

Transitioning from
Chronic Kidney Disease (CKD)
to
Renal Replacement Therapy (RRT):
*A Guide for CKD educators
and CKD patients*

Judith Bernardini
University of Pittsburgh

Outline

- ❖ This talk reviews various pathways for patients to receive appropriate information about RRT.
- ❖ Benefits, barriers and reactions to chronic disease are discussed.
- ❖ Various approaches to CKD education are presented and evaluated in randomized published trials.
- ❖ A case study illustrates common issues for the patient and the bearer of the information.

All too common pathway for dialysis initiation

Inadequate or no modality education



No decision



Patient uremic



Tunnelled catheter inserted for HD



↑ Risk of bacteremia

This is the all-too-common path for patients...Of course if no information is given, no decision is made.

No patient education: WHY?

- ❖ Lack of education services
- ❖ Lack of coordination of services
- ❖ Absence of commitment by care givers
- ❖ Control issues of MD and RN
 - ❖ We should not try to decide which modality is best for a patient
- ❖ Some patients assume MD only one skilled enough to make the "right" decision.

Lack of educ services----an obvious cause. Lack of coordination means there is no protocol to get the patient from the nephrologist to the CKD educator. Absence of commitment is shown by some physicians and nurses who do not consider patient education a basic right. Control issues are a major part of "no education"---many of us think we know what is best for our patients and want to control when they receive information as well as what information that will be. We think this patient is best for home therapy, the other for in-center, when this is simply NOT our decision. And there surely are patients who still think the MD or the nurse know what is best and so the patient wants to wait for us to tell them what to do. It is important to resist this and encourage the patient to get the information and assure them you will listen to their concerns and support whatever decisions they make.

Barriers to CKD Education:

- ❖ time restrictions with patients
- ❖ old habits
- ❖ "MUM" effect
- ❖ inadequate interaction skills
- ❖ lack of feedback on current performance
- ❖ low confidence in new approaches

Nephrologists especially have huge time restrictions with patients. Many systems must be evaluated during those brief clinic visits. The best the MD can do often is just to introduce the topic of CKD education and refer the patient to the educator. We all have old habits and probably informing patients was just not on our previous list of tasks. But it is now!! The "mum" effect is the old thing---if we don't talk about it, it is not happening. Many have inadequate interaction skills, so once again, docs need to be the referring link, not necessarily the giver of detailed info. Have you ever asked your patients after they start RRT how they felt about the period pre RRT? Did they get the info they needed and were you helpful or obstructive? We all are hesitant to try new things, but we need to be open to patient needs and our changing roles.

The Messenger

- ❖ Natural aversion to telling bad news
 - ❖ fear of "kill the messenger"
 - ❖ wish to shield the patient
- ❖ Few physicians or nurses are prepared
 - ❖ <10% of oncologists have any formal training to deliver message
 - ❖ only 32% observed interviews during training where "bad news" was given

If oncologists are poorly prepared, imagine how well nephrologists are prepared??

What is bad news?

Any information which adversely affects an individual's view of their future

What happens when a patient is told the "bad news" ?

(aka dialysis is impending)

Furthermore:

With repeated exposure to the bad news process, physicians and nurses may become less aware of their discomfort or not experience discomfort at all.

but the patient is hearing it for the first time...

Approach to chronic disease:

- ❖ 5 encounters with the patient before the patient actually "gets it".

Ptacek and Eberhardt, JAMA 1996

- ❖ IF MD introduces bad news at one clinic, RN, NP, PA, RD, SW can make subsequent contacts to allow the patient time to hear the same message repeatedly.

No wonder health care givers are often frustrated with patients. You think to yourself, I already explained this to this patient. But they need many encounters with the same or similar messages before they can really understand it. Let your team be helpers in this endeavor.

Case Study 1: Ms X is a 58 year old woman with CKD secondary to DM.

- ❖ Full time social worker with active social life.
- ❖ Told there is bad news, that she soon will need dialysis, GFR <15mL/min
 - ❖ Consult, so first meeting with nephrologist.
 - ❖ Previous physician told her it would be years before she needed dialysis

She actually was followed by another nephrologist for many years. Whether that person told her it would be years or she thought she heard it is not important. Perhaps she did not have enough encounters with the same message to get the message.

Case study 1, continued...

- ❖ Begins to cry.
- ❖ Develops anxiety, severe insomnia and depression.
- ❖ Difficulty making decisions and concentrating

We'll return to this case later...

Reactions pre-dialysis

- ❖ Term "end stage renal disease" is frightening
- ❖ Fear of death develops
- ❖ Stress of decisions about therapy
- ❖ Stress of learning and adhering to dietary and medical regimens
- ❖ Deny dialysis is needed
- ❖ Fear loss of job, income, lifestyle

Emotional responses

❖ Assess reactions—
let the patient know
you recognize their
reaction, acknowledge
your own sadness or
other emotions



crying



silence, disbelief



denial



anger

I often find patient anger the most difficult reaction to deal with.

Pre-dialysis Education

Primary Goal:

- ❖ To provide information about choices of therapy

Secondary Goals:

- ❖ Help patient accept RRT
 - ❖ Realize that they are choosing the therapy to *begin with*, but that many will eventually have all therapies at different times in order to prolong their lives and maintain their quality of life
 - ❖ May choose conservative therapy (no dialysis or transplant)—we need to support them and continue to provide non-judgmental care
- ❖ Help integrate RRT with patient's life
- ❖ Avoid admission for emergent start of dialysis
- ❖ Avoid temporary HD access

Perception of the patient "before you tell, ask"



This is so important. Just begin the conversation with a simple question--- what do you know about dialysis? Or transplant? Listen to them first---this is when you find out that their sister (or neighbor or friend) went on dialysis and felt terrible and lived only a few months. Imagine how frightening if this is all you know.

Determine the Patient's Goals and Priorities

- ❖ What's most important in the patient's life?
- ❖ What does he or she want to be able to continue to do?
- ❖ How important is independence to the patient?

97% of Dialysis Patients Want Survival Data

	Do NOT want to know	Would like to know	Absolute need to know
Life expectancy on dialysis	3%	46%	51%
Limitations on quality of life	1%	45%	54%
What it does to the body	3%	44%	53%
What it will accomplish	4%	43%	53%
Possible side effects	4%	48%	48%

And for the physician to provide it without having to be prompted

Fine A et al. *Perit Dial Int.* 2005;25:269-273.

Contrary to what we think, patients DO want to know. How you tell them is up to you, but clearly they don't want to have to beg for information nor to be denied. For the small number who really do not want to know, who use denial to its fullest extent, one must respect their needs as well. You can continue to offer education but cannot force someone to listen.

Patient Preferences: A review of published surveys

Benbassat et al, Behavioral Medicine 1998

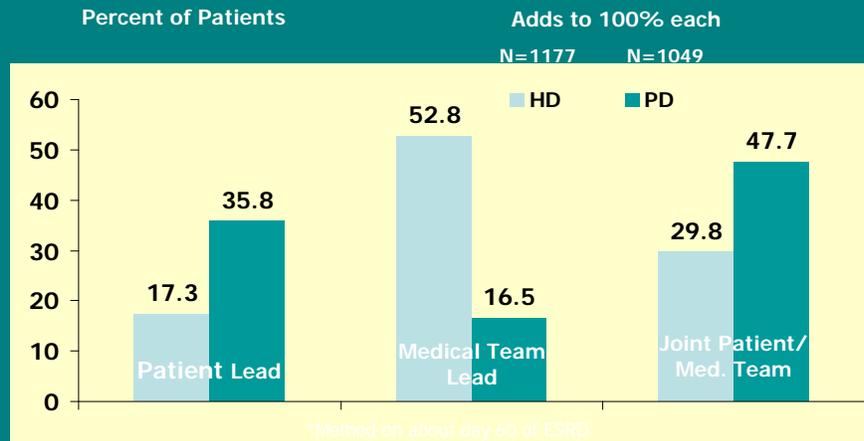
- ❖ The vast majority want to be informed about their disease
- ❖ Patient satisfaction higher when healthcare givers *shared* in care decisions
- ❖ With acute distress, lower interest in participating in decisions

Choices: PD versus HD

- ❖ Because there is no consistent evidence one modality is superior to the other, this choice should be primarily the patient's, based upon their lifestyle.
- ❖ There are few absolute contraindications for HD or PD:
 - ❖ The principal reason for the modality choice should be simply that the patient chooses it after receiving unbiased education about the modalities.

Informed Patients Often Choose PD

When Providers Choose, Most Patients Receive HD



The USRDS Dialysis Morbidity and Mortality Study: Wave 2. *Am J Kidney Dis.* 1997;30(suppl):S67-S85.
Schreiber M et al. *Nephrol News Issues.* 2000;14:44-46.

When asked which best described the process of selecting their method of treatment, 84 percent of patients treated with PD appeared to contribute substantially to the decision (Figure IV-4). In 36 percent they reported that they took the lead in the selection and 48 percent reported that it was a joint decision with the medical team. Among patients treated with HD, the medical team clearly played a larger role in selecting this treatment. 53 percent of HD patients reported that the medical team took the lead in selecting their treatment and in only 17 percent did the patient take the lead. In 30 percent it was a joint decision

The percent of patients choosing PD seems to be largely influenced by the scope of information they receive prior to therapy initiation. In the absence of thorough treatment option education, a significant number of patients may be assigned a therapy when, in reality, they would have selected an alternative option.

Effects of predialysis education

Klang et al, J Adv Nursing, 1998

- ❖ 28 patients with GFR <20mL/min
 - ❖ 4 group sessions with nurse educator
- ❖ 28 patients with "usual care" predialysis
 - ❖ Information from physician on

3 mo after started dialysis, CKD educ pts had:

- ❖ better mood, less mobility problems,
less functional disabilities, less anxiety

Effects of Patient Education on Initiation of RRT

Binik et al, J Nervous and Mental Dis, 1993

- ❖ 204 ESRD patients pre-dialysis or transplant
- ❖ randomly assigned to enhanced or standard education
 - ❖ Enhanced education initiated dialysis 4.6 months after standard education group
 - ❖ Speculated diet education alone may have delayed onset of dialysis

Pre CKD education and coping styles.

Devins et al, AJKD 2003

- ❖ random assignment of 297 patients to 90 minute, 1:1 educational intervention compared to "usual care"
- ❖ Intervention included phone calls every 3 weeks until dialysis began
- ❖ Compared coping mechanisms:
Intervention significantly delayed time to start of dialysis (17 vs 14 months, $p < 0.001$)

"usual care" being whatever the nephrologist had time and inclination to offer the patient.

Do Educated, Empowered Patients Have Better Outcomes?

Latham, JASN, 1998

- ❖ improved quality of life
- ❖ more likely to be employed
- ❖ more satisfied with care
- ❖ less utilization of health services
- ❖ cost effective:
for every \$ invested in patient education,
\$3-4 saved on ER, admission or MD visits

Can Patient Education Maximize Success of Therapy?

Golper, Nephrol Dial Transp, 2001

USRDS Wave 2 Study and CHOICE Study
1700 patients

- ❖ Education early in course of CRI
 - ❖ reduced anxiety
 - ❖ improved respect for healthcare givers
 - ❖ more likely to remain employed
 - ❖ more timely initiation of dialysis
 - ❖ improved compliance with therapy

Does Patient Education Influence Modality Choice?

Golper, JASN 2000

National Pre-ESRD Education Initiative

- ❖ 2850 patients enrolled
- ❖ 55% chose HD, 45% chose PD

↓
98% went on HD

↓

75% went on PD

- change in health status
- physician-driven change
- patient changed mind

How to evaluate your CKD education program

- ❖ What % of your CKD patients receive CKD education?
 - ❖ The goal is for 100% to receive CKD education
 - ❖ You may want to consider a protocol with an automatic referral to CKD education at a specific GFR (such as 30)
- ❖ What % of your CKD patients choose home therapies?
 - ❖ Research shows 30-50% will choose home therapy with good CKD education
 - ❖ If your center's take-on rate for home therapy is less than this, you should re-evaluate your CKD program

Return to Case Studies...

Case I, a 54yo woman with DM:

- ❖ Begins to cry.
- ❖ Develops anxiety, severe insomnia and depression.
- ❖ Difficulty making decisions and concentrating.

- ❖ She returned in 2 weeks with a friend to tour the dialysis unit.
- ❖ Numerous phone calls and clinic visits
- ❖ Chose APD
 - ❖ difficulty with training due to cognitive problems (depression)
- ❖ Placed on antidepressant; encouragement from staff
- ❖ After 1 month, returned to work and active social life

Note that even though this was an intelligent and highly motivated person, training was complicated and prolonged due to her cognitive barriers from depression. Remember that motivation is not enough to overcome other difficulties of learning. Experienced training nurses and antidepressants were the keys to helping this woman successfully complete PD training and become a competent home therapy patient.

Educational Options

- ❖ 1 on 1
- ❖ group session(s)
- ❖ nurse, physician or other educator
- ❖ meet or talk with a dialysis patient
- ❖ support group

Many centers use a number or all of these options at different times or for different patients. Talking with another patient may be in person at the clinic and can really help a CKD patient appreciate seeing someone who looks and feels well on RRT. Or it may be over the phone which can sometimes work well as it seems anonymous to both parties. Or it may be in a group session where a RRT patient tells their story to the group and tries to answer questions (but always with a nurse or doc so misinformation can be corrected if need be. Sometimes privacy between the CKD and RRT patient can be important too---- for example a CKD patient who wants to actually see the PD catheter in the abd and perhaps ask the RRT patient questions. It all depends on what each is comfortable with as to how this might work.

When to begin CKD education

❖ Options:

❖ as soon as CKD diagnosis is made

- ❖ This may not be altogether practical
- ❖ Advantage: allows for early education about diet and medications to delay onset of RRT

❖ when GFR is $\leq 30\text{mL/min}$

- ❖ At this point, all patients should receive CKD education about RRT
- ❖ This allows for timely placement of a permanent dialysis access or to address issues of donors for transplant or other issues of conservative treatment when requested

My approach :

- ❖ Referral from clinic or MD for each patient with $GFR \leq 30\text{mL/min}$
- ❖ Out patient
 - ❖ Call patient, set up individual tour of dialysis unit
 - ❖ Family and/or significant others invited to tour
- ❖ In patient
 - ❖ Visit patient, provide information
 - ❖ Clinic tour after discharge if possible
- ❖ After tour, send email or call MD about patient's choices, family dynamics, limitations, etc.
- ❖ Phone and clinic contact until begins dialysis
 - ❖ This keeps the patient from "falling through the cracks" during this critical period

What about the “parachute” patient?

(presents with ESRD and urgently needs dialysis)

- ❖ How can modality education be provided? Is PD an option for urgent start?
 - ❖ Yes! Nephrologist or nurse educator briefly presents choices of HD and PD.
 - ❖ PD can be used for urgent start if have infrastructure in which surgeon is available for urgent placement of PD catheter (just as have for urgent HD catheter).
 - ❖ PD catheter can be used immediately post-operatively if patient remains recumbent with low volumes.
 - ❖ Use cycler with continuous 1 liter exchanges over 24-48 hours.
 - ❖ Advantage of urgent PD is avoidance of HD catheter and subsequent risk of bacteremia. If patient chooses HD after urgent PD start, permanent HD access can be placed and change to HD done in orderly fashion when access mature.

Summary

- ❖ Pre-dialysis education is an important patient right.
- ❖ Formats vary--it is not clear what's best
- ❖ Several studies identify benefits of pre-dialysis education, including increasing the likelihood of a patient choosing a home therapy.

Question #1

- ❖ Which of the following statements about CKD education is true?
 - ❖ A. Pre-dialysis patient education is a basic right which all patients should be offered.
 - ❖ B. Most physicians and nurses are better at selecting the best modality for their patients.
 - ❖ C. Barriers to CKD education include the high cost; thus we should be selective in referring only the patients who are most likely to benefit from it.
 - ❖ D. Early referral to CKD education will not change the onset of RRT.
 - ❖ E. Studies show that 50% of CKD patients do not want to know about RRT survival data.

❖ Question #1: Correct Answer = A

Question 2

- ❖ A CKD education program can be evaluated by
 - ❖ A. Comparing your take-on rate for home therapy to those in published studies which have found 10% with CKD education will select home RRT.
 - ❖ B. Determining the percent of CKD patients who actually receive CKD education with the goal that all are offered the opportunity.
 - ❖ C. Remembering that patients only need to hear the information one time so it is best to provide the information closest to the time RRT is needed.
 - ❖ D. Recognizing that telling patients about RRT will only frighten them so it is best to protect them from the "bad news".

❖ Question #2: Correct answer = B