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InterMountain Messenger

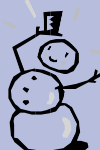
News from ESRD Network #15

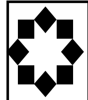
EPO Info ...

On September 22, 2003 CMS announced its intention to develop a "clinically and scientifically robust policy" to ensure appropriate administration of erythropoietin (EPO) in ESRD patients. In order to accomplish this, CMS invites interested parties to send scientific evidence related to EPO dosing and hematocrit/ hemoglobin levels.

The deadline for submitting evidence has been extended to January 15, 2004. Information can be submitted to Steve Phurrough, MD, MPA, Director, Coverage and Analysis Group, Centers for Medicare and Medicaid Services, Mail Stop C1-09-06, 7500 Security Boulevard, Baltimore, MD 21244-1850.

If you have questions or wish to schedule an appointment to discuss your submittal, you may contact Jackie Sheridan-Moore at 410-786-4635 or email jsheridan@cms.hhs.gov.





Views from the Experts

Self-Care: A Multidisciplinary Approach

Q: What are appropriate facility policies for handling self-care training?

A: In our self-care unit, we have a procedure manual similar to the one used in our home hemodialysis-training program but tailored to the clinic setting. The ultimate goal is to have the in-center patient achieve a similar level of independence as the home patient. The patients in the self-care unit participate according to the level of their comfort. Some patients, for instance, perform all of the necessary tasks except for cannulating themselves.

Q: What are the administrative advantages in providing self-care dialysis?

A: Self-care affords the patients another treatment option. For those persons who may not have a partner to assist with dialysis at home, they can still be given the choice of self-care. Self-care gives patients a sense of pride, increases self-esteem, and fosters a sense of control and independence. Interacting with other patients who have similar goals creates an environment that is positive for them. Our self-care patients have fewer hospitalizations, which makes for a better bottom line financially. As an administrator, another advantage is a higher nurse-to-patient ratio, primarily because this is a stable population. Self-care offers patients better continuity of care since they work with their primary nurse - she knows each of them very well.

Blenda Williamson
Administrator
DCI of Nashville, Tennessee

Q: What are the advantages and disadvantages of self-care from a patient perspective?

A: Studies show quality of life and opportunity for rehabilitation is

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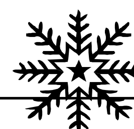

Pinpoint Ways to Enhance Patient Safety:

Include a patient on your Facility Safety Committee.

Develop a "Patient Safety Brochure."

Develop a "Patient Safety Poster."

Encourage patients to report unsafe conditions or events.

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greatest for home hemodialysis patients, followed by peritoneal dialysis patients, and then in-center hemodialysis patients. The mortality rate is lower for home hemo patients than it is for in-center patients. I think self-care is great for anyone with the ability to do it.

Q: Under what circumstances do you think self-care dialysis is good for patients? When is it not good?

A: I think any patient who is willing and able to do self-care should be encouraged. Old age is not a contraindication - most patients could do more self-care if properly trained. Home hemodialysis may not be for everyone, however. Patients with medical problems, such as cardiac arrhythmia, which make them unstable during dialysis, should probably dialyze in-center. A patient should also have a supportive family. A patient who does self-care in-center could have the same advantages as home hemodialysis patients as long as they don't slip into the "regular" dialysis routine in which the staff is in control.

Christopher Blagg, MD
Director, Northwest Kidney Center.
Seattle, Washington

Q: What are the pros and cons of self-care with regard to the renal diet?

A: Nutrition is a very personal issue, so it lends itself well to self-care. It's important for patients to know about how diet affects their health, but they also need a sense of making their own choices. Nobody wants to hear a lot of "no's." By letting patients manage their own care, such as monitoring their fluid consumption, they may be better able to set limits for themselves that they can live with. The only disadvantage in working with self-care patients who may be involved in home dialysis is that they don't have the regular contact with staff. I see my in-center patients once per week, so I can spend adequate time with each patient discussing lab values and goals. Sometimes home patients lose that close contact with the staff.

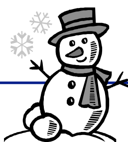
Q: What are the advantages for dietitians in working with self- care dialysis patients?

A: I welcome the patient who asks for more information, looks to me as a resource, and asks questions about the information I provide. In renal nutrition, dietitians are highly motivated and are concerned about patient well-being as a general rule. I think they welcome self-care patients for that reason. Self-care patients don't divorce themselves from their care; they try to understand what to do to make themselves feel better.

Maureen McCarthy, MPH, RD, CS
Renal Dietician
Oregon Health Sciences University
McMinnville, Oregon

Excerpts from Life Options *Renal Rehabilitation Report,* Volume 5, Number 1, reprinted with permission.

There will likely be no Network #15 Key Data collection in 2004. Please stay tuned for more details.



Tell Me More…

The Centers for Medicare and Medicaid Services follows the whereabouts of every ESRD patient dialyzing in the United States. The year-end survey (2744 report) is a census: a single-day snapshot of all these individuals, combined with facility information about treatments provided throughout the year. Your role in this process is essential—and mandatory. But here is a parcel of good news: We're here to help! Let's begin by reviewing the items you will be asked to report on …

Ending Patient Population – A list of every chronic, non-transient patient belonging to your facility on 12/31/03, *including* patients away on vacation, those who are in a hospital or rehab center, and ALL home dialysis patients. We **DO NOT** want you to include the names of transient patients (visitors) who are temporarily being treated by you on 12/31/03.

Death Events – A list of all patients whose deaths are attributed to your facility for 2003.

Total number of transient (visitor) patients treated during 2003.

Total number of dialysis treatments given to transient patients in 2003 — Treatment numbers often come from the billing department.

Total number of patients who completed self-dialysis (home dialysis) training during 2003 — These patients are divided into categories for CAPD, CCPD, or home hemodialysis. Patients are only counted once, unless they trained twice for two separate modalities.

Total number of treatments given to in-center dialysis patients in 2003 (including transient treatments).

IPD (Intermittent Peritoneal Dialysis) Treatments – Most facilities do not offer IPD.

Network 15 will use your Ending Patient Population and treatment load information to generate the 2744 survey report, which will require a signature of verification. All of this will take place in January and February of 2004. Together we can get the job done with minimal complications—but we must have a common resolve and a shared language.

Data Notes

How quickly the days fly by. It seems like yesterday that we were talking turkey and eggnog—in the same bite. Once again the trees have gone bare, goblins have retired to their lairs, and it's beginning to look a lot like ***the year-end survey***.
Joy! Rapture!

Dialysis and transplant facilities can expect to receive a final roster **prior to December 31st, 2003**. At that time we will also ask that you gather treatment load information, which is required for the 2774 census report. Here's a short list of things you can do now:

* Promptly submit all forms (2728, 501, 2746). This is key. The accuracy of the rosters depends on forms received to date.
* Assign one individual (data contact) to take charge of the survey process. This person must be able to identify your facility's Ending Patient Population on 12/31/2003.
* Find out who in your facility keeps track of treatment numbers—patients treated, number of treatments provided, etc. Most likely, this information will come from your billing department.
* Call the Network office if you have any questions about your responsibilities and/or what will transpire on 12/31/2003.

The year-end survey is not a perfect science, and we're always brainstorming ways to make the exercise less cumbersome, more accurate, and fully informative. **We do know that 2004 will bring significant changes in your day-to-day and monthly reporting process** (changes will be consistent nationwide). Keep your eyes and ears peeled for further details.

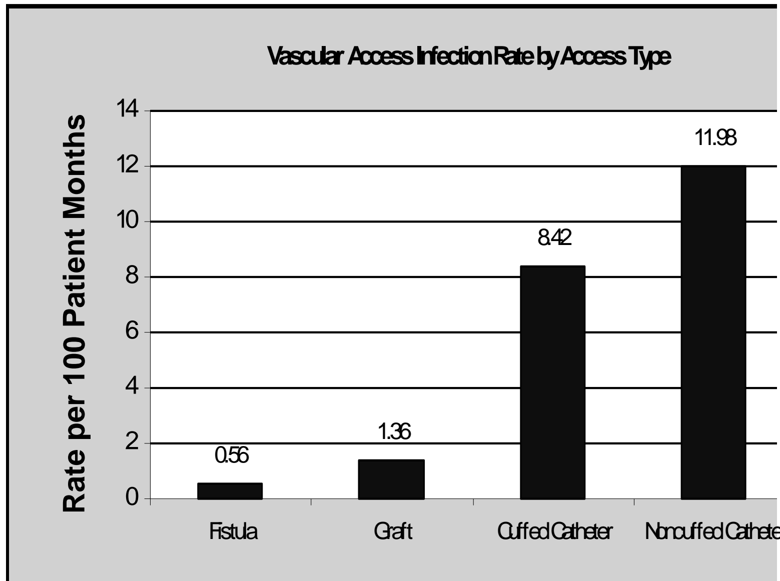
Other notes:

* Please have safe and delightful holidays.
* Please take the time to tell your loved ones that they are loved.
* Please remember that the capacity for joy is built into each moment.

Network #15 Information Systems Staff

Initial Results:
Fistulas Less Prone to Infection

The Dialysis Surveillance Network (DSN), initiated by CDC in August 1999, is a voluntary national system for monitoring bloodstream and vascular infections. The purpose of the DSN is trifold: to provide a method for individual dialysis centers to record and track rates of vascular access as well as other bacterial infections; to provide rates for comparisons among various dialysis centers; and to motivate practice changes and prevent infections. Participating centers submit data to the CDC and receive data analysis reports in return. There are no fees and participants receive no financial remuneration. Data from individual centers is confidential and released only to the specific facility reporting it. Both adult and pediatric outpatient dialysis centers are invited to participate.



From October 1999 to May 2001, 109 dialysis centers monitored patient event outcomes (including infections of the vascular access site) for the DSN. Among these facilities, the vascular access infection rate per 100 patient-months was 3.2 overall and varied markedly by type of vascular access: native arteriovenous fistulas had the fewest at .56, while noncuffed catheters had over 20 times that rate at 11.98 (*See graph above*).

This study indicates that while vascular access infections are common, the risk varies substantially among different vascular access types. These results can be used to further quality improvement at individual centers and to help evaluate the efficacy of specific infection control measures.

The full study can be found at: www.cdc.gov/ncidod/hip/Dialysis/dialysis.htm.

For information about enrollment in the DSN or to receive the new procedure manual, call 404-498-1109 or email jit1@cdc.gov.

Patient Story: A Smile for Treatment

by William Dant

Afiba Kwarm smiles a lot as she faces her dialysis machine. There is a connection. She faces her machine because she cares for herself in important ways during weekly treatments.

For example, when her machine sounds an alarm she knows what the warning means and is able to correct many situations herself. Also, her doctor has written orders allowing her to change the settings that control her temperature and the rate at which the machine takes off weight.

So one reason Kwarm smiles is because she likes being in charge of her own treatment. This is also helpful to her unit since technicians and nurses have more time to spend with other patients.

Kwarm says, "When I first started dialysis I was frightened and

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bewildered, but now my machine is part of my family because it keeps me alive." She also says, "It feels good to be in control if something goes wrong and to know what is happening during my treatment."

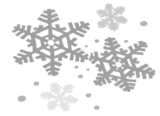
Once, while in treatment at another unit, Kwarm suggested to a young man dialyzing next to her that he ought to learn to control his machine. She said if he did, he would feel better. The man replied, "Why should I, when it's their job?" Kwarm told him, "It's nobody's job but your own to keep yourself alive. You have the brain, you have the eyes, and you have the ears. Keeping yourself alive is your responsibility and no one is paid to do that."

Her advice to other patients? "Take charge of your own body and learn the machine."

If you want to follow Afiba Kwarm's advice, talk to your nephrologist or social worker about increasing your level of self care.

Afiba Kwarm is a patient in Network #15. William Dant is chairperson of the Network #15 Patient Advisory Committee.

Honoring Patient Advance Directives



When patients, or their legally designated healthcare proxy, express their wishes regarding future medical care in the form of a living will, that directive may involve CPR refusal. This would require a Do Not Resuscitate (DNR) order.

This order does not restrict the provision of standard measures in dialysis treatment such as fluid resuscitation for intradialytic hypotension, nor does it preclude other forms of care meant to provide comfort and to relieve suffering. A DNR order becomes effective only when the patient has experienced a cardiac or respiratory arrest.

Honoring the decision of a patient not to undergo CPR is ethically justified by the principle of respect for patient autonomy and legally justified by the doctrine of informed consent and the patient's right to self-determination.

Below is a sample DNR order as suggested by the Robert Wood Johnson Foundation's End-Stage Renal Disease Peer Workgroup:

Advance Directive for a Do Not Resuscitate Order in the Dialysis Unit

Having considered the things that are important to me in life, my current medical condition, the probability that my medical condition will not improve in the future, and my feelings about life and the quality of my life, I hereby state my wishes.

I request that I not have cardiopulmonary resuscitaion (CPR) performed on me when my heart or lungs stop functioning.

I understand that CPR will probably not be successful in prolonging my life, or if it is, that my quality of life will probably not be satisfactory to me.

Based on the above reasons and after discussion with family, friends, and health care professionals to the extent to which I wish to have such discussions, I've come to the conclusion that I do not want CPR, even though I still want to continue my dialysis treatments.

In this regard, I hereby direct that if my heart or my breathing stops while being treated in the dialysis unit, I do not want to undergo CPR regardless of whether the stoppage of my heart or lungs is due to my underlying condition or a complication of the dialysis treatment.

Signature or Mark ____________________ Date __________

Witness ____________________ Date __________

Witness ____________________ Date __________

Notary (if required by state law) ____________________

Patient Address and the 2728 ...

When a patient starts chronic dialysis at your facility, and that individual will be going home to another state for permanent dialysis (and to apply for Medicare benefits) it is appropriate to put the patient's home address on the 2728 form. In this instance, the Network does not require that the address be local to the dialysis facility.

If you have not yet heard about the National Vascular Access Improvement Initiative/Fistula First Project, it's time for you to get more information! The project is a three-year national initiative to improve AV Fistula rates for ESRD patients. For more details visit **www.esrdnet15.org**, or call Network #15.

Happy Holidays from Network #15

Network #15

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