

ESRD NETWORK 13

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KIDNEY CONCERNS



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Is Anybody Listening?

by Margaret S. Washington, MSW, MSPH

The Kidney Patient's Role in Doctor/Patient Communication

The question is, "Doctor, can you hear me?" The answer is, "Patient, are you listening?"

This question and this answer are repeated hundreds of times a day as physicians and patients interact. The real question is, "Is anybody listening?" The real answer is, "Very few people are listening."

"A Mounting Crisis"

There is a mounting crisis in communication between doctors and patients—one that often impacts both in a negative way. Each is intent on making his/her point to the extent that they function as ships passing in the night. The nature of the dialysis experience, usually performed three times a week, makes this communication crisis urgent and in need of a close look, assessment, and strategies to address the problem.

Dialysis patients arrive at their facilities with their own particular problems and are confronted by the "unit problems," which often impact on the treatment environment and the quality of care they receive. Dialysis patients must empower themselves to become active partners in their treatment and demand to be treated with dignity and respect.

"Poor Communication"

Doctor, Can You Hear Me? Patient, Are You Listening? is the product of more than three decades of first-hand observation in a variety of healthcare settings. In a neighborhood health center, in two major metropolitan teaching hospitals, and as the former Executive Director of an End-Stage Renal Disease (ESRD) Network of 160 dialysis facilities and 10 renal transplant centers, I saw the same kinds of poor communication, including:

- Inattentiveness;
- Misunderstanding;
- Poor description of symptoms;
- Equally poor explanation of diagnoses, rudeness; and
- Cultural differences that became barriers to understanding.

Finally, as a consultant on effective communication in healthcare, I am confronted regularly by patients and physicians who are looking for better ways to understand each other.



“Experienced Observers”

The three years of research for the book involved mailed surveys, on-site surveys, focus groups, and one-on-one interviews. The respondent pool comprised more than 3,000 physicians and patients across the country. In all, 1,429 patients (572 of whom were renal patients) responded to the surveys, and 375 patients (151 of whom suffered from kidney failure) participated in the 35 patient focus groups. All were experienced observers of the health care scene.

Urban patients were more critical of healthcare providers in a number of areas, such as availability, office hours, costs, and frequency of prescription changes. Overall, rural patients were less likely to complain, and, in the focus groups, more reticent in their responses. Similar differences emerged in comparing the racial groups: Caucasians were generally accepting of the care they received and reluctant to criticize their physicians while African Americans were more outspoken and often critical of the care, which, they perceived, was influenced by their race and ability to pay. The sampling of Hispanic and Asian patients was small, but they appeared most satisfied with their current healthcare delivery.

Hearing and Listening

The doctor says: “We’re going to try a new medication for your blood pressure.” (Hands a prescription to the patient.) “Get this filled today.”

The patient hears: “Another \$60 at the pharmacy before my next check comes in.”

The patient says: “Let’s wait a few weeks to start the new medicine.”

The doctor hears: “She’s questioning my judgment. Why can’t patients follow directions?”

A “Humpty Dumpty” Meaning

Too often, the exchanges between doctors and patients are like Alice’s encounter with Humpty Dumpty in Lewis Carroll’s *Through the Looking Glass*. When Humpty Dumpty used the word “glory” out of context, Alice told him, “I don’t know what you mean by ‘glory.’” Humpty Dumpty smiled contemptuously. “Of course you don’t-till I tell you. . . . When I use a word, it means just what I choose it to mean-neither more nor less.”

Doctor-patient communication is often problematic. By definition and by connotation, words may have very different meanings to the doctor and to the patient. In addition to the complex language of medicine that can create a gulf in understanding, social and cultural factors can distance the physician from patients who live in a world he/she may never have visited. In the case of foreign-born physicians (or patients, for that matter), an accent or a limited understanding of idiomatic expressions may cause misunderstandings. Even more critical, perhaps, is the patient’s failure to understand the seriousness of his/her condition and the need to comply with instructions and the physician’s failure to understand the barriers-psychological, financial, or cultural-that may cause patient non-compliance.

“Good Communication”

Good communication is particularly important in the treatment of chronic illnesses such as hypertension, diabetes, and ESRD. Over the many years of interaction with physicians and their care teams, which include nurses, social workers, dietitians, and other healthcare professionals, patients ideally develop a partnership with their physicians and care providers. Essential to this partnership is the commitment of both patient and physician to accomplish the best possible outcome.



Patients must “own” their illness and the responsibility to follow medical direction, even when it means making significant lifestyle changes. Physicians must be willing to share with the patient the development of a treatment plan that recognizes patient participation. Both partners must pay particular heed to the art of “hearing and listening.”

Creating a Viable Action Plan

The problem of ineffective communication is solvable: there is an urgent need to execute a viable action plan to assure the best possible patient outcome. We are able to improve issues of poor communication if both parties—physicians and patients—commit to owning responsibility for their roles in a successful relationship. Both must critique their own behaviors and identify areas that need improvement.

Patients as a whole, and particularly those with long-term chronic illnesses, must develop the capacity to be attentive to their illness on a regular basis. To do so, they must develop an ongoing relationship with their doctors based on trust and mutual respect.

Making a Commitment

Patients must make a commitment to learn about their illness and exhibit a willingness to partner with their physicians by sharing information that will assist the doctor in making an accurate diagnosis and treatment plan.

Patients must assume responsibility for knowing their medications and the purpose of each, and they must strive to comply with the treatment plan. When patients are not able to follow the plan, they must inform the physician and seek help in overcoming the barriers to care that result in non-compliance.

Patients should learn how to describe their symptoms in a precise, meaningful way (“I’m short of breath after climbing a few stairs” may be the first step toward a diagnosis. “I’m feeling poorly” provides little guidance to the doctor.)

“Major Changes”

Patients should take note of any major changes in prescribed medications and any side effects they may be experiencing. They should feel free to question any changes in treatment or medication.

Patients should inform each physician they see about any chronic conditions they have, current medications they are taking, and adverse reactions they have experienced with specific drugs.

Also, patients should not be reluctant to say, “I don’t understand.” This statement is not a reflection of ignorance but rather an indication that you are willing to partner in your care and want to be armed with information that you understand.

Patient Rights and Risks

Patients must be aware of their rights, including the right to information in their medical records. Certain healthcare providers have specific rules governing medical record disclosures, and patients should be made aware of these rules.

Additionally, patients have the right to know the risks involved in any prescribed test or treatment and to understand the potential consequences of undergoing, or not undergoing, the treatment. They are usually



wise to follow their doctor's recommendations. Occasionally, however, physician-patient concerns, priorities, or beliefs come into conflict, and, in such cases, communication is especially important. Patients who are thinking about refusing treatment should discuss their concerns openly with the physician. There may be a compromise course of action that will satisfy both.

Patients should treat their doctors and staff in the same manner that they wish to be treated. Courtesy is contagious. When you believe that you have been treated with discourtesy by a physician or his/her staff, make your concerns known to the physician.

Conclusion

The ingredients of disrespect, mistrust, lack of cultural competency (failure to understand and accommodate racial, ethnic, and cultural differences), insensitivity, and poor communication of concerns combine to create a "conflict pie." Acknowledging the existence of the "pie" is the first step towards eliminating the conflict. Each partner (patient and doctor) must be willing to own responsibility for some slices in the pie (i.e., lack of availability, withholding information, mistrust, etc.)

Once the ownership of the conflict slice is acknowledged, the owner must recognize how it contributes to the problem of communication and look for ways to eliminate it or modify its impact. The ingredients serve as barriers to listening and hearing of patient and doctor concerns and frustrations. Mutual respect, open communication, and a willingness to accept responsibility for change will create a meaningful partnership for health—a partnership where each partner has an accepted, specific role to play and responsibility for making it work.

Patients who become full partners in their medical care will be the ultimate winners.
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About the Author:



Margaret S. Washington, MSW, MSPH, author of *Doctor, Can You Hear Me? Patient, Are You Listening?*, is President of Washington Associates, a Pittsburgh, PA-based consulting firm that provides training in communications to physicians, other healthcare providers, and patient groups across the country. An experienced healthcare administrator, she served for 23 years as Executive Director of the ESRD Network operating out of the University of Pittsburgh Medical Center. She is a Board member of the American Kidney Fund, co-author of articles in professional medical journals, and recipient of awards from the National Kidney Foundation of Western Pennsylvania, the Allegheny County Medical Society, and the American Medical Writers Association. For more information on *Doctor, Can You Hear Me? Patient, Are You Listening?*, visit <http://www.doctorpatienttalk.com/>.



Renal Resources and News

Home Dialysis Central

Home dialysis puts you in the driver's seat. You can schedule your treatments around your life or your job, dialyze longer or more often to feel your best, and you may even be able to have a more normal diet and fluid limit with home dialysis.

The non-profit Medical Education Institute has launched Home Dialysis Central (www.homedialysis.org)-a new Web site that aims to raise awareness and use of peritoneal dialysis (PD) and home hemodialysis.



AAKP Elects 2004-2005 Board of Directors

We are proud to announce Network 13 PAC Member, Carl Nettleton, was elected for board membership and will serve a 2 year term.

AAKP Creates Kidney Transplant Newsletter

The American Association of Kidney Patients (AAKP) is pleased to introduce its new, monthly electronic newsletter "Kidney Transplant Today." This newsletter is devoted to those who are interested in learning about kidney transplantation or those who have received a kidney transplant. For an electronic copy, interested subscribers should send their name and e-mail address to info@aakp.org. In the subject line, please type "Kidney Transplant Today."

Genzyme Launches the Renagel REACH Program: Expanding Access for Medicare Beneficiaries

The Genzyme Corporation announced today that it will enhance access to Renagel® (sevelamer hydrochloride) for Medicare beneficiaries through the new Renagel REACH ProgramSM, launched in partnership with major providers of Medicare-approved drug discount cards. Beginning today, Medicare beneficiaries are eligible to receive Renagel for either \$5 or \$25 per month, depending on income, by using a participating Medicare-approved drug discount card. Renagel helps to control serum phosphorus in patients with Chronic Kidney Disease on hemodialysis.

Genzyme is offering this benefit through several major providers of Medicare-approved drug discount cards. In order to receive this benefit, patients must sign up for a participating Medicare-approved drug discount card. For more information about the program, including which cards are participating, call the Renagel REACH Program at 1-800-847-0069. Information is also available on Genzyme's Web site at <http://www.renagel.com>.

Dialysis Facility Compare

The Dialysis Facility Compare (DFC) Web site <http://www.medicare.gov> provides both demographic information and 'quality measures' data about dialysis facilities that have been approved by Medicare. 

Nocturnal Dialysis, My Perspective

By: James Carter, Network 13 PAC Member

Nocturnal Dialysis is dialysis treatment that is administered during the night time hours, usually while the patient is resting. I read about nocturnal dialysis a few years ago, at which time the treatment was administered in Europe only. The procedure involved receiving treatment six nights a week – eight hours nightly. The article stated that patients were receiving dialysis treatment and then going straight to work. Every bit of research that followed my first reading about the treatment was extremely positive.

Dialysis is a procedure in which a patient with kidney failure has waste and fluid removed from their blood system. The two main types of dialysis are hemodialysis and peritoneal dialysis.

Hemodialysis – involves purification of the blood while it flows through an artificial kidney.

Peritoneal dialysis – involves fluid being placed into the abdominal cavity for purposes of getting rid of waste and excess body fluid.

Nocturnal dialysis is hemodialysis at night. - Hemodialysis is an intermittent process. Waste accumulates between dialysis sessions and is removed by the dialysis procedure.



Standard dialysis, as practiced in U.S. dialysis centers today, consists of three treatments weekly, lasting 3 – 4 hours each treatment. The 3 – 4 hour dialysis treatment is designed to remove 48 – 72 hours of waste and fluid accumulation in a shorter period of time. Sometimes the customary, standard procedure can lead to blood pressure instability and a “washed out” feeling after the dialysis treatment.

Nocturnal dialysis is designed to shorten the time between dialysis sessions – usually six nights per week at 8-hour intervals so that there is less accumulated waste and fluid to remove over a longer period of time. This leads to a gentler, less aggressive treatment that is better for most patients. Nocturnal hemodialysis is performed by the patient at home after sufficient training and certification. Not all patients are good candidates for this procedure as it takes motivation to care for oneself and attention to detail to perform a safe and effective procedure.

Presently, there are twelve patients who receive nocturnal dialysis in the New Orleans metropolitan area. Our treatment is administered **in-clinic** three nights a week with eight-hour sessions. Our procedure is given only three nights because of limitations on the number of treatments per week Medicare covers. Hopefully, this will change soon.

Nocturnal dialysis has been proven to be effective “almost as having your own kidneys”. I feel the benefits of this method of treatment cause fewer difficulties and have been proven to be user friendly as it relates to my access. I generally endure little or no cramping during this procedure. Additionally, patients receiving nocturnal dialysis may have fewer hospital stays and require less medication.

Come join us on the night shift!



Vitamin & Mineral Supplements For Those on Dialysis

By: Susan Knapp, MS RD LD, Network 13 Medical Review Board Member

What are vitamins and what do they do?

- Vitamins help your body to make energy from food.
- Vitamins are either water-soluble or fat-soluble. The water-soluble vitamins are the eight B Vitamins (called B-Complex) and Vitamin C (ascorbic acid). The fat-soluble vitamins are A, D, E, and K.
- B-Vitamins (folic acid, Vitamin B-12, Vitamin B-6) are needed to build red blood cells to keep you from becoming anemic, or improve your anemia. Anemia can make you feel tired, weak and short of breath.
- Taking either too much or too little of vitamins can be harmful to health.

Why do dialysis patients need special vitamins?

- Dialysis patients need to have a special balance of vitamins to feel their best—and their needs are different than those that don't have kidney disease.
- The diet for dialysis patients usually limits foods that are high in vitamins such as fruits, vegetables, beans, nuts, milk products, and whole grains.
- If your appetite is not good, you may not be able to get enough vitamins from your food.
- Dialysis itself washes away some water-soluble vitamins while it is cleaning the blood.
- Some medications may increase your need for certain vitamins.
- Regular vitamin supplements do not have enough of some vitamins (such as folic acid) and have too much of other vitamins (such as Vitamin A, C or D) and should not be taken instead of a renal vitamin.
- Examples of renal vitamins: Diallyvite®, Diatx®, Nephplex Rx®, Nephron FA®, Nephrovite Rx®, Nephrocaps®, Renaplex®, Renax®



When should the vitamin be taken?

To get the most benefit from your vitamin, take it after dialysis.

What is a mineral?

- Minerals or elements include iron, potassium, phosphorus, sodium, calcium, magnesium, and zinc.
- Minerals are needed in various amounts and ways throughout the body. Each mineral has several functions in the body. Examples include iron for red blood cells, calcium & phosphorus for the bones & teeth.

Do dialysis patients have special mineral needs?

- Dialysis patients usually need additional iron to make red blood cells to decrease anemia. Often this additional iron is given through the dialysis lines on hemodialysis. If oral iron is taken it should be taken 1 hour before or 2 hours after meals to keep from combining with phosphate binders. Although some renal vitamins have iron added to them, most do not.
- Potassium, phosphorus, and sodium usually are restricted in the diet and should therefore be avoided in supplements. Regular vitamin supplements may contain some of these.
- Phosphate binders such as calcium carbonate, Tums® or PhosLo® contain calcium. Thus, additional calcium from supplements is usually not needed.
- Magnesium is sometimes used for a phosphate binder, but additional should not be taken unless recommended by your dietitian or doctor.
- Your doctor or dietitian may recommend zinc if you are having problems with loss of taste. Some renal vitamins have a little zinc in them.



Word Search

Answers on pg. 8

Vitamins
 Vitamin A
 Vitamin D
 Vitamin E
 B Complex
 Folic Acid
 Ascorbic Acid
 Multi
 Stress
 Renal

B	I	D	A	C	B	M	U	L	T	I	V	I
C	V	I	T	A	M	I	N	S	P	A	I	R
O	I	C	R	L	A	N	S	U	F	N	T	O
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K	S	S	L	O	T	J	N	P	D	R	N	N
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E	L	E	M	E	N	T	S	U	W	Y	V	B

Supplements
 Calcium
 Phosphorus
 Zinc
 Iron
 Magnesium
 Minerals
 Elements
 Energy
 Anemia

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). Grievances 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 Network's Patient Services program.

Call 1.800.472.8664 for details.

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B	I	D	A	C	B	M	U	L	T	I	V	I
C	V	I	T	A	M	I	N	S	P	A	I	R
O	I	C	R	L	A	N	S	U	F	N	T	O
M	T	A	E	C	G	E	U	R	O	E	A	N
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KIDNEY KONCERNS NEEDS YOU!

Kidney Concerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for SPRING/APRIL. 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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