

ESRD NETWORK 13

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KIDNEY CONCERNS

SUMMER/JULY 2005

ISSUE 52

Study finds happiness persists, despite illness: Study of dialysis patients yields surprising findings “Used by permission of the University of Michigan Health System.”

ANN ARBOR, Mich. — Despite what able-bodied healthy people might think, people with severe illnesses and disabilities don’t wallow in misery and self-pity all the time.

In fact, a new study finds, such patients on the whole may be just as happy as those without major medical conditions. The finding adds to the growing body of evidence that ill and disabled people adapt to their condition and show a resilience of spirit that many healthy people can’t imagine. It’s published in the new issue of the *Journal of Experimental Psychology: General* by a team led by University of Michigan Health System researchers.

The researchers made their surprising finding by having 49 pairs of dialysis patients and healthy people report their mood every few hours for a week, using a handheld personal digital assistant (PDA) such as a Palm. The patients had all been in dialysis for at least three months, visiting a hemodialysis center three or more times a week for hours at a time to have their blood cleaned because their kidneys had failed.

Lead author Jason Riis, a former U-M graduate student now at Princeton University, programmed the PDAs to beep randomly during each two-hour period of an entire week, and prompt participants to report their mood at those random moments by completing a quick series of ratings.

“The big advantage of using PDAs is that you can get representative snapshots of a person’s experience, rather than just relying on their overall impressions of their lives,” says Riis, adding that several studies have shown such overall impressions to be biased in a variety of ways. “Our snapshots revealed that the patients were in good moods the vast majority of the time, and that their moods were not substantially worse than those of the healthy people.”

“This is further evidence that people adapt emotionally to serious adversity, such as end-stage kidney failure,” says senior author Peter Ubel, M.D., a U-M professor of internal medicine and psychology, and a staff physician at the VA Ann Arbor Healthcare System. “People who haven’t experienced such adversity assume that it would destroy their happiness when in truth it probably would not.”

In fact, the researchers found that the healthy participants grossly underestimated the extent to which patients can adapt to dialysis. When asked to imagine that they were themselves dialysis patients, and to estimate the percentage of time that they would experience various positive and negative mood levels, the healthy participants assumed that they would be miserable.

They thought they would experience negative moods most of the time, and on average have moods that were much lower than what the real patients actually experienced.

Interestingly, the patients themselves seemed to underestimate their own adaptation. When asked to imagine the moods they would experience if they had never experienced kidney failure, the patients estimated that they would experience much better moods than those actually experienced by the healthy study participants.

The study involved healthy participants whose age, gender, race and education were similar to the patients. In all, 60 participants were white, 36 were black, and one was Hispanic.

The study does more than just give the first-ever glimpse into the hour-by-hour happiness of seriously ill and healthy people, Ubel notes. It may also help influence policy-level and personal decisions about treatments for serious illnesses.

For instance, someone who has been healthy but who is facing a decision about whether or not to have a colostomy, an amputation or a risky operation might worry that the procedure would make his or her life miserable. But in fact, it probably wouldn’t.



That's not to say that a major health catastrophe doesn't change a person's life, nor that going on dialysis, losing a limb or using a wheelchair doesn't change a person's experience of life, Ubel says. It's also not to say that such a major change wouldn't come without periods of frustration and difficulty, risk of depression or effects on a person's social or economic situation.

But the evidence from the new study, and from studies before it, suggests that people who have gone through such changes tend to adapt their emotional response to their new life. In the words of some of Ubel's patients, "What use is there in complaining?"

"People are more resilient than they think they can be, and can get through things that they probably would have never thought they could," says Ubel. "The fact that people seem to be so poor at estimating the effect of illness on mood calls into question some of the ways we use such quality-of-life estimates in policy making and research."

In addition to recording the "snapshots" of mood, and the predictions of what life would be like in the other group's shoes, the researchers also had the patients and healthy controls recall the moods they had experienced during the week they had carried the PDA. While healthy people slightly underestimated their previous week's average mood, the patients were quite accurate in recalling theirs. The researchers speculate that the patients' recall accuracy may be involved in the adaptation process, but say that further research is needed on this area.

The researchers now hope to expand the use of moment-based well-being measures to assess people with a range of health conditions, including those associated with pain and mental illness, where the adaptation story may be quite different.

There was no difference between the 49 patients and the 49 healthy participants in the average hour-by-hour rating of their overall mood, which on the whole tended to be on the positive side. There was also no difference between the two groups in the average measures of specific momentary moods, such as "depressed," "pleased" or "worried/anxious." Even questions about pain, tiredness and overall life satisfaction showed no significant differences.

In addition to Ubel and Riis, the study team included George Loewenstein of Carnegie Mellon University, Jonathan Baron and Christopher Jepson of the University of Pennsylvania, and Angela Fagerlin of the University of Michigan. Ubel directs, and Fagerlin is a member of, the U-M Program for Improving Health Care Decisions, www.pihcd.org.



Dialysis Facility Compare

Where do you go when you need information on other dialysis facilities in your area? A patient asks what unit in his area offers peritoneal dialysis or home dialysis, could you tell whom to contact? You have a patient that needs evening dialysis due to his job, could you tell him what unit offers evening hours? You want to compare your facility's quality measures with the units in your area, is there a place to go to find this? Now you can. The Dialysis Facility Compare (DFC) Web site www.medicare.gov provides both demographic information and 'quality measures' data about dialysis facilities that have been approved by Medicare.

What are the three quality measures?

- ✦ The percent of patients at a facility with Urea Reduction Ratio (URR) of 65 or greater (known as 'adequacy of hemodialysis').
- ✦ The percent of patients treated with Epogen® with a Hematocrit of 33 or greater. (URR and Hematocrit are based on 2002 data).
- ✦ Patient survival information. The survival data is based on the period from January 1999 to December 2002.

Before reviewing this data, be sure to view the Data Collection Details, Glossary, and adequacy, anemia, and survival data explanation, from the DFC Web site. The data is limited to Medicare beneficiaries and only those who are receiving hemodialysis.

The Web site also offers the dialysis facility characteristics.

- ✦ Address and telephone number of the facility
- ✦ The facility's initial date of Medicare certification
- ✦ Shifts starting at 5 PM or later (if you need your treatments in the evening)
- ✦ The number of treatment stations
- ✦ The types of dialysis offered (in-center hemodialysis, peritoneal dialysis, and home hemodialysis training)
- ✦ Facility ownership type (profit or non-profit)
- ✦ Chain name (if applicable)



Transplantation: Are You Informed?

By: Heather Powell-Network 13 Patient Advisory Member

I hope everyone is familiar with the word transplantation. A transplant is not for everyone, but I encourage you to speak with your doctor today if you are interested and find out if you are a good candidate. A transplant can be a wonderful experience, but as in all aspects of treatment you must do your part. What is your part you ask?

Let's look at the top 10 things that you need to know to be successful with a transplant:

#1- Know your transplant team (doctor, transplant coordinator, social worker, etc...): their names, positions, phone number. Don't be afraid to call them and ask questions. Follow your doctor's guidelines. If you don't understand something clarify it with your doctor or other health care team member. Your health care team is there to help you so you need to be able to communicate with them. Communication is a key component to any relationship!

#2- Know the signs and symptoms of rejection. Contact your transplant doctor as soon as possible if you think you are experiencing rejection. The earlier rejection is caught the better off you are.

#3- You will take medication for the lifetime of your transplant so know your medications well. Keep a list of the name, strength, and dose in your purse or wallet. Know their purpose, what they look like, and when to take them. Never quit taking them without your doctor's order. Never break or crush them. Get to know your pharmacist!

#4- Be aware of medication side effects and let your doctor know the ones you struggle with. Your doctor can help you or refer you to someone who can. Know if your medicine interacts with any food or other medications. Do not take any other medicine (even over the counter) without talking to your doctor first. Talk to your doctor before you get any vaccination as well.

#5- Keep your appointments for lab work and doctor visits. These are very important and will be on a weekly basis at first but will decrease as time goes on.

#6- Check your weight, temperature, and blood pressure daily. Any temperature, change in weight (3 to 5 lbs), or high blood pressure should be reported to your doctor.

#7- Be careful and avoid infections. Wash your hands often. Keep some liquid hand sanitizer in your purse, car, or on your person. You can also use antibacterial hand lotion. Avoid people with colds, coughs and other infections. Do not handle your pet's litter box or pick up after them...someone else will have to take over this job. Avoid sun exposure and wear sunscreen.

#8- Consult your transplant team before going to the dentist (this includes a general check up for teeth cleaning). You may need to take an antibiotic before you visit your dentist.

#9- Join a support group and share your experience. It is always good to hear from those that have "been there and done that". Knowing you are not alone in your experience is always beneficial.

#10- Resume your normal activity and enjoy your new lease on life. Eat healthy and enjoy the variety of foods you can have now that you couldn't have before. Drink lots of water! Include a daily exercise routine! Count your blessings!

Independent Order of Odd Fellows Grand Matriarch Project Provides Educational Gift

Mary Jo Smith- Grand Matriarch

A check in the amount of \$35 was presented to ESRD Network 13 by the Grand Ladies Encampment Auxiliary of the Independent Order of Odd Fellows in memory of JoRita Hamilton, past Grand Matriarch. The money will be utilized for patient education activities in her honor. Network 13 extends their appreciation for the gift in Ms. Hamilton's memory.

Weighing in on Fluid

By: Susan Knapp, MS RD LD

One of the biggest challenges that dialysis patients face every day is fluid control. This becomes even more difficult as urine volume decreases when residual kidney function declines.

Why is it important?

Excess fluid in the body can cause many problems. Some of these problems are swelling of the hands or feet (edema), swelling around the middle (ascites), high blood pressure, blood pressure drops and cramping during dialysis, feeling more “wiped-out” following dialysis, fluid in the lungs causing shortness of breath, damage to the heart, and heart failure.

How much fluid is enough?

How much dialysis patients can drink, depends upon how much urine they make, if any. A typical fluid allowance for most people on dialysis is a quart or liter per day. For those on hemodialysis, the best way to judge your fluid intake and balance is by how much weight you gain between treatments. Weigh yourself before and after each dialysis treatment. Goals for weight gains are usually 1 to 4% of your body weight. So, if you weigh 70 kilograms, your goal weight gains are between 0.7 and 2.8 kilograms, or 1.5 and 6.2 pounds. (One kilogram equals 2.2 pounds.) Your fluid recommendations may be given to you in terms of liters, milliliters (ml), cubic centimeters (cc), quarts or cups. Your health care team can help you to determine how much fluid is best for you and how much that is in terms of your measurements.

1 liter = 1000 cc = 1000 ml = 1 kg of water = 1 quart + 1 1/3 ounces

1 quart = 960 cc = Four 8-ounce cups = Two pints = 32 ounces

What counts as fluid?

Anything that melts or pours at room temperature counts as fluid. This includes all beverages, ice, soups, gelatin, pudding, popsicles, and ice cream. Fluid in food isn't usually counted, because it should equal fluid you lose in ways we can't measure, such as sweating. However, some foods such as fruits and vegetables do have a lot of fluid in them, 80 to 90%. If you are having problems with excess fluid gains these “juicy” foods may also need to be considered.

What affects fluid intake?

The main influences on fluid intake are (1) sodium intake, (2) blood sugars, if diabetic, (3) habit, and (4) others.

Sodium intake usually has the most affect on fluid intake. Fluid weight gains between dialysis treatments are usually directly related to sodium intake. The biggest source of sodium is salt—added at the table, by the cook, or by the manufacturer. Salt is sodium chloride. Salt contains approximately 2400mg. of sodium per teaspoon. The typical diet in America contains up to 8 grams (8000 mg.) of sodium. Usually a total of 2000 to 4000 mg. of sodium per day is recommended both for hemodialysis and peritoneal dialysis patients. Therefore the typical American diet has two to four times as much sodium as is recommended for those on dialysis.

If you are on peritoneal dialysis you may be able to be more liberal with sodium, but this varies between individuals. Just like with hemodialysis, excess sodium intake while on PD can increase thirst and lead to excess fluid weight gain. As a result you would need to use more concentrated dialysis solutions – which have higher dextrose (sugar) content. The frequent use of the higher dextrose solutions makes diabetes more difficult to control, causes dry weight gains, increases triglycerides (fat in the blood), and may decrease how well the peritoneal membrane is able to clean the blood.

Each 1-kilogram of fluid weight gain equals 1 liter of fluid, which is about 1 quart. It also equals approximately 3100 to 3350 mg of sodium (that is the normal amount of sodium in the blood). If your sodium level is normal and you gain 3 kilograms over 3 days, your average sodium intake would be about 3200mg times 3 kilograms divided by 3 days = 3200mg per day. This is close to the usual recommended sodium intake. If you gain twice as much, or 6 kilograms, your average sodium intake would also be twice as much (3200mg X 6 kg / 3 = 6400mg).



Even if you don't add any salt to the foods, your sodium intake can be quite high. There may be some hidden high sources of high sodium foods in your diet. You might want to work with your dietitian to help to identify some possible hidden high sodium sources in your diet. These may include sodium added by the manufacturer in the form of salt, monosodium glutamate (MSG), or various sodium compounds used for flavor enhancement or as preservatives. Foods that are high in sodium without the customer adding anything additional include preserved meats (hotdogs, ham), pickles, soups, olives, "helper" meals, and frozen or packaged dinners (like macaroni & cheese). A solution containing sodium, phosphorus, and potassium is frequently added to "fresh" meats to extend the shelf life of the product. This is referred to as enhancing. They are usually labeled as "Extra Juicy" or something similar. Although the label must indicate the additional sodium added, the print is usually very small. So look closely to be sure you are buying fresh, not "enhanced" meat. Eating out frequently can definitely be a source of excess sodium. Items to avoid or limit include condiments, gravies, and sauces. Many foods contain "hidden" sodium, whether eaten out or at home.

Try seasoning with some herbs and spices in place of salt or other high sodium seasonings. You might try growing an herb garden in containers to have some of your favorite herbs readily available. Some herbs that do well in pots that you might like to try are basil, chives, mint, parsley, rosemary, and thyme. Since drying concentrates the flavors, use 3 teaspoons of fresh herbs in place of 1 teaspoon of dried herbs. Spices such as cinnamon, nutmeg, fresh garlic or ginger, and pepper can be used to add flavor to your foods.

If you are diabetic, high blood sugars increase your thirst. Typical goals for good diabetic control with hemodialysis patients are: (1) HbA1c of less than 7% (which equals an average blood sugar of approximately 150), (2) fasting glucose level of less than 140 mg/dL, (3) glucose after eating of less than 200 mg/dL, and (4) avoidance of low blood sugar (hypoglycemic episodes). Work with your medical team to create and achieve appropriate goals for you. This may require adjusting your food intake and / or your medications. In addition to many other benefits, exercise helps with blood sugar control.

Drinking too much fluid also may be a result of habits that have developed over many years. Most of us have been told all of our lives to drink plenty of water. It is difficult to change behaviors and takes time – but it can be done. Your family and friends may not initially understand why, if you have kidney problems, you cannot drink to flush the kidneys and make them work. Educating others to not refill your drinks or encourage you to drink more may be very helpful.

Other things that can increase thirst include smoking, chewing tobacco, and poor teeth or oral health. Some medications may contribute to dry mouth or increased thirst. Examples of these include diuretics (water pills), some blood pressure medications, and antihistamines. Check with your pharmacist or physician if you think this may be problem for you.

Suggestions for Fluid Control

Ideas to decrease thirst:

- Suck on ice cubes or sugar-free popsicle
- Suck on sugar-free hard candy, especially sour candy like lemon drops
- Eat grapes that you have frozen
- Chew sugar-free gum, especially tart flavored, such as lemonade
- Rinse mouth with chilled water or alcohol-free mouthwash
- Spray mouth with water or flavored water using small spray bottles
- Use special products designed for dry mouth (gel, gum, mouthwash)
- Decrease sodium intake
- Control blood sugar
- Avoid smoking and chewing tobacco

Ideas to decrease fluid intake:

- Use small cups for drinking (instead of partially filled larger cups).
- Measure out the fluid allowance for the day and pour out an equivalent amount as it is consumed.
- Plan ahead to save enough fluid for swallowing pills.
- Use applesauce for swallowing pills.
- Postpone fluid intake. Thirst is usually greatest immediately following dialysis treatment. Delaying taking a drink for a few hours until the fluid re-distributes within the body can help decrease overall intake.



MEDICARE PART D - Application for Extra Help with Drug Plan Cost & Important Dates

The new Medicare prescription drug coverage, which begins January 1, 2006, will come with high out-of-pocket costs. Most people who enroll will pay a **monthly premium** (estimated to be about \$37) and as much as \$3,600 in deductible and coinsurance before their **out-of-pocket costs** go down to only 5 percent for each prescription. "Extra help" is a program that will help people with low incomes and assets pay for those out-of-pocket costs.

Social Security is mailing applications for extra help to people whose Social Security income is below the income limits for the program. You may be eligible for extra help even if you don't get an application from Social Security. Moreover, getting an application does not necessarily mean you will get extra help.

You are eligible for extra help if your 2005 monthly income is below \$1,197 (\$1,604 for couples) and your assets are below \$11,500 (\$23,000 for couples). In addition, some people are automatically eligible for extra help and do not have to apply for it, so they will not be getting applications in the mail. These are people who are enrolled in Medicaid, Supplemental Security Income (SSI) or a Medicare Savings Program (MSP).

If you are not enrolled in one of these programs, you can apply for extra help by filling out the print or online Social Security application. If you do not get one in the mail, you can get a print application by calling 800-772-1213. The online application is available at www.socialsecurity.gov.

Even if you think your income or assets are above the limit, you may still qualify because certain types of income and assets are not included. For example, your house and part of your earned income will not be counted.

The chart below shows the different levels of extra help available.

If you have Medicare and...	And your assets are...	Then your premium and deductible are...	And your copayment is...
Have Medicaid and			
2005 income below \$9,570—\$12,830 for couples (100 percent FPL)*	Below state Medicaid limits	\$0	\$1/generic and \$3/brand name (no copayment after \$5,100 in total annual drug costs)
2005 income above \$9,570—\$12,830 for couples (100 percent FPL includes Medicaid spend-down)	Below state Medicaid limits	\$0	\$2/generic and \$5/brand name (no copayment after \$5,100 in total annual drug costs)
Do not have Medicaid and			
Have 2005 income below \$12,920—\$17,321 for couples (135 percent FPL)	Below \$7,500 for individuals and \$12,000 for couples	\$0	\$2/generic and \$5/brand name (no copayment after \$5,100 in total annual drug costs)
Have 2005 income below \$14,356—\$19,246 for couples (150 percent FPL)	Below \$11,500 for individuals and \$23,000 for couples	Sliding scale monthly premium and \$50 deductible	15 percent coinsurance (\$2/generic and \$5/brand-name copayment after \$5,100 in total annual drug costs)

Important Dates 2005

July 1, 2005

SSA and States begin processing *Extra Help with Drug Plan Costs* applications and notifying applicants of decision.

On-Line *Extra Help with Drug Plan Costs* applications available at www.medicare.gov on the web.

September 15, 2005

CMS announces the approved Prescription Drug Plans and Medicare Advantage Plans for 2006.

October 13, 2005

Plan Compare tool available at www.medicare.gov on the web.

Medicare Personal Plan Finder available at www.medicare.gov on the web.

November 15, 2005

Open Enrollment in drug plans begins and runs through May 15, 2006.

January 1, 2006

Medicare Part B coverage begins for Medicare beneficiaries enrolled in a plan.

Look for more information on Medicare Part D in the October 2005 edition of Kidney Concerns

What Are My Options If I Have A Grievance?

STEP 1

Try your facility first...
 Contact your facility's social worker...
 Ask for and follow the facility's written grievance procedures...
 If not satisfied...

STEP 2

Contact the Network...
 Ask for the Patient Grievance Policy...
 Visit our Web site for a copy of the policy...
 Speak with the person in charge of Patient Services.

What is a grievance?

A grievance is any concern about treatment in a dialysis or transplant facility.
 A grievance may be filed by the patient, a family member, or another person acting on the patient's behalf (per HIPAA guidelines).
 A grievance referred to the Network are processed according to written grievance procedures.

What is the Network?

Network 13 is under contract with the Centers for Medicare & Medicaid Services to serve the states of Arkansas, Louisiana, and Oklahoma.
 The Network collects patient information and works to improve patient care in dialysis and transplant facilities. Processing written grievances and trying to resolve patient concerns is an important part of the quality improvement program.

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NIH Encourages African Americans to Talk About Kidney Disease

National Kidney Disease Education Program (NKDEP) Launches Initiative

The National Institutes of Health's (NIH) National Kidney Disease Education Program (NKDEP) is launching an initiative this week to encourage African Americans to use family reunions to talk to their families about their risks for kidney disease. According to the NIH press release, African Americans are four times more likely than whites to develop kidney failure. Diabetes and high blood pressure are the main factors in 70 percent of those kidney failure cases. Since high blood pressure and diabetes are hereditary, family reunions are a good place to talk about the issue. NKDEP has made available an online Kidney Connection Toolkit that contains all the information needed for individuals to inform their relatives on ways to prevent kidney disease.

The Kidney Connection Toolkit and additional information on the initiative may be found online at: www.nkdep.nih.gov/familyreunion.

Rehabilitation:

How Does Your Garden Grow?!

Katharine Buzzard, RN, CNN, Malvern Kidney Center

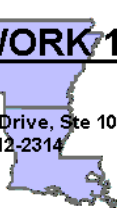
The head nurse, dietician and patients at Malvern Kidney Center have planted a renal friendly garden.

The garden is used for patient education for low potassium and phosphorus vegetables. The garden contains peppers, cabbage, cucumbers, collard greens, turnip greens and green beans. Vegetables are shared with patients at harvest time.



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Upcoming 2005 Patient Conventions

AAKP 32nd Annual Convention -
"Quality First: Patients Driving Excellence"
September 1-4, 2005 - Las Vegas NV
JW Marriott Las Vegas Resort & Spa
Contact AAKP National Office 800.749.2257
or visit www.aakp.org for brochure

RSN 2nd Annual Conference
Health, Happiness and Hope
September 29-October 1, 2005 - Chicago IL
Sheraton Hotel and Towers
Contact 818.543.0896 or
visit www.renalnetwork.org for brochure



KIDNEY KONCERNS NEEDS YOU!

Kidney Koncerns is published quarterly by the Patient Advisory Committee of ESRD Network 13.

The next edition is scheduled for Fall/October. To make this newsletter a success, we need your assistance. If you are interested in contributing to this newsletter, please send any articles, materials and/or ideas to:

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