



Network

Consumer News

LARGE PRINT VERSION

Dialysis and Your (Health-related) Quality of Life

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Dialysis saves your life, but it can also change it. Depending on which type you choose, dialysis may change what you can eat and drink, how many medications you need, and what you can do each day. If you work, dialysis can make you more or less able to keep your job.

Health-related quality of life (HRQOL) is your rating of:

- Your own physical health
- Your own mental health
- How much of a burden kidney disease is

As it turns out, HRQOL is vital. Why? Because it predicts your risk of a hospital stay and a longer or shorter life. And there are steps you can take to improve your HRQOL and your chances of living long and well.

Taking the KDQOL-36 Survey

Your care team will measure HRQOL by asking you to take a survey called the KDQOL-36, which has 36 questions in 5 sections:

- Physical health
- Mental health
- Burden of kidney disease

- Symptoms and problems
- Effects of kidney disease on daily life

The questions ask things like, “During the past 4 weeks, how much were you bothered by itchy skin?”

There are no right or wrong answers. The point is just to find out how you feel about your own life in each of the five areas. The survey takes about 10-15 minutes to do. Not sure what to answer? Go with your first instinct. It’s best if you can complete the survey by yourself. A member of the care team may help you if you can’t—but answer honestly. The scores won’t mean a thing if you pretend to feel better than you really do.

You can choose not to take the KDQOL-36, or not to answer a question. Please answer the first 12 questions, though! Your clinic needs at least those 12 to look at your risk of poor outcomes and offer you help if you need it.

Medicare Requires HRQOL Surveys

New Medicare rules as of October 14, 2008, require clinics to give all adults on dialysis the KDQOL-36 at least once a year. The results must be used to help make a Plan of Care for you, to help you feel your best.

Having Medicare require the KDQOL-36 is a big deal!

A Life and Death Matter

The link between low HRQOL scores and the risk of hospital stays and death was first found more than 10 years ago.

A doctor gave a HRQOL survey to 1,000 people on dialysis. Two years later, those who rated their physical function low were more likely to have had a hospital stay. And, they were twice as likely to have died.

How to Improve YOUR Odds

When you take the KDQOL-36 survey, your clinic should give you your scores. If they don’t, ask for them! Your scores will be compared to people who are like you in age, gender, and diabetes status. Your scores and the comparison will tell you a lot about your own future risk.

Using the KDQOL-36 to measure HRQOL scores gives you and your clinic vital information that can't be found in any other way. Your care team will talk with you about your scores. They may ask you what you would like to focus on if your scores are not all where you would like them to be. If not, tell them what you want to work on.

Conclusion

Your HRQOL scores on the KDQOL-36 survey are vital clues about how well you are doing now, and may do in the future.

Anything that makes you feel better physically and/or mentally can help you to stay out of the hospital and live longer. So, set a goal. Take a step! Let your dialysis team help you reach your goal. Move forward toward a good life on dialysis.

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WANT TO KNOW MORE

Studies have found a number of things that can help improve HRQOL scores. Some of them might work for you.

This article was an abbreviated version of an article written by the Medical Education Institute, Inc. (MEI).

The original article contains specific things that can improve your scores in addition to references to research studies. You may locate the article at www.homedialysis.org.

If you would like a copy of the article or would like additional information, please contact Northwest Renal Network at

1.800.262.1514

or

Visit our website

www.nwrenalnetwork.org

LEARNING POINT

Improving your HRQOL improves your odds of living healthy, happier and longer.

RELATED WEB RESOURCES

American Association of Kidney Patients

www.aakp.org

National Kidney Foundation

www.kidney.org

Kidney School

www.kidneyschool.org

Home Dialysis Central

www.homedialysis.org

If you would like the information but do not have access to the Internet, please contact us:

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