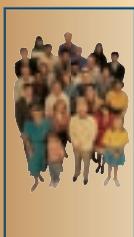


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QUALITY: WHAT DOES IT MEAN TO YOU?

Improving Quality of Care in Dialysis

By Adeera Levin, MD, FACP



Adeera Levin, MD, FACP

*There are
scientific
measurements
available
to rate
quality care.*

QUALITY OF CARE MAY SEEM LIKE A FUZZY CONCEPT TO YOU. YOU MAY FIND IT HARD TO MEASURE QUALITY WHEN IT COMES TO DIALYSIS. But, in try-

ing to figure out what “quality” in dialysis care means, many of the important aspects have been clearly defined. There are scientific measurements available to rate quality of care.

The National Kidney Foundation (NKF), through its Kidney Disease Outcomes Quality Initiative (KDOQI), has developed clinical practice guidelines to help dialysis professionals—doctors, nurses, social workers and dietitians—improve outcomes for people with chronic kidney disease (CKD). Since the KDOQI program began in 1995, studies have shown improvement in many patient outcome measures, such as anemia, dialysis adequacy and dialysis access.

research. They define important aspects of dialysis care, such as the amount of dialysis treatment patients need, and they recommend clinical measures that help tell how well people on dialysis are doing. Your care team should do the tests described in this article on a regular basis and make changes to your treatment if your results are not in the target range. When your lab results are where they should be, you will be more likely to feel better and live longer.

to find your delivered dose of dialysis. This tells whether you are getting the right amount of dialysis to remove enough wastes from your blood and keep you healthy. Your result is called your Kt/V. According to KDOQI, for hemodialysis patients, Kt/V should be at least 1.2 per treatment. For people on peritoneal dialysis, the weekly Kt/V should be at least 1.7. In hemodialysis, another measure that may be used to check delivered dialysis dose is called urea reduction ratio, or URR. If URR is used, the result should be at least 65 percent per treatment.

The KDOQI recommendations are based on scientific

For example, your care team should do a monthly blood test

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This publication is a part of the National Kidney Foundation’s Kidney Learning System (KLS).™


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THERE ARE TIMES WHEN THE MEANING OF QUALITY IS CLEAR AND OBJECTIVE. We know that an individual needs an “adequate” amount of dialysis, measured by such things as Kt/V. We also know that a person who is on dialysis should have a hematocrit and hemoglobin that are in specific ranges. It is generally agreed that the ideal hemodialysis access is an arteriovenous fistula. Much scientific evidence exists that supports each of these findings. The National Kidney Foundation’s (NKF) Kidney Disease Outcomes Quality Initiative (KDOQI) has evaluated that research data and used it to develop clinical practice guidelines in these and other areas, confirming that there are indeed certain standards that should be met.

However, there are other areas where quality measurements are more subjective, personal and individual. Quality of life— what is important and of value to you emotionally, socially, physically and vocationally—is one such area. What is crucial to one person’s well-

being might not be of equal meaning to another individual. For example, to some life would be incomplete if they were no longer able to run marathons, yet others are quite satisfied with being able to take a walk in the park. On the other hand, someone might find certain life situations intolerable or unbearable, while someone else might view the same situation with a totally different perspective. Research has also shown that we are not very good at evaluating another person’s quality of life. This is most likely because it is very difficult for us to assess someone else’s situation without allowing our own value judgments, experiences and circumstances to get in the way.

However, regardless of whether we are talking about quality medical care or quality of life, both contribute a lot to one’s ability to live a full, productive life. Quality in all aspects of life is vitally important, which is why we have dedicated this entire issue of *Family Focus* to



Karren King

the topic. We hope that this issue will give you a wide lens with which to view quality, as well as ways that you can improve the overall quality in and of your life.

Our next issue will be the last that was planned by our 2006 Editorial Board. It will feature diabetes, the major cause of chronic kidney disease, and will highlight the NKF’s newest KDOQI guidelines. It is also with great sadness that I share with you that the next issue of *Family Focus* will be the last. While the NKF will continue to find ways to educate those individuals who are on dialysis and their families, it has decided to move in another direction.

It is also with great sadness that I write about the recent loss of *Family Focus* Editorial Board member, Josephine Mahi. Josephine had chronic kidney disease and had been on in-center hemodialysis since 2000. She was a fairly recent member of the Editorial Board, having been with the newspaper for less than one year. Although she was with us for only a brief time, her contributions were always enlightening, and we appreciate the opportunity that we had to work with Josephine.

In closing, I want to thank you for your support and interest in *Family Focus*. You have been an inspiration to each of us.

Karren King, MSW, ACSW, LCSW
For the Editorial Board

Dear *Family Focus*,



READING YOUR PAPER HAS BROUGHT A LOT OF EASE AND HOPE. I feel now as if I do have a future ahead of me. A bright future. I cannot and will not let a little thing like dialysis stop me from living when in reality it helps me to live. It’s hard but I abide by the rules

because I want to live. The staff at my unit has made it easy for me to go through with my treatments, and I am very grateful to them.

Thank you,
Donna Nelms

Donna is 37-years-old and receives treatment in West Warwick, Rhode Island.

Family Focus

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Improving Quality of Care in Dialysis *Continued from page 1*

Over the past 15 years, many improvements have been noted in dialysis dose in the United States. Data published by the United States Renal Data System (USRDS; www.usrds.org) and the Dialysis Outcomes and Practice Patterns Study (DOPPS) showed a 50 percent increase—from 0.99 in 1986 to 1.53 in 2003. This improvement is due to more awareness of the importance of dialysis and to the development of clinical practice guidelines such as the KDOQI guidelines on hemodialysis adequacy.

Anemia treatment is another important part of quality care for people on dialysis. Most people with kidney disease get anemia because their kidneys no longer make enough of the hormone erythropoietin (EPO), which stimulates red blood cell production in the body. To treat this problem, medications and iron supplements are used to

raise red blood cell production. Hemoglobin is the key measure recommended by KDOQI to tell if people are getting the right amount of anemia treatment and are responding well to their treatment. Hemoglobin levels should be 11 g/dL or higher. Results from the DOPPS showed the importance of reaching the recommended hemoglobin level. The study reported that people who raise their hemoglobin level have a much lower risk of death. Other data from 2006, although preliminary, show that most people on dialysis are reaching the KDOQI target for hemoglobin, but 15–20 percent are still below the target.

The following chart lists other important clinical measures (tests) recommended by KDOQI. To ensure that you are getting quality dialysis care, you should know what your numbers are.

Ask your dialysis care team about your results. Keep track of your numbers. Your dialysis care team may be able to give you a tracking tool. Or, you can use the Dialysis Lab Log available from the NKF by calling 800.622.9010 or visiting the Web site at www.kidney.org. If any of your results are not in the target range, ask your care team what can be done to improve them. Some of the steps you can take to help include:

- **TAKE** all your medications as prescribed for you.
- **FOLLOW** your special diet carefully.
- **FOLLOW** your fluid and sodium (salt) limits.
- **DO** all the dialysis treatments prescribed for you; do not skip treatments.
- **BEGIN** your treatment on time and complete the full treatment.

- **LEARN** all you can about your kidney disease and its treatment. Call the NKF toll-free at 800.622.9010 for a list of brochures on dialysis or visit the Web site at www.kidney.org
- **SPEAK** to your care team if you have any problems or questions. 

Dr. Adeera Levin is a professor of medicine and the co-director of the Clinical Investigator Program at the University of British Columbia. She also serves as the executive director of the British Columbia Provincial Renal Agency, the Director of the Kidney Function Clinic at St. Paul's Hospital in Vancouver, Canada, and the KDOQI Co-Chair at the National Kidney Foundation.

Important Clinical Measures (Tests) Recommended by KDOQI

Name of Test	What It Checks	KDOQI Recommended Target
Kt/V	Dialysis dose	At least 1.2 per treatment for HD; at least 1.7 per week for PD
URR (Hemodialysis)	Dialysis dose	At least 65 percent per treatment
Hemoglobin	Anemia control	11 or greater
Serum ferritin	Iron stores in body	At least 200 (HD); at least 100 (PD)
Transferrin saturation (TSAT)	Iron stores in body	At least 20%
Albumin	Nutritional health	4 or greater
Phosphorus	Bone health	3.5–5.5
Calcium	Bone health	8.4–9.5
Blood pressure	Blood pressure control	Less than 140/90 pre-dialysis; less than 130/80 on dialysis
Total cholesterol	Heart health	Less than 200
LDL cholesterol	Heart health	Less than 100
HDL cholesterol	Heart health	40 or more
Triglyceride	Heart health	Less than 150

Abbreviations: HD, hemodialysis; PD, peritoneal dialysis; URR, urea reduction ratio.

FOR RETIRED ATTORNEY ROBERT GROSS, QUALITY IN HIS DIALYSIS EXPERIENCE IS SUMMED UP IN ONE WORD: PATIENCE.

More than anything, he appreciates patience in his care team and a caring atmosphere during treatment sessions. Quality is a personal experience and is therefore different for each individual. Another person, for example, reported having a horrible time in the treatment chair with restless legs syndrome (RLS), which is a strong urge to move your legs often accompanied by uncomfortable sensations that start or become worse when you are resting. One day her primary care nurse gave her a newspaper clipping from a medical column. In the article, the doctor described RLS and suggested avoiding all caffeine-rich drinks like coffee, tea and colas. The person tried the advice and after a couple of weeks it worked. Quality of life for this individual was quite simply relief from restless twitching during dialysis.

Today, people with CKD, both those on dialysis and those in the earlier stages of CKD, and their caregivers can compare Medicare-certified dialysis facilities by services provided, characteristics and three quality measures— anemia, hemodialysis (HD) adequacy and patient survival—by using the Dialysis Facility Compare (DFC) tool launched in January 2001 on Medicare's Web site (go to www.medicare.gov, then click on "Compare Dialysis Facilities in Your Area" at the bottom of the page). The anemia tab measures how well people on dialysis at a facility have their anemia (low red blood cell count) under control. The HD tab measures how many individuals at a facility get enough waste removed from their blood during dialysis treatments (urea reduction



QUALITY in Dialysis

By Josephine Mahi

Knowing what quality dialysis care means to you can improve your quality of life.

ratio [URR] of 65 or greater). The patient survival tab measures if the people treated at a facility generally live longer than, as long, or not as long as expected.

The DFC tool also includes other types of information on HD and peritoneal dialysis (PD) for individuals on dialysis and family members, such as dialysis and kidney disease publications, links to other kidney disease Web sites, statement of rights and responsibilities of people who dialyze and contact information for End Stage Renal Disease (ESRD) Networks and state survey agencies. Care teams and nephrologists usually measure monthly blood tests for levels of albumin, hemoglobin and Kt/V (URR) as markers of quality of life. However, quality of life, including physical and mental health and spiritual factors are equal, if not more important matters for people with kidney failure in dialysis facilities, based on the information gathered from participants with CKD in the study, "Promoting Excellence in End-of-Life Care" by the National Program Office of the Robert Wood Johnson Foundation (1).

Those individuals who participated in the study responded to interviewers' questions based on the McGill Quality of Life Questionnaire, the Satisfaction of Life Scale, and two patient satisfaction scales, with one adapted from the Kidney Disease Quality of Life instrument. The interviewers included a new scale exploring the effects of spiritual beliefs and patient supports. Issues such as encouragement from

the care team and their level of satisfaction with doctors, nurses and social workers were important. More research needs to be done to help dialysis care teams improve quality of life with an informed understanding of the psychological and social needs of the person on dialysis.



Josephine Mahi

To support the educational needs of people on CKD and their families for a better quality of life, the National Kidney Foundation launched Kidney Learning System (KLS) in April 2003. KLS provides live programs and audio/video and printed materials for people with CKD. Visit www.kidney.org/KLS or call 800.622.9010. Request a copy of the NKF Patient and Family Council Dialysis Patients' Bill of Rights and Responsibilities, or view it online at www.nkfkidneypatients.org

The demand for quality in dialysis should be a priority for people with CKD because it would lead to better outcomes and decreased hospitalizations. Concerns about cost efficiency and dialysis care delivery should bring about changes in the future. With the leadership of Congress,

concerned physicians and the voices of patients, there may come a time when dialysis providers receive payment based on measurements of the quality of care given. 

REFERENCE

1. Robert Wood Johnson Foundation. Executive summary of findings from the ESRD Quality of Life for Dialysis Patients Questionnaire Study. <www.mywhatever.com/cifwriter/library/41/pe3656.html>

Editor's Note:

Josephine passed away in February. She had chronic kidney disease and had been on in-center hemodialysis since 2000.

Hands



By John Rider

There is a special group
Who come into this place,
With hands of love and kindness,
Bringing helpful care and grace.

Sometimes the day is hard
With many ups and downs
But they handle each and every one,
Without any grumps and frowns.

Their hands are sure and nimble,
As we watch them do their work
With the sounds of daily business,
There is never time to shirk.

Friends of those who come here,
Are amazed at all they do
They encourage all of us folks,
Without an ounce of rue.

Their hands and great big hearts,
A wonder in every way
Let's clap our hands for them,
Let's honor them today.

John's wife dialyzes at Cedar Valley Dialysis Center in Waterloo, Iowa.

TREATMENT GUIDELINES FOR HEMODIALYSIS (HD) AND PERITONEAL DIALYSIS (PD) ADEQUACY, VASCULAR ACCESS AND ANEMIA (LOW RED BLOOD CELL COUNT) WERE FIRST PUBLISHED IN 1997 AND FIRST UPDATED IN 2001.

Because a number of important studies were done to improve treatment for people on dialysis since 2001, new information was available and the National Kidney Foundation decided that it was time for another update. These new guidelines were outlined in the supplement to the July 2006 edition of the *American Journal of Kidney Diseases* (AJKD) and are highlighted below.



Your stage of kidney disease is based on the presence of kidney damage and your glomerular filtration rate (GFR), which is a measure of your level of kidney function. Thus, the treatment of your kidney disease is based on your level of

"Whether you receive HD or are on PD, it is important for you to work with your doctor to be sure that your blood pressure is under good control."

kidney function. People with a GFR less than 30 ml per minute should know about the different ways to replace kidney function, including HD in a dialysis center or at home, PD and kidney transplant. If your GFR falls to 15 ml per minute or less, regular dialysis may need to be started. Consultation with a kidney doctor (nephrologist) will help decide when dialysis should be

started and allow the doctor to take care of other medical problems that may be present because of kidney disease. For people who receive HD three times a week, the recommendation about how much dialysis is needed has not changed. The amount of dialysis is based on blood work obtained at the start and end of the dialysis session. These numbers show how much dialysis has cleaned your blood of the waste products that build up when your kidneys do not work. The reduction ratio between the blood urea nitrogen level at the start and end of dialysis (the urea reduction ratio or URR) should be higher than 65%, which is about equivalent to a Kt/V (your delivered dose of dialysis) of 1.2 or more. This recommendation is based on a study called the HEMO Study. This study was done in more than 1,800 people in the United States who received HD three times

per week and showed that increasing the time for each dialysis treatment by about 30 to 45 minutes per session did not lower the death rate for people on dialysis. There are now new recommendations that help your doctor decide how much dialysis you need if you dialyze either more or less than three times per week. Getting HD less than three times a week is not

National Kidney Foundation's Dialysis Guidelines Updates

By Michael Rocco, MD

Updated guidelines help to determine the treatment plan that's best for you.

recommended unless your doctor is able to test your urine to be sure that your kidneys clear enough waste products on their own.

For individuals on PD, the minimum amount of dialysis you should get has been lowered to achieve a weekly Kt/V of 1.7. This change is based on several studies done in Mexico and Hong Kong that showed this lower dose of dialysis did not result in a higher rate of death. All people on PD should have enough dialysis to be at least at this level, and some may require levels higher than 1.7 to stay healthy. Your doctor will determine if you need a higher amount of dialysis. You need to bring your collection of dialysis fluid and urine (if you make any) to the home training unit at least three times a year to help determine if you are getting enough dialysis.

Whether you receive HD or are on PD, it is important for you to work with your doctor to be sure that your blood pressure is under good control. Blood pressure control includes not only taking your blood pressure medicines, but also not eating too much salt or drinking too much fluid. If you are on HD, limiting your fluid intake not only makes controlling your blood pressure easier, you are less likely to have cramps or low blood pressure during treatment. For those on PD, if you limit the amount of fluid you drink, you may need to use fewer dialysate bags with a high dextrose or sugar concentration.

If you are preparing for HD, plans for a vascular access should be made at least six months before you start dialysis. Planning early will help improve the chances that a fistula (also known as an arteriovenous [AV] fistula), the preferred type of access, will be ready to use when you start dialysis. A fistula is the best type of access because they last longer and have fewer problems than grafts or catheters. A gortex graft should be considered for dialysis access only if a fistula cannot be placed. The use of catheters for dialysis access should be discouraged because long-term catheter use results in a higher risk of infections and death compared with fistulas or grafts. Once a fistula is placed, the doctor should examine it about six weeks later to find out if the fistula is growing normally or if some additional surgery will be needed to make the fistula usable for dialysis. The guidelines inform doctors and dialysis units how to monitor the access on a regular basis to allow them to find and fix problems as early as possible to keep the access from failing.



Peritoneal Dialysis

The dialysis unit should have a plan to look at the quality of care for all people on dialysis. Recommendations of what to look at are included in the guidelines. Finally, recommendations are given for children who are on either HD or PD.

Evaluation and treatment of anemia for people on dialysis

Continued on page 12

QUALITY MEANS DIFFERENT THINGS TO DIFFERENT PEOPLE. The U.S. Office of Personnel Management defines “good” quality health care as doing the right thing at the right time in the right way for the right person and getting the best possible results (1). Experiencing quality in your life means investing time and energy in yourself. Ways to begin investing are to understand and manage your disease. “Doing the right thing” belongs to both you and your health care team.

In 1998, the Centers for Medicare and Medicaid Services (CMS) developed End Stage Renal Disease (ESRD) Clinical Performance Measures (CPMs) based on the National Kidney Foundation’s Kidney Disease Outcomes Quality Initiative (NKF-KDOQI™; ref. 2). Sixteen CPMs were identified to measure and report the quality of dialysis services provided under Medicare (3). However, the performance measures relating to bone health, nutrition, anemia, diabetes and blood pressure are expected outcomes for all people with CKD, regardless of stage of kidney failure or treatment. Table 1 lists several of these quality measurements (see page 7).

These measurements are only a few pieces of the puzzle required to achieve high quality care for you. Although your health care team is responsible for providing the education, you need to understand each measurement and how to get to your target as you go about your daily activities. Of course, you should participate as a team member to ensure that you are meeting your goals on a monthly basis. The table shows a checklist to help you track if you met your target.

QUALITY OF CARE: You Are in Charge

By Jennifer Vavrinchik, MSN, RN, CNN

Take charge of your health by making healthy lifestyle choices.

If not, develop an action plan with your health care team to achieve your goals.

Being faced with a chronic illness and ongoing treatment can be a frightening experience, especially at first if you do not know what to expect. It is your responsibility to apply what you have learned to everyday living, and in return, lessen your fears and live life to the fullest. Examples may be learning new recipes for a CKD diet and savoring every



Your health care team has a responsibility to “do the right thing” and provide quality care, but ultimately, you are in control of your care.

bite, learning to enjoy activities again because your energy level has improved or going back to work because you have learned to manage your disease. Taking small steps each day toward a more normal and healthy lifestyle will bring you one step closer to achieving your goals toward

a quality life. One thing that might help is to get involved with patient organizations to learn more about your disease and how others like you manage their daily activities. Ask yourself and your doctor and staff what changes you need to make. Pick one or two and work on them little by little. This is the essence of self-management, which links with higher physical and mental functioning (4). Ask your health care team the following questions throughout your care.

1. HOW can I keep my quality measurements in the goal range? By medication, diet, lifestyle?
2. WILL I see my laboratory results every month? Who will review them with me?
3. WILL someone help me with my diet and make suggestions for menus and recipes that are good for me?
4. WHAT help can I get with questions about health insurance and prescription drugs?
5. WHO will help me with work and family issues? Are there support groups for me and my family to discuss these issues?
6. WHAT are my treatment options? Which treatment modality (HD, PD or transplant) is best for me?
7. WHAT kind of vascular access do I have and how do I care for it? Am I a candidate for a fistula?
8. WILL I have access to my medical records? Having access to your medical records allows for greater

knowledge and coordination of care for both you and your health care team.

9. WILL my various doctors and health care team talk to one another to coordinate my care?

The more you know about your treatment and health status, the better able you will be to care for yourself and live a quality life. Expect no less. Your health care team has a responsibility to “do the right thing” and provide quality care, but ultimately, you are in control of your care. Get involved with the health care team to set your monthly goals. Ask questions! The bottom line is to invest in you and quality will follow. 

REFERENCES

1. Office of Personnel Management. Federal Employees Health Benefits Glossary. 28 April 2006. <www.opm.gov/insure/health/about/glossary.asp>
2. National Kidney Foundation. Clinical Practice Guidelines. 11 June 2006. <www.kidney.org>
3. Center for Medicare and Medicaid Services. Clinical Performance Measure (CPM) Project. 11 June 2006. <www.cms.hhs.gov/CPMProject>
4. Curtin, R.B. Self-management, Knowledge, and Functioning and Well-being of Patients on Hemodialysis. *Nephrology Nursing Journal* 41:1286–1292, 2003.

Jennifer Vavrinchik holds a Master of Science and Bachelor of Science in Nursing from the University of Cincinnati. She has 18 years experience in nephrology as a clinical educator, and staff development and client services professional.

Your Child's Health

By Joseph T. Flynn, MD, MS

YOU MAY NOT KNOW THAT THE KIDNEYS CONTROL BLOOD PHOSPHORUS, A MINERAL FOUND IN BONES. The kidneys also turn the vitamin D that we get in our diets into a hormone that helps our bodies absorb calcium, which is important for keeping bones strong and healthy.

When the kidneys fail, phosphorus builds up in the blood and levels of calcium and vitamin D fall. These changes lead to higher amounts of parathyroid hormone (PTH), which is made by the parathyroid glands, and weaker bones (commonly known as rickets). The medical term for this condition is renal osteodystrophy, which is one of the major reasons children with chronic kidney disease may not grow normally.

The signs and symptoms of renal osteodystrophy are listed in Table 1. Fortunately, blood tests and X-rays can be used to check for signs of renal osteodystrophy, and medications such as phosphate binders and special forms of vitamin D can be used to treat it. Although pediatric nephrologists have known about renal osteodystrophy for many years, they did not agree on guidelines for how to watch for it and treat it.

This changed in October of 2005, when the National Kidney Foundation's Kidney Disease Outcomes Quality Initiative published *Bone Metabolism and Disease in Children with Chronic Kidney Disease* as a supplement to the *American Journal of Kidney Diseases*. This publication is the result of three years' work by eight volunteer experts in kidney disease, pediatrics, nutrition, bone and mineral metabolism disorders who reviewed scientific evidence

New bone disease guidelines for children highlight the importance of early intervention

published in medical journals before writing the guidelines.

Many aspects of renal osteodystrophy in children are highlighted in the new guidelines. For example, the guidelines point out that osteodystrophy begins early in the course of CKD in children and that



Good nutrition, especially getting enough calcium and vitamin D, and avoiding too much phosphorus, is the first step recommended by the guidelines in managing osteodystrophy.

children must have enough calcium in their diets in order to grow and develop properly. The importance of vitamin D and proper nutrition in children with CKD is stressed, as is the need to check levels of calcium, phosphorus and PTH regularly.

As seen in Table 2 (p. 11), the new guidelines vary for different stages of CKD. This is because some of the goals and treatments used for earlier stages of CKD are different than those for people on dialysis, and vice versa. For example, treating the problem of not enough dietary vitamin D is helpful in mild to moderate CKD Stages 2, 3 and 4, but probably is not helpful in CKD Stage 5, when dialysis is needed.

Good nutrition, especially getting enough calcium and vitamin D, and avoiding too much phosphorus, is the first step recommended by the guidelines in managing renal osteodystrophy. However, as kidney function gets worse, nutrition alone is not enough and medications must be used. The new guidelines give detailed instructions on what medications to use and what doses to prescribe for different stages of CKD.

The two most important medications discussed by the guidelines are phosphate binders and activated vitamin D. Phosphate binders are medicines that, when taken with food, help to control the amount of phosphorus absorbed by the body. In children with CKD, it is common to use calcium-containing phosphate binders such as calcium carbonate, which comes in a liquid and as a chewable tablet. These medications also offer extra calcium, which may be lacking in the diets of many children with CKD.

However, it has recently been learned that too high a calcium intake can be harmful for those on dialysis, because they

may develop abnormal calcium deposits, especially in the heart and blood vessels. The guidelines therefore point out that too much calcium intake from the use of calcium based phosphate binders should be avoided in children with advanced CKD, especially those who are on dialysis (CKD Stage 5; see Table 2). The best treatment for these children may be one of the non-calcium-containing phosphate binders.

Activated vitamin D, commonly called calcitriol, is used when PTH levels rise in CKD. This form of vitamin D is chemically the same as what is produced by normal kidneys. The guidelines give clear recommendations for when to start calcitriol in children with CKD, what doses to use, and what levels of PTH should be targeted.

The overall goal of these new guidelines is to help doctors who treat children with CKD make sure that renal osteodystrophy is well controlled. Hopefully, this will lead to improved growth for children with CKD and will also allow them to live more normal lives. 

Joseph T. Flynn is a professor of Clinical Pediatrics at the Children's Hospital at Montefiore in Bronx, NY.

See page 11 for Table 2

Table 1. Signs and symptoms of bone disease in children with CKD

Symptoms:	Bone pain Poor linear growth/short stature (height) Fractures Bowed legs Calcium deposits in skin Itchy skin Waddling walk
Signs:	High phosphorus levels Low calcium levels High PTH level Low vitamin D levels Rickets Fractures Abnormal calcifications

KIDNEY TRANSPLANTATION IS ONE TREATMENT CHOICE FOR END STAGE KIDNEY DISEASE, ALSO KNOWN AS ESRD OR KIDNEY FAILURE. A successful transplant can improve both quality of life and overall health for many people.

There are many factors that can shape the outcome of a kidney transplant. As anti-rejection (immunosuppressive) medications have gotten better over the years, so have transplant outcomes, allowing for excellent long-term survival of the kidney transplant even if a “perfect match” is not

As might be expected, the long-term outcomes in kidney transplantation relate to tissue matching.

available. Some of the factors related to long-term outcome can be controlled by either you or your transplant team. Other factors may be beyond control.

LIVING DONOR VS. DECEASED DONOR

Kidneys for transplantation come from two sources: kidneys from **living donors**—family members, spouses, friends or others who wish to donate—or kidneys from **deceased or non-living donors**—people who have died and donated their organs for transplant. Most transplant centers encourage living donor transplants for many reasons. A blood relative may give a closer genetic match, which can have a lot to do with the success of the transplant. Over the long term, most living donor kidney transplants do better as compared with deceased donor transplants. Also, a living donor’s kidney will be

YOUR KIDNEY TRANSPLANT: Finding the Best Match and the Best Outcome

By Gopa B. Green, MD

Finding a match and following your treatment plan are important factors for a successful transplant.

removed in a scheduled surgery, thus eliminating the wait for a deceased donor. Finally, the chance that the kidney will work immediately after the surgery is much greater with a living donor transplant because of the short length of time the donor kidney is without blood supply. Many people feel uncomfortable asking

kidney will function compared with a living donor kidney, as measured in half-life. Half-life means that half of the kidneys within the particular category will function fewer than the stated years and half will survive longer.



Dr. Gopa Green

Overall, the national one-year patient survival rate after deceased donor kidney transplantation is 94.2 percent; the national one-year kidney survival rate is 88.4 percent. These numbers improve to 97.6 percent and 94.5 percent for living donor kidney transplants.

family members or friends to donate a kidney. Although the subject may be difficult to talk about, family and friends are often very interested in being evaluated as living donors.

If someone has been approved for a transplant and does not have any living donors, then he or she will be placed on the deceased donor national waiting list. The following table compares the estimated length of time a deceased donor

Type of kidney transplant	Kidney graft half-life in years
<u>Living donor</u>	
HLA identical (perfect match)	26.5
Offspring/Parent	18.7
Spouse/unrelated friend	15.8
Distant relative	18.4
<u>Deceased donor</u>	
HLA identical (perfect match)	17.3
Non-HLA identical	10.9

Adapted from the United Network of Organ Sharing Scientific Renal Transplant Registry, based on data from 1998-2001.

TISSUE OR HUMAN LEUKOCYTE ANTIGEN MATCHING

Tissue or human leukocyte antigen (HLA) matching relates to genetic matching between donors and recipients. Genes occur in pairs and are inherited, one set from each parent, and have features that makes each of us an individual. Some of these features are blood proteins, called antigens, that play an important role in the immune system—the way our bodies fight off germs and disease. Kidney transplant professionals define six antigens, known as HLA, in each donor and recipient. The best compatibility is a six-antigen match between a donor and a recipient. This match, which occurs 25 percent of the time between siblings, also occurs from time to time by chance in the general population.

As might be expected, the long-term outcomes in kidney transplantation relate to tissue matching. The best long-term outcomes are between people who match all six antigens. Over the last several years, however, because immunosuppressive medications have gotten so much better, less perfectly matched organs now function almost as well. This means that living donors who are not matched for any antigens may still confidently donate, knowing that the long-term outcomes for recipients of a zero-antigen-matched organ appear quite good. Similarly, poorly tissue-matched deceased organs do well in many recipients.

Continued on next page

Your Kidney Transplant *Continued*

DONOR FACTORS: AGE, SIZE, "EXTENDED CRITERIA"

Other factors that seem to play a role in long-term outcomes include the age of the donor and size of the donor, with kidneys from older (age 60 or above) or smaller-sized donors (especially when transplanted into larger-sized recipients) having slightly worse long-term function.

Your transplant center may also discuss "extended criteria donor kidneys" with you. These organs come from donors who would not have been considered in the donor pool in the past, because of their age (older than 60 years) or other medical conditions, such as a history of stroke or high

blood pressure. However, outcomes with these "less than perfect" organs have still been generally excellent and may be preferable to remaining on dialysis for some people.

COLD ISCHEMIA TIME, DELAYED GRAFT FUNCTION, OR EARLY REJECTION EPISODES

Cold ischemia time refers to the amount of time the donated organ is in iced storage between the donor and recipient (usually minutes for a living donor transparent, hours for a deceased donor transplant). As cold ischemia time increases, particularly greater than 24 hours, the risk of slower initial kidney function increases. Your transplant surgeon works

hard to ensure that kidney transplants take priority over other surgeries to try to reduce the amount of time the kidney is without blood flow. It has also been shown that kidneys that do not function well right away (a condition known as delayed graft function) have worse long-term function. Similarly, people who suffer from early acute rejection episodes have shorter half-lives of their kidney transplants than those who get through the first year of transplant without any signs of rejection.

ADHERENCE WITH MEDICATIONS AND HEALTH CARE FOLLOW-UP

The last major factor that affects long-term outcomes in kidney transplantation is the involvement of the person who gets the transplant. In almost all cases, the

recipient's immune system will recognize the transplant as "foreign" and will require immunosuppressive medications to prevent rejection for as long as the kidney transplant functions. Missing medication doses is unfortunately still the most common cause of rejection that can lead to failure of a kidney transplant. Making sure that you follow your transplant team's instructions and seeing your doctors for regular office visits is the key to transplant success.

Dr. Gopa B. Green is a transplant nephrologist at the Northern California Kidney Transplant Center in Santa Rosa, California.

"QUALITY: IT IS DEPENDENT UPON ME."
ROANNE FAITH DALE, SOMEONE WHO HAS BEEN ON DIALYSIS FOR 33 YEARS, gave this important view of quality as it relates to dialysis. She went on to relate that "it is my job to ensure that the care I receive is of the highest possible quality. Asking questions and being informed helps me to understand what constitutes quality care. I encourage everyone to work with their health care team and to ask questions. If you do not understand something, look for information in the great booklets that the National Kidney Foundation supplies to your dialysis center or go to their Web site www.kidney.org."



Fred Manfred

In addition to this wisdom, other voices

**FAMILY FOCUS VOICES:
Keeping on Track With Quality**

By Mary Beth Callahan, ACSW/LCSW

listed such quality components as a caring and sympathetic staff; a clean and sterile environment; and emergencies that are handled quickly, efficiently and professionally. One individual talked about traveling to various clinics and feeling that quality varied. Her experience at her home clinic was that "each patient becomes the responsibility of two care nurses trained in the Kidney Disease Outcomes

Quality Initiative, (KDOQI) namely dialysis adequacy, health of vascular access and sufficiency of hemoglobin/hematocrit. To minimize errors, all medications,

delivery procedures and dialyzer re-use are cross-checked...The net result is a gratifying atmosphere of friendship and cooperation in the clinic."

Celeste Lee stated that "Quality is when my family and I feel confident and comfortable agreeing for me to undergo dialysis as a life-saving treatment while continuing to be able to live a productive and meaningful life."

Fred Manfred gave good advice for keeping on track with quality: "Dialysis quality is a locomotive and patients are the engineers who need to allow their entire medical staff, family



Celeste Lee

and friends to be the stokers of the coal."

Family Focus appreciates your comments and hopes that this newspaper helps you to remain aware of issues that enhance the quality of your health care.

To view past voices, questions and responses, visit www.familyfocusvoices.org.

Mary Beth Callahan is a social worker at Dallas Transplant Institute. She has worked with people with kidney failure in hemodialysis, peritoneal dialysis and transplant since 1984.

THE NATIONAL KIDNEY FOUNDATION'S KIDNEY DISEASE OUTCOMES QUALITY INITIATIVE (NFK-KDOQI™) GUIDELINES

summarize many of the best practices for dialysis outcomes, including nutrition recommendations (1). Every nutrient has a specific purpose in maintaining your health on dialysis. Just as a puzzle is complete when each piece is in its proper place, your body is nutritionally complete when all the needed nutrients are present in the right amounts. You can survive and thrive on dialysis by adapting these key facts to your own health plan!

 **FACT #1: YOU NEED ADEQUATE DIALYSIS TO SURVIVE**

AND THRIVE. Hemodialysis provides only 20 percent of the filtration normal kidneys provide, so every minute of treatment is needed to remove waste. Blood urea nitrogen (BUN) is the waste product from digestion of protein. One way to measure the efficiency of your dialysis is to see how well BUN is removed during your treatment. The amount of urea cleaned from your blood during dialysis is called urea reduction ratio (URR). Your URR should be 65% or more. Another way to measure dialysis adequacy uses a calculation that includes your body weight and the time required to remove the body fluid that contains urea. This is called Kt/v (say *kay-tee-over-vee*). Your Kt/v should be 1.2 or more on hemodialysis and 1.7 or more on peritoneal dialysis. Your dialysis prescription is individualized to meet your needs. Getting enough dialysis improves the quality of your life and helps you live longer!

Take time to learn about the time, dialyzer size and type and speed of blood flow and dialysis fluid your physician has chosen for you. Monitor your vascular

Missing a Piece of the Nutrition Puzzle?

By Joanne Cooke, MS, RD, CSR

Maintaining a healthy diet is the first step to surviving and thriving on dialysis.



access and report any changes to your nurse. Adequate dialysis and your access create a life-line for health! Your diet is also prescribed to meet your unique needs, and the food you eat creates waste that must be removed. Good management of your food and fluid helps to make your dialysis as effective as possible. Be sure to limit sodium (salt) intake to reduce thirst and make fluid removal easier.

 **FACT #2: MANAGING PARATHYROID HORMONE (PTH) KEEPS BONES AND BLOOD**

VESSELS HEALTHY. PTH is a substance produced by four tiny glands in the front of the neck called the parathyroid glands. Hormone production from these glands is balanced by the activation of vitamin D from healthy kidneys. When kidneys fail, vitamin D is no longer activated, and the glands produce too much PTH. This can cause calcium to fall to an unhealthy level as it becomes unbalanced with phosphorus. A special form of vitamin D is prescribed to improve PTH levels and calcium absorption so that bones remain healthy and blood vessels and other target organs get the vitamin D they need to remain healthy.

Have you ever been on a team? Teams have a shared goal. The dialysis team has your health as its goal! Do your part to manage your parathyroid gland by taking phosphorus binders and other medications as directed and controlling dietary phosphorus. Your dietitian can teach you how to take the right amount and type of phosphorus

in the foods you eat. Invest the time to learn how each of your medications work. Kidney failure causes phosphorus to accumulate in the body, raising production of PTH. High levels of phosphorus create hard deposits of phosphorus in blood vessels and soft tissues, including your heart. Keep your phosphorus at 3.5–5.5, calcium at 8.4–9.5 and intact PTH levels at 150–300 for better quality of life!

 **FACT #3: PREVENT HEART DISEASE! IT IS THE NUMBER**

ONE KILLER OF PEOPLE ON DIALYSIS. Controlling your phosphorus with diet and medication will reduce calcification, or hardening, of heart valves. You can control high blood pressure through proper fluid management, sodium restriction and medication to prevent left ventricular hypertrophy—a harmful condition that enlarges the left ventricle of the heart. Your dietitian can guide you in selections of heart-healthy foods that are low in sodium, fat and cholesterol to reduce the risk of heart disease. Researchers recommend monitoring your blood level of homocysteine, a harmful amino acid that is often elevated in people on dialysis. Homocysteine levels above 25 are associated with increased risk of heart and blood vessel problems. Your doctor or dietitian can recommend a special kidney vitamin with the right amount of folic acid and vitamins B6 and B12 to keep homocysteine levels in the normal range. Be sure to take this vitamin after dialysis to prevent its removal during treatment (2).



FACT # 4: ADDRESS FACTORS UNDER YOUR CONTROL.

You can control many nutrition-related factors with help from your family, staff and friends. Blood sugar, cholesterol, phosphorus, potassium, albumin and fluid gains are all monitored regularly at dialysis. Team up with your dietitian to develop a strategy for the best possible lab results.

Physical condition is part of health. Maintain the best physical fitness possible. Your albumin level is an indirect marker of your protein status. Protein is required to build and maintain strong muscles. If you do not eat the protein your body requires, it will destroy your muscles to get it, making you weaker. Keep your albumin above 3.7 by eating enough quality meat and eggs and adequate calories to permit storage of the protein. Exercise and movement build muscle, so start moving! The more you do, the more you will be able to do! People with muscle can care for themselves better and bounce back from illness faster (3). Start with a light program of activities and give yourself time to improve. Success feels great and is a great motivator! 

REFERENCES

1. National Kidney Foundation. K/DOQI, clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. Accessed online June 12, 2006. <http://www.kidney.org/professionals/kdoqi/guidelines_ckd/toc.htm>
2. Fedje L, Moore L, McNeely M. A role for oral nutrition supplements in the malnutrition of renal disease. *J Renal Nutrition* 6:198–202, 1996.
3. Nabel J, Heacock P, Royse D. An exploration of the relationship between nutritional status and quality of life in chronic hemodialysis patients. *J Nephrol Soc Wk* 16:53–63, 1996.
4. National Kidney Foundation. *K/DOQI Clinical Practice Guidelines for Bone Metabolism and Disease in Children with Chronic Kidney Disease*. AMJ Kidney Dis 46:S1-S122, 2005 (suppl 1)

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GOOD QUALITY OF LIFE IS SOMETHING WE ALL WANT, WORK TOWARD, AND EXPECT. However, research shows that as a group, people on dialysis report poorer quality of life than healthy people (1). Despite progress in dialysis treatments in recent years, many people on dialysis still say that they are greatly burdened by worsening physical function, more disabling conditions, and the inability to stay in their jobs, problems that make quality of life even worse. In general, poor quality of life is linked with poorer health and higher risk of death (2). Health-related quality of life depends on many things, including nutrition and physical activity. There is research that shows that patients who report the highest quality of life during the first months after starting dialysis, also report the highest physical activity levels (3). Another study found that dialysis patients who took part in an exercise program also reported improved health-related quality of life (4). This information is especially important for people on dialysis to

QUALITY OF LIFE and Physical Activity: Just Do It!

By Steven A. Soltys, CPT and Patricia L. Gordon, RN, PhD

know because it suggests that staying active could be a way of preventing early disability in part by maintaining or improving quality of life.



Steve Soltys on his Wave Board

Someone who can speak about this on a personal level is Steve Soltys, a certified personal trainer, who has been on hemodialysis for three years. Here's what he has to say:

“Wakeboarding, snowboarding, weightlifting, rock climbing, I can go on and on. These are the activities that are a big part of my life. I am also a personal trainer. I teach people, old and young, the basics of weightlift-

ing and how to create a proper workout program. When I was 28, I was diagnosed with kidney failure. At 33, I was placed on dialysis. I lost 30 pounds and I was weak. I felt ill and tired and could barely eat. I had to listen to doctors tell me how I was limited to ‘light activities.’ The activities that I was used to doing and wanted to continue to do seemed out of the question to them. I have always been the positive type, and to me, it was only a matter of time before I was going to be back to normal. While I was in the hospital, a male nurse told me something I will never forget. He said, “Listen to your doctors, but never let them take anything away from you.” He meant that once I became healthy, to be active, to get back to doing my stuff. If you quit, give up the stuff you like to do, you WILL become depressed and start to go down a road where it is hard to come back.

I am 36 now and still on dialysis. I have such an active life I forgot to put my name on the transplant list. Sounds odd, but between dialysis treatments, I am too busy to think about it. Some of you are not as active and as healthy as I am, but here is some advice. We are all different, so get the O.K. to exercise from your doctor. Start off easy. Find where your limits are and go from there. Just get moving somehow! You are alive and that is what counts. So get out there, be active, stay positive, and live.”

In addition to staying very physically active, Steve also credits his excellent quality of life to the support of his family and friends; especially his daughter, Deliah.

Becoming more physically active can seem like a daunting task, but raising your activity level even a little can have beneficial effects. Try parking the car farther away in the parking lot, taking a stroll around the mall or the neighborhood, getting to dialysis early and walking a few laps in the hallway or

Continued on page 15

Your Child's Health *Continued from page 7*

Table 2. Selected recommendations of pediatric bone disease guidelines

CKD Stage GFR	Stage 2 60-89	Stage 3 30-51	Stage 4 15-29	Stage 5 <15 or dialysis
Measurement of calcium and phosphorus	at least yearly	at least every 6 months	at least every 6 months	Ca, P at least every month PTH at least every month
	if PTH is above target range, look for and treat vitamin D deficiency			Treatment of dietary vitamin D deficiency not helpful
	Use calcium-based phosphate binders initially to lower phosphorus levels			Use calcium-based phosphate binders in infants and young children. Either Ca-based or non-Ca based phosphate binders may be used in older children and adolescents.
PTH Target*	35-70 pg/mL	35-70 pg/mL	70-110 pg/mL	200-300 pg/mL

QUALITY CAN MEAN DIFFERENT THINGS TO DIFFERENT PEOPLE.

Although there are certain things we would all agree are important to quality in the dialysis center, such as trained staff, good equipment, and a safe building, there are other aspects of care that are meaningful to each of us depending on our personal perspective. For example, my mother felt a doctor had to be very authoritarian—strict and decisive—to be good. Another person might not feel comfortable with an authoritarian doctor, and would prefer a doctor with whom they can easily communicate—a two-way street.

There are guidelines that dialysis centers must satisfy in order to meet the basic standard of quality. These standards are checked by government agencies such as the Centers for Medicare and Medicaid Services as well as state agencies. A certain level of quality is required by Medicare for dialysis facilities to operate safely.

The National Kidney Foundation (NKF) has worked with representatives in kidney care, including people with chronic kidney disease, dialysis professionals, and

QUALITY in the Dialysis Center

By Mary Beth Callahan, ACSW/LCSW

It's important to define what quality care means to you.

government agencies, for many years in developing the Kidney Disease Outcomes Quality Initiative (KDOQI). Thousands of articles have been reviewed to help define quality in dialysis care. You can find this information in brochures offered by the NKF or at their Web site: www.kidney.org. Talk to your health care team about what you find.

It is important to be aware of and ask questions about the quality of your health care. Some questions might include: “What are you looking for, Dr. White, when you review my lab values?” or “How did someone come up with four hours as the length of time I



Dialysis centers must look at their quality of care on a regular basis.

need to dialyze? How is this quality care?” or “I am having problems with my access. Can

you talk to me about what is the best way for staff and me to care for my access?”

I would suggest that there are *basic* issues of quality and then there may be aspects of care for which dialysis centers provide a “value-added” element that brings extra quality. “Value-added” quality may be exercise equipment in the center for people to use while on dialysis or a better patient-to-staff ratio—the amount of staff needed per person on dialysis—than is required. Value-added qualities could be considered features that are added to improve patient outcomes (such as exercise equipment, as listed above), even though they are not *required*.

Dialysis centers must look at their quality of care on a regular basis. Most dialysis centers use a process called continuous quality improve-

ment (CQI) to improve the parts of their care system that need improvement.

W. Edwards Deming, known as the Father of CQI, helped develop the approach. This method of quality review looks at a process and what could be done differently in that process so that the outcome could be improved. An example of a CQI project might be that only 80 percent of the people in a dialysis center have a hemoglobin (red blood cell count) level at the goal set by the doctor or clinic. The target range for hemoglobin should be Hgb 11 g/dL or above. What can the clinic do to increase the number of people on dialysis who meet the goal? Sometimes people who receive dialysis in the unit may be members of the team for quality improvement projects. Regardless of whether or not people on dialysis are formally on the CQI team, remember that your input is important. You are the one experiencing the care. Remember, in the words of W. Edwards Deming, “Quality is everyone’s responsibility.” 

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NKF's Dialysis Guidelines Updates *Continued from page 5*

and those with CKD not yet on dialysis are now covered in the guidelines. Individuals with anemia should first be evaluated to find out why their red blood cell count is low. The guidelines will then help your doctor treat anemia with the use of medicines (erythropoietin-stimulating agents) that aid the bones in making more red blood cells. These medicines can be given

as an injection either under the skin or in a vein. Your doctor should also be sure that you have enough iron in your blood to make more red blood cells. Once treatment for anemia is started, the goal should be to get the red blood cell count (or hemoglobin level) higher than 11. There does not appear to be any benefit to having a hemoglobin level more than 13.

By working with your doctor to help achieve these goals, you are also helping yourself improve your health while you are on dialysis. Talk with your doctor and others involved in your care to find out which goals you are meeting and how your doctor can help you to improve in areas where you currently do not meet these goals. 

Dr. Michael V. Rocco is a Professor of Medicine and Nephrology at Wake Forest University School of Medicine in Winston-Salem, NC and the vice-chair for the National Kidney Foundation's Kidney Disease Outcomes Quality Initiative. He received his MD degree at Vanderbilt University in Nashville, TN and his Master's degree in epidemiology at Wake Forest University.

THE KIDNEY CARE QUALITY INITIATIVE (KCQI) WAS FORMED LATE LAST YEAR by the members of Kidney Care Partners (KCP), a coalition of patient and professional associations, dialysis organizations and manufacturing companies. The goal of KCQI is to suggest ways for Medicare to link future payment for kidney care to the quality of care. KCQI's objectives are to define, assess, monitor and reward quality kidney care. Because dialysis providers might be inclined to show preference to certain patients (for example, those who are healthiest and therefore are expected to have better outcomes, also known as "cherry picking" in the kidney disease community) as an unintended result of payment change, KCQI recommendations were designed to insure that all people on dialysis will be treated equally, without regard to the number or severity of their illnesses or their economic status.

The KCQI recommends that dialysis clinics use tools that measure patient satisfaction and quality of life. In addition, KCQI has adopted clinical measures of quality care in the dialysis setting, including measures for anemia management, adequacy of dialysis and vascular access. For example, the KCQI anemia measure provides that someone receiving hemodialysis or

peritoneal dialysis treatment should have a hemoglobin of 11 g/dL or greater. These measures are based on the clinical practice guidelines that the National Kidney Foundation (NKF) developed under the Kidney Disease Outcomes Quality Initiative (KDOQI) program, which, in turn, have been included in Medicare's Clinical Performance Measures (CPM) project. An additional measure suggested by KCQI, but not previously covered by the KDOQI or CPM initiative, is immunization (vaccination) rate. In measuring the immunization rate for flu vaccinations, people with a history of allergic reactions to previous flu vaccines would not be counted, because their doctors may not want to expose them to immunization again. Furthermore, any individual may refuse to be vaccinated and that refusal would not be counted against the dialysis clinic or the person's doctor.

KCQI is focused on improving safety, effectiveness and efficiency of care. The KCQI measures will make it possible to compare the performance of dialysis clinics and kidney

doctors. Under the KCQI process, providers can be evaluated both on the ability to meet benchmarks or targets as well as on improvement over previous performance. Additional measures, such as transplant referral rates, were considered but not included in the KCQI recommendations.

The KCQI plan was presented to a new Kidney Care Quality Alliance on July 26, 2006. The Alliance includes organizations representing the health care community at large. For example, some of the members of the Alliance are the Federation of American Hospitals, the National Medical Association, the National Partnership for Women and Families and the Society of General Internal Medicine.

At the Alliance meeting on July 26, 2006, Barry Straube, MD, Chief Medical Officer and Director of the Office of Clinical Standards and Quality at the Centers for Medicare and Medicaid Services, thanked KCP for taking the initiative for quality reform. He compared the development of the

Kidney Quality Alliance favorably with the activities of other quality alliances, including the Hospital Quality Alliance, the Ambulatory Care Quality Alliance, the Pharmacy Quality Alliance, and the Cancer Care Quality Alliance.

The NKF was represented in the development of the KCQI initiative by its president, president-elect, and immediate past president, Drs. Warnock, Collins, and Pereira, respectively. Under consideration, as the next step, would be review of the quality measures by the National Quality Forum (NQF). The NQF is a private, nonprofit membership organization created to develop and implement a national plan for health care quality measurement and reporting. The mission of the NQF is to improve American health care through support of consensus-based national standards for measurement and public reporting of health care performance data that provide meaningful information about whether care is safe, timely, beneficial, patient-centered, equitable and efficient. 



Dolph Chianchiano is the senior vice president for health policy at the NKF National Organization in New York City.

Kidney Care Quality Initiative

By Dolph Chianchiano, JD, MPH

New quality initiative suggests ways to improve dialysis care.

My First Day at Dialysis

By Donna Nelms, Warwick, Rhode Island

My first day at Dialysis
Was so very frightening to me
I didn't know what to expect
I didn't know what I'd see
So I went in and to my surprise
I saw rows of chairs and machines
And a lot of people inside
I was led to my chair and machine
I still could not believe what I had seen.
So many patients, so much staff
Who were there to comfort me

And make me laugh
I sat there for three hours
Still a little afraid
Because of the alarms going off
And all the noises the machines made
But then I looked around
And saw patients just like me
And thought it's not so scary
This is how it has to be
And after my first day at dialysis
It's no longer frightening to me

IN 2005, THE CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS) ANNOUNCED THE FIRST EVER MEDICARE BREAKTHROUGH INITIATIVE called the Fistula First Breakthrough Initiative (FFBI). A Breakthrough Initiative is a national project adopted by CMS that reflects a substantial area for improvement between what currently occurs and what can occur to improve the overall quality of care people on Medicare receive. Medicare is committed to improving the quality of life for people on dialysis. One way of having a better quality of life is through getting and using a native arteriovenous (AV) fistula for dialysis.

All people receiving hemodialysis need a vascular access. The veins in your arms cannot supply enough blood for dialysis; so a vascular access must be created. Three types of vascular accesses are used for hemodialysis: fistulas, grafts and catheters. AV fistulas are thought to be the “gold standard” for dialysis because they have fewer infections and complications compared with other forms of vascular access, such as grafts and catheters. Because a surgeon creates the

THE FISTULA FIRST BREAKTHROUGH INITIATIVE: Improving the Quality of Life for People on Dialysis

By Kimberly F. Thompson, RN, BSN, CNN, Sarah A. Yelton, RN, CNN and Cathy Long, BA, RHIT

Fistulas are the first choice for vascular access.

fistula by joining an artery and a vein together, the access must mature or develop. While a fistula matures, the higher flow of blood will cause it to expand and strengthen. Fistulas are also less likely to clot or become infected and once mature, AV fistulas give the best blood flow to and from the dialysis machine. More blood flowing through your fistula means more blood is supplied to the dialysis machine and you receive a better treatment. Additionally, less clotting equals fewer revisions or dec clotting, and fewer infections means less time spent in the hospital. Grafts and catheters are the other forms of dialysis access and for some people, the only option available, however both are prone to infection and clotting. If you have a graft or a catheter, check with your health care team for a referral to a vascular surgeon for evaluation of a fistula.

Before looking at the many activities the FFBI has sprouted, it is important to recognize the valuable work previously done by volunteer doctors, health care providers and the National Kidney Foundation (NKF).

In 1997, the NKF began a project called Dialysis Outcomes Quality Initiative, commonly referred to as the DOQI guidelines. Developed by volunteer doctors and other members of the health care team, the DOQI guidelines gave evidenced-based information for improving care for people on dialysis. The guidelines serve as the foundation of quality care for all people on dialysis and have been used and recognized throughout the world. Over the years, the DOQI guidelines have expanded to include all stages of kidney disease. As such, the name has since changed to Kidney Disease Outcomes Quality Initiative or the KDOQI guidelines. Currently, there are 10 sets of guidelines available to guide quality care for people with kidney disease, and several more sets of guidelines are currently underway.

The KDOQI 2002 Vascular Access guideline no. 29 states that “65 percent of people or more just starting dialysis [also called “incident”] and at least 40 percent of those undergoing dialysis [also called “prevalent”] should have a

fistula placed” (1). CMS uses this guideline as one way to evaluate dialysis units each year to make sure that people on dialysis are getting good care. One of the areas needing improvement was found to be placement and use of fistulas for dialysis.

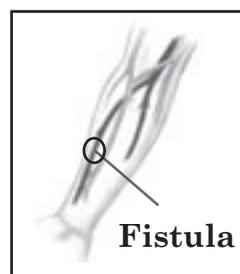
Knowing that people on dialysis lived longer, healthier lives when a fistula was used for dialysis, Medicare launched FFBI in 2005. Working together, CMS, the End Stage Renal Disease (ESRD) Networks, the Institute on Healthcare Improvement, the NKF and many other partners in the kidney community hope to increase the rate of fistulas to 66 percent for people on dialysis by the year 2009. Six task forces (Community Education, Practitioner Education, Program Operations, Clinical Practice, Quality Measures, and Marketing and Communication) were formed to find ways to help more people understand the importance of fistulas and to help raise the number of people who have them. The roles and the activities of these task forces are briefly described below:

1. Community Education Task Force

This task force reviews information—booklets, videos, and Web-based materials—available in the kidney disease community about fistulas. A list of materials found to meet the high standards of the FFBI has been created and will be offered to everyone in the kidney disease community. This “Community Education Tool” is available on NKF's Web site www.kidney.org

2. Practitioner Education and the Clinical Practice Task Forces

These groups have helped define the education and



Kidney Machine

By Sandra P. Bass

Kind hearted people help you out
Intelligent nurses hurry about
Dialysis is such a scary word, I know
Need it in my life, to keep me on the go
Every other day, 4 hours each
Yes, it keeps me on my feet.

Made by man for my use
A-Cleanin' my blood to give me a boost
Cramping can hurt so bad
Hey, My times up! I'm so glad.
In case you didn't know this before
Never get off early to shorten your time
Even I know this is my lifeline.

Sandra Bass has been on dialysis for nine years. She dialyzes in Roxboro, North Carolina.

Continued on next page

Continued from previous page

tools that surgeons, radiologists, other physicians, nurses and other members of the health care team need to help people with CKD learn about the benefits of fistulas. This task force made a training video for surgeons, and a cannulation (needle placement into a vascular access) video aimed at improving the placement and use of fistulas. For more information about these videos or to order a copy, please contact your local ESRD Network. A listing of the ESRD Networks across the nation can be found at www.esrdnetworks.org. Clicking on your state will take you to your network's homepage.

3. Program Operations Task Force

This task force thoroughly reviews payment, billing, reimbursement and other financial issues to find areas that might discourage fistula placement.

4. Quality Measures Task Force Cannulation techniques

have a big effect on how well a fistula works. This task force is looking at research on the different cannulation techniques, such as the "buttonhole technique," used around the world to learn the best ways of keeping a fistula strong and in good working order.

5. Marketing and Communication Task Force

The very important work of this task force will find the best ways to share information about the work of all of the task forces to ensure that the kidney disease community around the world has the most up-to-date information on the benefits of AV fistulas and the successes of this Initiative.

Through strong community partnerships, with members like the ESRD Networks, CMS and the NKF, dialysis units around the country are placing more fistulas. When this project originally began, the prevalent (people already on dialysis) rate for fistulas in the United States was 32.4 percent. As of May 2006, it

increased to 42.5 percent. The kidney community has shown great improvement over the last several years and remains hard at work to achieve the goal that every person on dialysis, who is eligible for a fistula, receives one.

For more information and resources on dialysis access options, specifically fistulas, please go to www.fistulafirst.org. If you do not have Internet access, please ask a member of your health care team for more information.

REFERENCES

1. KDOQI Guidelines 2000. National Kidney Foundation. 2001. http://www.kidney.org/professionals/kdoqi/guidelines_updates/doqi_uptoc.html#va

Kimberly F. Thompson is the Patient Services Coordinator for Heartland Kidney Network (ESRD #12) serving over 250 dialysis facilities located in Iowa, Kansas, Missouri and Nebraska. Sarah Yelton has been the Quality Improvement Director

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Hemodialysis Access: What You Need to Know is available for order by calling the NKF at 800.622.9010.

Physical Activities *Continued from page 11*

get a pedometer and track your weekly steps; try to increase the number you take by a little bit each week. Finally, if you are interested in working with a personal trainer like Steve, look in your local yellow pages under Physical Fitness Consultants and Trainers. You can also search the Internet. Two certifying organizations that provide trainer locator services throughout the country are the National Strength and Conditioning Association (www.nscf.org/trainers/locator) or call 800.815.6826) and the American Council on Exercise (www.acefitness.org/profreg/default.aspx) or 800.825.3636). Call the

National Kidney Foundation at 800.622.9010 for a copy of *Staying Fit With Kidney Disease*. So get moving! Do it today!

REFERENCES

1. Lowrie EG, Zhang H, LePaine N, Lew NL and Lazarus JM: Health related quality of life (QoL) among dialysis patients: associations with contemporaneous measures and future mortality (abstract). *Journal of the American Society of Nephrology* 9:219A, 1998.
2. Kalantar-Zadeh K, Kopple JD, Block G and Humphreys MH: Association among SF36 quality of life measures and nutrition, hospitalization and mortality in hemodialysis. *Journal of the American Society of Nephrology* 12:2797-2806, 2001.
3. Kutner NG, Zhang R and McClellan WM: Patient-reported quality of life

early in dialysis treatment: effects associated with usual exercise activity. *Nephrology Nursing Journal* 27:357-367, 2000.

4. Painter PL, Carlson L, and Carey S. Improvements in physical functioning and health-related quality of life following exercise training in hemodialysis patients. *American Journal of Kidney Diseases*. 35:482-492, 2000

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Patricia Gordon, a registered nurse and an exercise physiologist, is on the faculty of the Department of Physiological Nursing at the University of California, San Francisco. Her research specializes in muscle function and kidney disease.

It Could Be Me By Janice Talley

As I watch each morning, each day
A woman...a man walking their way.
Some stumbling or too weak or
blind to see,
I think it could be me!

Weighing in on the big scale,
Watching the numbers vary to
no avail.
Some with pillows or blankets
in hand or just a key.
I think it could be me!

Sights washed, temp-a-dot in mouth,
blood pressures taken
Getting laid back in big chairs,
sometimes not so gently,
Leaving you a little shaken.
Watching your blood flow, like it's
a decree,
I think it could be me!
Some reading the paper or a book,
Some gazing out the window with
a blank look.
Some trying to sleep, others
watching t.v.,

I think it could be me!

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All the Life Savers

By Frank McEntee

As I begin my sixth year on dialysis I often think about
The patients and staff I have met along the way.
You have touched my life in more ways
Than you may realize by what you do and say.

In this poem I mention four patients and fifteen staff members
But none of them by name.
See if you can figure out who they are
Or decide as a group which names are the same.

To the patient whose war stories
I shall always remember and treasure.
To the one who took the time to research a problem
Having her as my nurse will always be my pleasure.

To the nurse who is always on the go
But when a patient dies cannot control her tears that will flow.
For the one who prays for the patients and staff.
To the nurse who could always make me smile or laugh.

To the nurse who with the punches could always roll
But in an emergency she had the situation under control.
To the patient who would worry more about her grandson than her own health.
To the patient who being a gentleman throughout his life was his greatest wealth.

To the soft spoken person who would chase our financial worries away.
To the patient who died too young but his courage I still admire to this day.
To the one whose Southern accent and warmth would calm a patient's fears.
To the nurse who was so compassionate I could not control my tears.

To the one who helps us to keep our numbers and levels in order.
To the one with the perpetual smile who anyone would be proud
to have as a daughter.

To the one they say is so strong, yet when I showed her a poem she cried.
To the nurse who is almost a doctor and to the doctor most patients want
by their side.

To the nurse who made our days so bright by her caring ways and
pleasant personality.

To the one who is so fast yet so proficient was a sight in itself to see.
To all of you, especially those who keep the machines running and help us
to better cope.

It's the little things you sometimes do, you may not realize, that gives us so
much hope.

For some patients they will become tired of this life and seek the brightest of
God's light.

For others, with their last ounce of strength, they will try to win this their
final fight.

These are just a few of the many people who have touched my life
But there are far too many for me to name.
But it is what all of you do for all of us on a daily basis
That is your true glory - that is your true fame.

God bless and thank you for everything.

*Frank McEntee is a dialysis patient at Hackensack University Medical Center
in New Jersey.*