

HEMO Study Form 48

QUALITY OF LIFE ASSESSMENT

SELF-ADMINISTERED

[English Version]

This form contains questions concerning how your life is affected by receiving dialysis treatments. Please answer the questions on the following pages to the best of your ability. The form will take approximately 45 minutes to complete. Please let us know if you have any difficulty completing the form.

This form combines questions from the Short Form 36 Health Survey, the Index of Well-Being, the Kidney and Dialysis Quality of Life™ questionnaire (KDQOL™) and questions developed for the Hemodialysis (HEMO) Study.

*The development of the KDQOL was supported by a subgrant from the University of Arizona to RAND and an unrestricted grant from Amgen to RAND. See reference: Hays, R.D., Kallich, J.D., Mapes, D.L., Coons, S.J., and Carter, W.B. (1994). Development of the Kidney Disease Quality of Life (KDQOL) Instrument. *Quality of Life Research*, 3, 329-338.*

HEMO Study Form 48. Quality of Life and Health Status Questionnaire

This questionnaire is to be completed during Baseline week 5 and annually during Follow-up at F12, F24, etc. The form is available in English and Spanish and in the Interviewer format in both English and Spanish. If patient is unable to complete form on his own, or requests help in administration, please use Form 49, the Interviewer-Administered version.

Detailed instructions for Form 48 are given in the Manual of Operations, Chapter 6. The patient should complete the form without help from others, including friends or family. The Study Coordinator should NOT interpret or explain questions for the patient or assist the patient in completion of the form, but may read the question verbatim for the patient.

Patients may leave a question blank if they are unable to or choose not to answer a question.

1. Patient Identification Number..... _ _ _ _ _
2. Patient Name Code _ _ _ _ _
3. Visit Date _ _ / _ _ / _ _
4. Visit Type..... _
5. Week/Month Number _ _ _
6. Was the assessment administered in (1 = English, 2 = Spanish)..... _

7. Here are some words and phrases we would like you to use to describe how you feel about your life **now**. For example, if you think your life is very "boring," circle "1." If you think it is very "interesting," circle "7." If you think it is somewhere in between, put the circle around the number where you think it belongs.

(Circle one number on each line)

a. Boring	1	2	3	4	5	6	7	Interesting
b. Miserable	1	2	3	4	5	6	7	Enjoyable
c. Hard	1	2	3	4	5	6	7	Easy
d. Useless	1	2	3	4	5	6	7	Worthwhile
e. Lonely	1	2	3	4	5	6	7	Friendly
f. Empty	1	2	3	4	5	6	7	Full
g. Discouraging	1	2	3	4	5	6	7	Hopeful
h. Tied down	1	2	3	4	5	6	7	Free
i. Disappointing	1	2	3	4	5	6	7	Rewarding
j. Doesn't give me much chance	1	2	3	4	5	6	7	Brings out the best in me

8. We have asked a little about various parts of your life. Now we want to ask about your life as a whole. How satisfied are you with your life as a whole **these days**? (Circle the single number which comes closest to how satisfied or dissatisfied you are with your life as a whole.)

(Circle one number on each line)

Completely satisfied	1	2	3	4	5	6	7	Completely dissatisfied
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YOUR HEALTH

9. In general, would you say your health is:

(Circle One Number)

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

10. **Compared to one year ago**, how would you rate your health in general now?

(Circle One Number)

Much better now than 1 year ago	1
Somewhat better now than 1 year ago	2
About the same as 1 year ago	3
Somewhat worse than 1 year ago	4
Much worse than 1 year ago	5

11. The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

(Circle One Number on Each Line)

	Yes, Limited a Lot	Yes, Limited a Little	No, Not Limited at All
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

d. Climbing several flights of stairs	1	2	3
e. Climbing one flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. Walking more than a mile	1	2	3
h. Walking several blocks	1	2	3
i. Walking one block	1	2	3
j. Bathing or dressing yourself	1	2	3

12. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

(Circle One Number on Each Line)

	Yes	No
a. Cut down the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Were limited in the kind of work or other activities	1	2
d. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

13. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

(Circle One Number on Each Line)

	Yes	No
a. Cut down the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Didn't do work or other activities as carefully as usual	1	2

14. 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?

(Circle One Number)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

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

(Circle One Number)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

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

(Circle One Number)

Not at all	1
A little bit	2
Moderately	3
Quite a bit	4
Extremely	5

17. These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the **past 4 weeks**:

(Circle One Number on Each Line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

18. 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)?

(Circle One Number)

All of the time	1
Most of the time	2
Some of the time	3
A little of the time	4
None of the time	5

19. How **true** or **false** is **each** of the following statements for you?

(Circle One Number on Each Line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

20. Did you do any regular "aerobic" exercise before kidney failure (such as walking, running, bicycling, swimming, etc.)?

(Circle One Number)

Yes, I exercised 3 or more times per week	1
Yes, but I exercised less than 3 times per week	2
No, I did no regular aerobic exercise	3

21. Do you now do any regular aerobic exercise?

(Circle One Number)

Yes, I exercise 3 or more times per week	1
Yes, but I exercise less than 3 times per week	2
No, I do no regular aerobic exercise	3

22. How **true** or **false** is **each** of the following statements for you?

(Circle One Number on Each Line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I make every moment count	1	2	3	4	5
b. I usually finish the important things I need to do each day	1	2	3	4	5
c. My kidney disease interferes too much with my life	1	2	3	4	5
d. I get very little done these days	1	2	3	4	5
e. Too much of my time is spent dealing with my kidney disease	1	2	3	4	5
f. I have enough time to accomplish the things I most want to do	1	2	3	4	5
g. I feel frustrated dealing with my kidney disease	1	2	3	4	5
h. I feel like a burden on my family	1	2	3	4	5

23. These questions are about how you feel and how things have been going during the **past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**...

(Circle One Number on Each Line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you isolate yourself from people around you?	1	2	3	4	5	6
b. Did you react slowly to things that were said or done?	1	2	3	4	5	6
c. Did you act irritable toward those around you?	1	2	3	4	5	6
d. Did you forget things that happened recently, for example, where you put things, appointments?	1	2	3	4	5	6
e. Did you make unreasonable demands on your family and friends?	1	2	3	4	5	6
f. Did you have difficulty doing activities involving concentration and thinking?	1	2	3	4	5	6
g. Did you have difficulty reasoning and solving problems; for example, making plans, making decisions, learning new things?	1	2	3	4	5	6
h. Did you get along well with other people?	1	2	3	4	5	6
i. Did you have trouble keeping your attention on an activity for long?	1	2	3	4	5	6
j. Did you become confused and start several activities at a time?	1	2	3	4	5	6

24. During the **past 4 weeks**, how many days did your **health** cause you to stay in bed for $\frac{1}{2}$ a day or more?

(Circle One Number)

Did not stay in bed	1
1 day	2
2 days	3
3 to 4 days	4
5 to 8 days	5
9 to 14 days	6
15 to 30 days	7

25. During the **past 4 weeks**, to what extent were you **bothered** by each of the following?

(Circle One Number on Each Line)

	Not at All	Somewhat	Moderately	Very Much	Extremely
a. Soreness in your muscles	1	2	3	4	5
b. Muscle spasms or twitching	1	2	3	4	5
c. Joint pain	1	2	3	4	5
d. Stiffening of joints	1	2	3	4	5
e. Ache in bones	1	2	3	4	5
f. Back pain	1	2	3	4	5
g. Chest pain	1	2	3	4	5
h. Headaches	1	2	3	4	5
i. Cramps during dialysis	1	2	3	4	5
j. Cramps after dialysis	1	2	3	4	5
k. Easy bruising	1	2	3	4	5
l. Itchy skin	1	2	3	4	5
m Dry skin	1	2	3	4	5
n. Trouble getting your breath	1	2	3	4	5
o. Shortness of breath	1	2	3	4	5
p. Faintness or dizziness	1	2	3	4	5
q. Lack of appetite	1	2	3	4	5
r. Loss of taste	1	2	3	4	5
s. Dry mouth	1	2	3	4	5
t. Excessive thirst	1	2	3	4	5

During the **past 4 weeks**, to what extent were you **bothered** by each of the following?

(Circle One Number on Each Line)

	Not at All	Somewhat	Moderately	Very Much	Extremely
u. Lack of strength	1	2	3	4	5
v. Fatigue, weakness	1	2	3	4	5
w. Washed out or drained	1	2	3	4	5
x. Numbness in hands or feet	1	2	3	4	5
y. Low blood pressure	1	2	3	4	5
z. High blood pressure	1	2	3	4	5
aa. Trouble concentrating or thinking	1	2	3	4	5
bb. Trouble with memory	1	2	3	4	5
cc. Swelling of ankles	1	2	3	4	5
dd. Hot or cold spells	1	2	3	4	5
ee. Trouble sleeping	1	2	3	4	5
ff. Sleepiness during the day	1	2	3	4	5
gg. Blurred vision	1	2	3	4	5
hh. Nausea or upset stomach	1	2	3	4	5
ii. Clotting or other problems with your access site	1	2	3	4	5

End of Part I

If you are splitting the form into two days stop here.

25.jj. Was the form done in one day or two days? (1=one day, 2=two days)....._____

**EFFECTS OF KIDNEY DISEASE
ON YOUR DAILY LIFE**

26. Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much do the effects of kidney disease **bother** you in each of the following areas?

(Circle One Number on Each Line)

	Not at All	Somewhat	Moderately	Very Much	Extremely
a. Fluid restrictions?	1	2	3	4	5
b. Dietary restrictions?	1	2	3	4	5
c. Limits on what you can do?	1	2	3	4	5
d. Your sleep?	1	2	3	4	5
e. Your ability to work around the house?	1	2	3	4	5
f. Your ability to work at a paying job?	1	2	3	4	5
g. Your family responsibilities?	1	2	3	4	5
h. Your family relationships?	1	2	3	4	5
i. Your relationships with friends?	1	2	3	4	5
j. Your ability to travel?	1	2	3	4	5
k. Your energy level?	1	2	3	4	5
l. Your ability to lift objects?	1	2	3	4	5
m. Being dependent on doctors and other medical staff?	1	2	3	4	5
n. Being dependent on a kidney machine?	1	2	3	4	5
o. Time available to get things done?	1	2	3	4	5

How much do the effects of kidney disease **bother** you in each of the following areas?

(Circle One Number on Each Line)

	Not at All	Somewhat	Moderately	Very Much	Extremely
p. How much money you have?	1	2	3	4	5
q. Stress or worries caused by kidney disease?	1	2	3	4	5
r. Your personal appearance?	1	2	3	4	5
s. Having to take medications for kidney disease?	1	2	3	4	5
t. Question omitted	-	-	-	-	-

This next question is personal, but your answers are important in understanding how kidney disease impacts on people's lives.

27. How much of a problem was each of the following during the **past 4 weeks**?

(Disregard this question.)

(Circle One Number on Each Line)

	Not A Problem	A Little Problem	Somewhat of a Problem	Very Much a Problem	Severe Problem
a. --	-	-	-	-	-
b. --	-	-	-	-	-
c. --	-	-	-	-	-
d. --	-	-	-	-	-
e. --	-	-	-	-	-

28. How often during the **past 4 weeks** did you...

(Circle One Number on Each Line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. have trouble falling asleep?	1	2	3	4	5	6
b. feel that your sleep was not quiet (moving restlessly, feeling tense, speaking, etc., while sleeping)?	1	2	3	4	5	6
c. get the amount of sleep you needed?	1	2	3	4	5	6

29. For each of the following statements please indicate whether these describe you during the past few days and are related to your state of health.

(Circle One Number on Each Line)

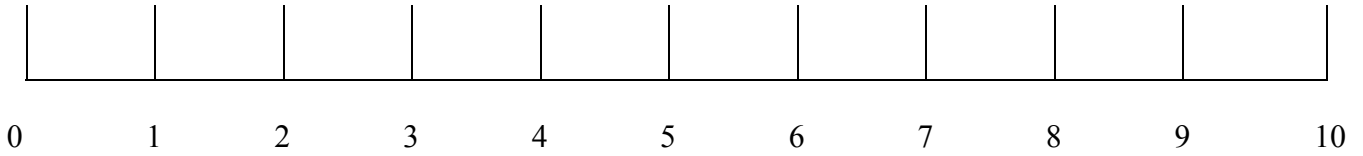
	Yes	No
a. I spend much of the day lying down in order to rest	1	2
b. I sit during much of the day	1	2
c. I am sleeping or dozing most of the time -- day and night	1	2
d. I lie down more often during the day in order to rest	1	2
e. I sit around half-asleep	1	2
f. I sleep less at night, for example, wake up too early, don't fall asleep for a long time, awaken frequently	1	2
g. I sleep or nap more during the day	1	2

30. On the average, how many hours do you sleep in a 24-hour period? (Please count any naps during the day as well as your sleep at night.)

Number of Hours:

31. On a scale from 0 to 10, how would you rate the quality of your sleep during the **past 4 weeks**?

(Circle One Number)

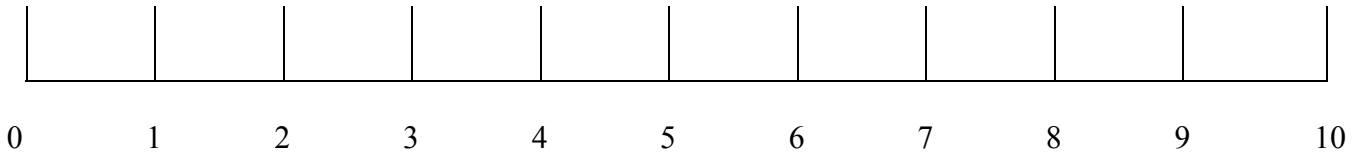


Poor Quality

High Quality

32. On a scale from 0 to 10, how much energy have you had during the **past 4 weeks**?

(Circle One Number)

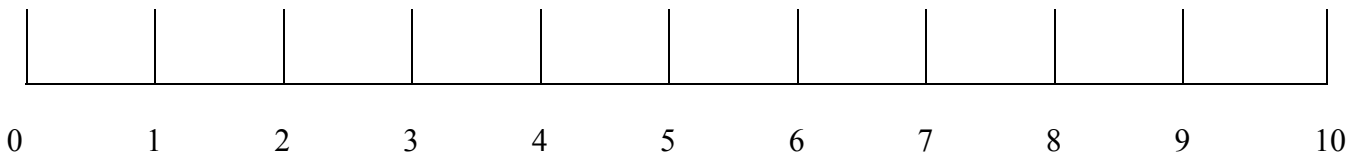


No energy at all

A great deal of energy

33. On a scale from 0 to 10, how would you rate your pain on average during the **past 4 weeks**?

(Circle One Number)

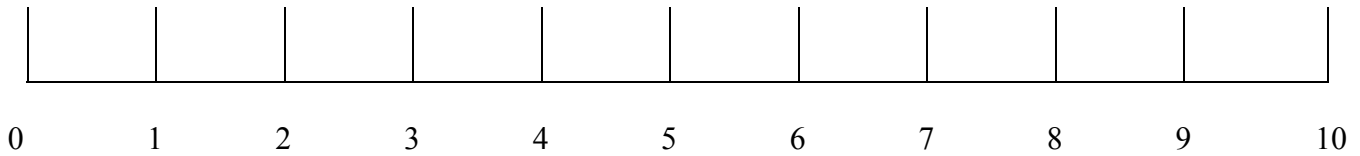


No pain

Pain as bad as you can imagine

34. On a scale from 0 to 10, how would you rate the extent to which you are able to do everything you'd like to do?

(Circle One Number)

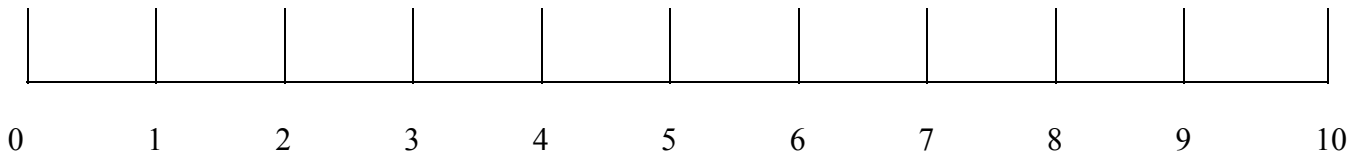


Able to do nothing

Able to do everything

35. Compare your life with kidney disease to the lives of people without kidney disease. On a scale from 0 to 10, how would you compare your life to that of people without kidney disease?

(Circle One Number)

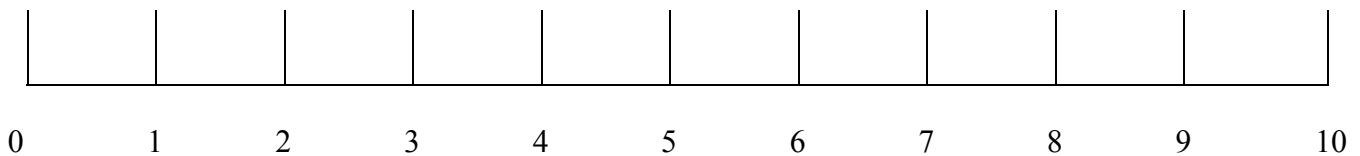


Completely different from people without kidney disease

The same as people without kidney disease

36. Overall, how would you rate your health?

(Circle One Number)



Worst possible (as bad or worse than being dead)

Half-way between worst and best

Perfect health

37. How do you feel about your life now?

(Circle One Number)

Delighted	1
Pleased	2
Mostly Satisfied	3
Mixed (About Equally Satisfied and Dissatisfied)	4
Mostly Dissatisfied	5
Unhappy	6
Terrible	7

38. During the last 7 days, how many "good" days and now many "bad" days did you have?
(Your total may range between 0 and 7 days)

Number of Good Days:

Number of Bad Days:

39. In terms of your **satisfaction** with your family and social life, circle one number to rate each of the following:

(Circle One Number on Each Line)

	Poor	Fair	Good	Very Good	Excellent
a. The amount of togetherness you have with your family or friends	1	2	3	4	5
b. The support and understanding your family or friends give you	1	2	3	4	5
c. The amount you talk things over with your family or friends	1	2	3	4	5

40. During the **past 4 weeks**, was someone available to help you if you needed and wanted help?

(Circle One Number)

Yes, as much as I wanted	1
Yes, quite a bit	2
Yes, some	3
Yes, a little	4
No, not at all	5

41. How many dialysis **staff** persons do you feel close to?

(Circle One Number)

None	1
1 to 3 staff members	2
4 or more staff members	3

42. How many dialysis **patients** do you feel close to?

(Circle One Number)

None	1
1 to 3 patients	2
4 or more patients	3

43. Think about the care you receive for kidney dialysis. In terms of your satisfaction, how would you rate your care at this facility?

(Circle One Number on Each Line)

	Very Poor	Poor	Fair	Good	Very Good	Excellent	The Best
a. Friendliness and interest shown in you as a person?	1	2	3	4	5	6	7
b. Care received overall	1	2	3	4	5	6	7

44. How **true** or **false** is each of the following statements?

(Circle One Number on Each Line)

	Definitely True	Mostly True	Neither True Nor False	Mostly False	Definitely False
a. The staff who care for me believe dialysis patients should work full-or part-time if they are able	1	2	3	4	5
b. Dialysis staff here encourage patients to lead as normal a life as possible	1	2	3	4	5
c. Dialysis staff here encourage me to be as independent as possible	1	2	3	4	5
d. The dialysis staff here work with me to develop an individualized care plan to meet my goals	1	2	3	4	5
e. Dialysis staff here counsel me on achieving full potential for rehabilitation	1	2	3	4	5
f. My family members and close friends believe dialysis patients should work full-or part-time if they are able	1	2	3	4	5
g. I believe most dialysis patients should work full- or part-time if they are able	1	2	3	4	5
h. Working full- or part-time would negatively affect the health of dialysis patients	1	2	3	4	5
i. Dialysis patients who have a job face discrimination at work because they are on dialysis	1	2	3	4	5

45. Think about your six dialysis treatments in the **past two weeks**. Think about how you have felt on your way to the dialysis unit *before* those dialysis treatments. How often have you felt...

(Circle One Number on Each Line)

	All of the Time	Most of the Time	Some of the Time	A Few Times	Rarely	Never
a. Weak	1	2	3	4	5	6
b. Low in energy	1	2	3	4	5	6
c. Worn out	1	2	3	4	5	6
d. Sluggish	1	2	3	4	5	6
e. Worry or dread about how I will feel during the dialysis treatment	1	2	3	4	5	6

46. Again, think about how you have felt on your way to the dialysis unit *before* your six dialysis treatments in the **past two weeks**. How often have you had...

(Circle One Number on Each Line)

	All of the Time	Most of the Time	Some of the Time	A Few Times	Rarely	Never
a. Shortness of breath	1	2	3	4	5	6
b. Headache	1	2	3	4	5	6
c. Bone, joint or back pain	1	2	3	4	5	6
d. Nausea	1	2	3	4	5	6
e. Itching	1	2	3	4	5	6

47. Think about the **past two weeks**. Think about how you have felt when you leave the dialysis unit *after* your six dialysis treatments. How often have you felt...

(Circle One Number on Each Line)

	All of the Time	Most of the Time	Some of the Time	A Few Times	Rarely	Never
a. Weak	1	2	3	4	5	6
b. Low in energy	1	2	3	4	5	6
c. Worn out	1	2	3	4	5	6
d. Sluggish	1	2	3	4	5	6
e. Dizzy or faint	1	2	3	4	5	6
f. Muscle cramps	1	2	3	4	5	6

48. Think about how you have felt *during* your six dialysis treatments in the **past two weeks**. During your treatments, how often have you had...

(Circle One Number on Each Line)

	During all of my treatments	During most of my treatments	During some of my treatments	During a few of my treatments	Rarely	Never
a. Itching	1	2	3	4	5	6
b. Thirst	1	2	3	4	5	6
c. Headache	1	2	3	4	5	6
d. Chest pain	1	2	3	4	5	6
e. Chills	1	2	3	4	5	6
f. Muscle cramps	1	2	3	4	5	6
g. Dizziness or light headedness	1	2	3	4	5	6
h. Fainting or passing out	1	2	3	4	5	6
i. Shortness of breath	1	2	3	4	5	6
j. Nausea	1	2	3	4	5	6
k. Pain in your dialysis access arm or hand	1	2	3	4	5	6
l. Uncomfortably warm or cold feeling	1	2	3	4	5	6
m. Vomiting	1	2	3	4	5	6
n. Restless feeling	1	2	3	4	5	6
o. Boredom	1	2	3	4	5	6
p. Bone or joint pain	1	2	3	4	5	6
q. Back pain	1	2	3	4	5	6
r. Trouble concentrating or trouble thinking clearly	1	2	3	4	5	6

49. Think about the **past two weeks**. How often did you...

(Circle One Number on Each Line)

	All of the Time	Most of the Time	Some of the Time	A Few Times	Rarely	Never
a. Get too little sleep at night	1	2	3	4	5	6
b. Have a poor night's sleep	1	2	3	4	5	6
c. Have trouble falling asleep at night	1	2	3	4	5	6
d. Wake up during the night	1	2	3	4	5	6
e. Find yourself kept awake by rest less legs	1	2	3	4	5	6
f. Awaken suddenly gasping for breath	1	2	3	4	5	6
g. Feel sleepy during the day	1	2	3	4	5	6
h. Use a sleeping pill	1	2	3	4	5	6

50. Think about the **past two weeks**. How many hours did you usually sleep at night?

(Circle One Number)

Less than 4 hours a night	1
4 to 5 hours a night	2
6 hours a night	3
7 hours a night	4
8 or more hours a night	5

51. Think about waking up at night in the **past two weeks**. What was the longest you stayed awake?

(Circle One Number)

Less than 5 minutes	1
6 to 19 minutes	2
20 to 59 minutes	3
1 to 2 hours	4
More than 2 hours	5

Questions 52 and 53 ask about any graft, fistula or catheter you have used for dialysis during the **past three months**.

52. During the **past three months**, how much physical pain have you had from problems with your dialysis access or from tests or operations on your access?

(Circle One Number)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

53. Think about the **past three months**. How much have problems with your dialysis access or tests or operations on your access interfered with the rest of your life? Please consider your work, other regular daily activities, and social activities with family, friends, neighbors or groups.

(Circle One Number)

Not at all	1
Very little	2
A moderate amount	3
A good deal	4
A great deal	5
A very great deal	6

Form 48, July 5, 1995

201. Date this form completed..... _ _ / _ _ / _ _

202. Certification number of person completing this form..... _ _ _ _

<p>Clinical Center Use Only</p> <p>Data Form Entered _ _ / _ _ / _ _</p> <p>Person Entering this Form</p>
