THE FOLLOWING IN THE PAST 4 WEEKS?]

Becoming sexually aroused?

1. Not a problem
2. A little problem
3. Somewhat of a problem
4. Very much a problem
5. Severe problem
8. DON'T KNOW
9. REFUSED

QUESTIONS SS11A TO SS11C ARE ONLY ASKED IN FOLLOWUP 2

Q:SS11A

There are a number of different treatment options for patients with kidney failure. If you were eligible for all of the following treatments, which would you rank as your 1st preference?

1. Peritoneal dialysis
2. In-center 3 times weekly hemodialysis
3. In-center 6 times weekly hemodialysis
4. Home 6 times weekly daily hemodialysis
5. Home 6 times weekly nocturnal hemodialysis
6. Kidney transplant
7. NO PREFERENCE – SKIP TO FINALQ
8. DON'T KNOW – SKIP TO FINALQ
9. REFUSED – SKIP TO FINALQ

Q:SS11B

Which would be your 2nd preference?

1. Peritoneal dialysis
2. In-center 3 times weekly hemodialysis
3. In-center 6 times weekly hemodialysis
4. Home 6 times weekly daily hemodialysis
5. Home 6 times weekly nocturnal hemodialysis
6. Kidney transplant
7. NO 2ND PREFERENCE – SKIP TO FINALQ
8. DON'T KNOW – SKIP TO FINALQ
9. REFUSED – SKIP TO FINALQ

Q:SS11C

Which would be your 3rd preference?

1. Peritoneal dialysis
2. In-center 3 times weekly hemodialysis
3. In-center 6 times weekly hemodialysis
4. Home 6 times weekly daily hemodialysis
5. Home 6 times weekly nocturnal hemodialysis
6. Kidney transplant
7. NO 3RD PREFERENCE
8. DON'T KNOW
9. REFUSED

Q:FINALQ

That's all of my questions! Do you have any additional comments before we end the survey?

Q: THANKYOU

Thank you for your time!

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