Management of Chronic Kidney Disease

A Web-based Training

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Overview and Standards of Care

This presentation is on the management of progressive chronic kidney disease. I am going to discuss the standards of care for patients with chronic kidney disease, the current levels of success in implementing those standards of care, barriers to improving care, identifying and monitoring chronic kidney disease, some strategies for improving CKD outcomes in the primary care setting, some advice on collaborating with a nephrology consultant, and then I'll describe some educational materials available from the National Kidney Disease Education Program.

There are a number of guidelines available describing treatment for people with chronic kidney disease. The National Kidney Foundation has a set of guidelines, the National Health Service of England has a set of guidelines, and there are several other guidelines.

When you look at all of these guidelines together, there is a remarkable consensus on the treatment that's advised for people with progressive kidney disease. It's advised that patients receive at least six months of multidisciplinary comprehensive clinical management prior to the initiation of dialysis, longer if possible.

This multidisciplinary management should include education on treatment modalities, on dietary instruction, and management of all the complications of chronic kidney disease.

In addition, it's recommended that risk factors for cardiovascular disease be reduced to the greatest extent possible, since the major cause of death for people with chronic kidney disease is cardiovascular disease. So, this includes exercise and stopping smoking and control of hyperlipidemia.

Excellent blood pressure control is recommended, management of calcium, phosphorus, and hyperparathyroidism if present are recommended. Evaluation and monitoring of anemia is also recommended. Treatment recommendations for anemia at this time are somewhat up in the air.

Hepatitis B immunization is recommended. It is also recommended that patients be maintained on an ACE inhibitor or angiotensin receptor blocker as long as it is tolerated.

Ideally, patients should be assessed for transplant and referred for transplant prior to initiation of dialysis, and finally, it's key that patients have access for dialysis in place prior to their initiation of dialysis. This means ideally that patients who are going to be treated with hemodialysis have a functioning AV fistula placed and mature at the time of initiation and that patients who are going to be treated with peritoneal dialysis have a Tenchkoff catheter in place that's usable when needed.

Well, there is this remarkable consensus on how patients should be treated. How are we doing? *Healthy People 2010* was the first edition of the Healthy People document which included objectives for chronic kidney disease. This document was published in

2000. So the recommendations that are included within the *Healthy People* have been present for sometimes. Adherence with implementing these objectives has been monitored by the United States Renal Data System, and there are several objectives, which reflect some aspects of chronic kidney disease care.

It's recommended that patients with diabetes and chronic kidney disease receive medical evaluation and what is specified by medical evaluation is fairly simple: two hemoglobin A1cs, lipid evaluation and eye exam in the past year. The goal that was set was 36%, which is a fairly low bar. You can see in this slide though that even that low bar was not achieved and only barely over 30% of patients with diabetes and kidney disease received that monitoring care.

It's recommended that patients with diabetes and chronic kidney disease be treated with an ACE inhibitor or an ARB. You can see on this slide that there hasn't been much increase in the percentage of patients receiving those classes of drugs over the past seven to eight years.

Blood pressure control is probably the single-most effective intervention in slowing the progression of kidney disease, and this slide shows that for patients who've lost more than half of their kidney function, which is specified in CKD stages III, IV, 25% were unaware of their hypertension, about 7% were aware but not treated.

Nearly 50% were aware and treated but not controlled, and only about 20% of patients with chronic kidney disease who were hypertensive, were aware, treated, and controlled. The proportion of patients with chronic kidney disease who received counseling on nutrition and treatment choices and cardiovascular care prior to the start of dialysis is also somewhat deficient. The goal set was 45%.

This slide shows that nearly a third of patients did not even see a Nephrologist prior to the initiation of dialysis, and even more concerning is that only 13% of patients had dietary consultation prior to the start of dialysis. Nutritional interventions are very effective in people with chronic kidney disease. So it's very disappointing that such a small proportion of patients ever saw a dietitian.

At the time that this data was collected a routine treatment of anemia and CKD was recommended, and what's interesting about this slide on treatment of anemia is that even patients who were followed by a Nephrologist for 12 months prior to the initiation of dialysis, started dialysis with a hemoglobin less than 10. And although the standard of care for treatment of anemia is unclear right now, what this does suggest is that early referral to a Nephrologist is not the answer or not the only answer to improving outcomes in chronic kidney disease.

Finally, it's very concerning that only a very small minority of patients begin hemodialysis with a mature fistula in place. Nearly, 80% of patients start dialysis with a catheter in place. This is a very important to pay attention to, because catheters are associated with many complications, infection, thrombosis, inadequate dialysis, but in

addition, it's thought that the presence of a catheter is associated with chronic inflammatory state, which is thought to contribute to the high morbidity and mortality in patients on dialysis during their first year.

It's very key to try to move ahead on this and for primary providers aren't used to thinking about vascular access. The process of getting an access placed really has to begin years before patients need to start dialysis.

So we are not doing very well. Now, defining the optimal care for people with CKD is not the primary barrier to improved outcomes. The key barrier is how to deliver the appropriate care to those who need it. We know that lack of appropriate care or late referral to a Nephrologist, they are sometimes seen as synonymous, I do not think they are. These are associated with more rapid progression of CKD, worse health status at the time of initiation of dialysis, higher mortality after starting dialysis, and decreased access to transplant.

We have some evidence that interventions in CKD care can improve outcomes. These include reports that formal CKD education can slow the progression of CKD and delay the initiation of dialysis, that comprehensive care can increase utilization of fistulas at the initial dialysis treatment, that multidisciplinary care improves survival and that it reduces hospitalizations after people start dialysis.

Models for Improving Care

There are some models of improving care in CKD, although there are not the kind of large comprehensive models that we see in other chronic diseases. The Renal Physicians Association has an advanced CKD patient management toolkit. This is really designed for nephrology offices and has not actually been tested yet. I am going to describe the efforts by a large HMO, the Kaiser Permanente HMO of Southern California, and then talk a little bit about Indian Health Service and Community Health Centers as well.

The Southern California Kaiser Permanente HMO has about three million members. They've had routine reporting of estimated GFR since 2003, but they have modified the conventional staging algorithm to better identify patients at risk of progression. And they split stage III, which is GFR between 30 and 60 into two groups, a low-risk group and a high-risk group. The high-risk group was defined as patients with proteinuria more than 300 milligrams per day and/or diabetes and/or an estimated GFR plus half the age is less than 85, and that estimated GFR cut off is there to eliminate patients who have simply an age-related decline in GFR. The low-risk group had met none of those conditions. The Southern California Kaiser Permanente has a fairly high-risk population of patients with CKD, with many diabetics and a significant number of African-Americans; they use an integrated approach.

You can see on this slide that they have a quite a significant number of patients with CKD. They have about 60,000 patients with GFRs less than 60, stages III, IV, and V

excluding the patients who are in the low-risk group, which is called Chronic Stage III; and remember these patients are patients without diabetes with low levels of albuminuria with an eGFR plus half their age, which is greater than 85. And by taking those patients who met those criteria and eliminating them from population management they reduced the number of patients for whom they had to develop and implement focused population management interventions to reduce the burden of CKD.

You can see that there are almost over 48,000 patients who had what we call Chronic Stage III versus 55,000 patients who had modified stage III or the group of patients at risk for progression. This is important because all primary providers are very busy, and if you are going to devote any more time to managing CKD you'd like to direct your efforts towards those patients who are at most risk of progression.

The Kaiser Permanente System also includes relatively easy access to nephrology referral. They have 60 full-time nephrologists. There is no disincentive since it's a prepaid system. There is a culture referral, and in fact many of the patients who should be seen were seen.

The guidelines in general that they employed were that patients with GFRs less than 30 should be referred unless aggressive management wasn't indicated. For patients with GFRs above 30, they did not recommend routine referral unless they had very high level proteinuria, refractory hypertension, whether there was a question of diagnosis or an unexplained change in kidney function. And for most of the patients with GFRs above 30, their management was integrated into other population efforts.

The number of patients that were seen by nephrologists was quite high, you can see in this that. For patients who had stage IV or V, which is GFRs less than 30, more than three quarters of those patients had been seen by a nephrologist in the last year, and that's significantly better than the data that I showed you earlier from USRDS.

Now, the care of CKD was integrated into the primary care system, and in fact 85% of the visits by CKD patients were to primary care providers. And not only that, most of these visits were actually coded for CKD, which is a major problem in assessing the burden of chronic kidney disease because a significant proportion of visits by patients with CKD to their providers are not coded as CKD visits. It was routine in their system for a patient-specific information and advice to be provided at the time of the visit and there were tools for management and decision support built into their electronic medical record.

How did Kaiser Permanente do on quality measures, and for all patients with CKD. About 44% of patients had a blood pressure less than 130 over 80. About 80% of patients had an assessment of albuminuria in the last year. About 84% of patients were on an ACE inhibitor or an ARB, and the patients had pretty comprehensive management and assessment of their hyperlipidemia.

For patients with advanced kidney disease, GFR is less than 30, 86% of those patients were assessed for anemia. Only 13% had hemoglobin less than 11 and this data was collected at the time when routine use of erythropoietic agents was recommended in patients with CKD and significant anemia. More than 75% of patients had been seen by a Nephrologist. Interestingly, even though this comprehensive system was in place over 60% of patients chose not to attend a class on preparation for dialysis.

So the outcome measure that was defined by Kaiser Permanente was called optimal start of end-stage renal disease, and you are considered to have an optimal start if you initiated renal replacement therapy on peritoneal dialysis, which means your very first treatment was with peritoneal dialysis. If you received the preemptive transplant, which means you were transplanted before you started dialysis, or if you had a mature AV fistula in place, which was used at your first hemodialysis if that was your modality choice.

Now, all three of these measures can only be achieved in settings where patients have excellent care prior to the initiation of dialysis, and about 54% of patients achieved an optimal start of dialysis. Now, this is important because I think it's likely that some similar measure is going to be included in the quality improvement organization scope of work which is going to be released by Medicare in the next year or two, and that will be a 50-state program looking at quality of care for people with diabetes and chronic kidney disease.

Improving CKD Care

Once again, defining optimal care is not the primary barrier to improved outcomes, getting that care to the people who need it is the barrier we have to overcome. In trying to deliver better CKD care to those people who need it, two factors must be kept in mind. First, there are significant health disparities in chronic kidney disease. The rates of end-stage renal disease are four times higher in African-Americans than in Whites. It's about twice as high in American Indians and Alaska natives and also Hispanics; it's increased in Asians as well.

The second factor which must be kept in mind is that the greatest opportunity for improving care is in addressing people with diabetes and chronic kidney disease. The panel on the right shows the increase in rates over the last 30 years in end-stage renal disease, and the blue line, which shows end-stage renal disease due to diabetes is the cause which has escalated the most.

The other causes have been relatively flat for the last 20 years - that's cystic disease, glomerulonephritis and hypertension. What has driven the increase in burden of chronic kidney disease and end-stage renal disease in the United States is the rising burden of diabetes, particularly type 2 diabetes.

The way that Medicare looks at this is the big blue circle is the total Medicare population, the pale blue is the patients with hypertension, even paler blue is patients

with diabetes and the green is people with CKD. You can see that nearly everyone with CKD has either hypertension and/or diabetes.

So this is significant because we need to address the problem of CKD in the context of these other chronic diseases and consider ways to implement improvements in managing chronic kidney disease as within the context of treating hypertension and diabetes.

The paradigm that we're trying to implement is shown in this diagram. On the left vertical axis is Glomerular Filtration Rate or kidney function and the horizontal axis is Time. The typical course in someone who doesn't receive any treatment is shown by the darkest line, which is a gradual decline in kidney function from about 100 to 120 milliliters per minute per 1.73 m2 down to 10 or 15, at which point the patient reaches the point of kidney failure and usually begins dialysis or receives a transplant.

What's happened traditionally is that the patients have had chronic kidney disease, it's not been directly addressed until the creatinine reaches a level which is alarming to the primary provider, at which point the patients are referred or something is done and that's that red line. And what happens is patients continue to progress because that's the nature of kidney disease. It's generally not reversible, but they progress at a lower rate, and they reach kidney failure at somewhat later time.

Ideally, what we'd like to do is demonstrated by the lightest line, which is where people are identified with chronic kidney disease and the treatment is initiated earlier. The patients will still progress, but they will progress at a slower rate, earlier in the course and they will gain even much more time till they reach kidney failure. In fact many patients will never reach the point where they will have serious complications or reach kidney failure.

But who is taking care of these patients where that light gray line takes off from the dark line, where their kidney function is mostly intact. Those patients are followed in diabetes clinic or by other primary care providers. So it's essential that chronic kidney disease be identified in the primary care setting and it be addressed in the primary care setting; that's where the greatest impact will be felt.

So what are the challenges to improving chronic kidney disease care? Well, it remains under diagnosed, while estimated GFR reporting is routine in most places, it's not universal. The other test, which is important for defining CKD, urine albumin, is not performed as consistently as we would hope. The implementation of recommended care is poor as I showed earlier and there are many reasons for that. Predominantly most clinicians feel inadequately educated about chronic kidney disease if not actually intimidated by kidney disease.

They are uncertain about how to interpret diagnostic tests, they don't have an intuitive feel for estimated GFR and they have a very difficult time interpreting the albumin-creatinine ratio if it's obtained.

The clinical recommendations are generally not implemented in part because they tend to be voluminous and more of a barrier than a help because they are tend to be complicated and very hard to integrate into routine care along with all of the other guidelines that primary providers have to implement. Many providers lack confidence in their understanding of kidney disease and they are uncertain of when and how to collaborate with a Nephrologist.

The program that I direct, the National Kidney Disease Education Program, was established about ten years ago to address these issues, and to reduce the morbidity and mortality caused by kidney disease. We promote early detection of chronic kidney disease, not just to identify the maximum number of patients with kidney disease in the population, but to assist providers to identify those patients at greatest risk of progression, to help them identify who they should focus with what limited extra effort they can put into the care of those patients. We promote evidence-based interventions. And in fact there are very few evidence-based interventions in kidney disease and we are trying to promote coordination of the federal responses to CKD.

Our general approach is to help apply the Chronic Care Model to chronic kidney disease. I am not going to describe the Chronic Care Model in detail. It's a paradigm of chronic disease management, which has been shown effective in reducing health disparities through system's change. And it's useful in chronic kidney disease because it helps us identify where we need to develop new approaches to better bring the care that is needed to those who need it most.

So what can primary care providers do? They can recognize and test at risk patients. And there are two tests, equally important, estimated GFR which measures kidney function and the urine albumin-creatinine ratio which identifies patients with kidney injury. They can screen for complications including anemia, malnutrition, metabolic bone disease. They can treat patients for cardiovascular risk, addressing smoking, exercise, and cholesterol. They can refer patients to a dietitian for nutritional guidance. These nutritional interventions are very important and very effective.

But the most radical thing that primary providers can do is to talk to patients about CKD and its treatment. Some performance measures that might be useful in a primary care setting, which we've helped implement elsewhere are simple: to be sure that all patients with diabetes have an estimated GFR and an albumin-creatinine ratio every year to control blood pressure and to implement the use of ACE inhibitors and ARBs in all those patients who will tolerate it; to screen patients with chronic kidney disease for complications, and this basically means adding a calcium, a phosphorus, and albumin, to routine SMA7 that's obtained yearly; and finally to document CKD education and we have developed four key concepts which I'll describe later which could be addressed very briefly and without extending the patient visit unduly.

The American Association of Diabetes Educators in 2009 produced its first position statement on diabetic kidney disease and emphasized that patients with progressive

kidney disease would be well-served by early kidney disease education including discussion about renal replacement therapy options. This is new territory for diabetes education. It has not traditionally been seen within the role of the diabetes educator, but if you have a patient who has lost two-thirds of their kidney function and is likely to live long enough to progress the end-stage renal disease, it's wise to bring up the topic well before dialysis is needed so that patients can begin to understand their own disease and help them understand why it's important to adhere to the recommended therapy.

Identifying and Monitoring CKD

So what are the key issues in identifying and monitoring chronic kidney disease? I will discuss estimated GFR, the albumin-creatinine ratio and the issues related to staging. The definition of chronic kidney disease, which is pretty widely accepted, includes patients with evidence of decreased kidney function or kidney damage which has been present for more than three months. So the decrease in kidney function means an estimated GFR less than 60 milliliters per minute and the evidence of kidney damage includes pathologic or radiologic abnormalities or a history of the kidney injury, but for the most part the evidence of kidney damage is proteinuria. So most people are identified as having chronic kidney disease on the basis of decreased GFR or evidence of kidney damage as evidenced by proteinuria.

What is Glomerular Filtration Rate? The way I explain this to the patients is that the kidneys function as filters. They are not one big filter like the oil filter you would put into a truck. Each kidney is made up of about one million filtering units called nephrons, which each filter a tiny amount of fluid, but the total amount of fluid that they filter together is significant. And the way we can estimate how much kidney damage there is, is to estimate the amount of kidney filtering. That will give us a rough idea of the number of functioning nephrons. If you've lost half of your nephrons, your kidneys will only filter about half as much blood each minute.

Now we can't measure GFR directly in the clinical setting, but we can estimate it. And how do you get an intuitive sense of what a normal GFR is? Well, the cardiac output in a typical human being is about 6 liters per minute. About 20% of that cardiac output goes to the kidneys; about 10% goes to each kidney, so about 1.2 liters per minute of blood goes to the kidneys.

Now, what gets filtered is the plasma, not the cells, and so plasma makes up about half the blood volume. So that means there is about 600 milliliters of plasma delivered to the kidneys every minute. Obviously, all of the plasma in the blood doesn't get filtered because that would leave 100% of cells in the blood vessel and the blood wouldn't flow any further. Only about 20% of the plasma delivered to the kidneys actually passes through the glomerulus. So 20% of 600 is 120 milliliters per minute, that gives you an intuitive idea of where the normal GFR comes from.

We estimate the GFR. It's important to remember that the estimated GFR which is provided on the lab report is not the patient's actual GFR. It's the best guess of what the

GFR is in that person based on four variables, the creatinine, the age, the gender, and the race. It's important to remember that these estimating equations are based on large populations of people, and the estimated GFR in fact is a very good estimation of the average GFR in a hundred people who have that creatinine, that age, gender, and race. However, for any individual, the actual GFR will be distributed somewhere around that estimated GFR.

So one way to think about this is to use the analogy of the estimated date of confinement. The best guess for when a woman will deliver is based on the last menstrual period. And although, the estimated day of confinement is the best guess on when they will deliver only a minority of women will actually deliver on that day, they'll deliver two weeks before and after that estimated day.

So it's important to realize that the GFR that you get is an estimate, it's the best guess, but it is not the actual GFR. It's also important to remember that like all estimates of kidney function based on the creatinine, it's only useful if the creatinine is relatively stable. So if someone has acute kidney injury and their creatinine is changing day-by-day, you cannot plug this creatinine into the estimating equation and getting a meaningful idea of what the patient's kidney function is.

It's also affected by muscle mass. Creatinine is a waste product of muscle mass, and for people who have either very large muscle mass or very decreased muscle mass, the serum creatinine will give a misleading estimate of their kidney function. In fact, the variables in the estimated equation all reflect factors that are related to muscle mass - age, gender, and race.

The second test we use to assess kidney status is looking for proteinuria or albuminuria, and a significant proportion of the patients with CKD are identified on the basis of urine albumin alone. It's very important because urine albumin is a very important prognostic marker in chronic kidney disease. It's a marker for cardiovascular disease, and it actually may be a surrogate outcome for disease progression and risk reduction. It's also a potential tool for patient education and self-management. Patients know how much albumin they have in their urine or they know whether it's increasing or decreasing that can help them as they manage their own disease, in the same way that knowing their hemoglobin A1c or estimated average glucose helps him understand how well they are doing.

There are a number of issues related to routine measurement of urine albumin, which have made routine use of this test somewhat difficult. First, there are a large number of tests related to protein, creatinine, albumin in the urine, which really confuse many providers and just a partial list is shown here.

The test that is the standard test is the albumin/creatinine ratio on a spot urine specimen. So what this means is the ratio of albumin to creatinine in a spot specimen is equivalent to the albumin excretion in grams over 24 hours. Why is that? Well, if you assume that albumin and creatinine are both excreted throughout the day at fairly

constant rates that means that the ratio on a spot specimen will be the same in 24 hours. Well, why does that tell you anything? It tells you something because in 24 hours most people will put out about 1 gram of creatinine. So the ratio is generally expressed as milligrams albumin per gram creatinine. Traditionally, the upper limit of normal is 30 milligrams albumin per gram creatinine, which is equivalent to 30 milligrams of albumin per day.

Now, urine albumin excretion is a continuous variable, and although we have traditionally broken the abnormal levels into microalbuminuria and macroalbuminuria. Microalbuminuria is above 30 but below 300 milligrams per day or 300 milligrams per gram, which is the level at which the conventional dipstick becomes positive. Microalbuminuria is above 300 milligrams per gram.

The distinction between microalbuminuria and macroalbuminuria is simply based on what the old dipstick used to show. It does not have physiologic meaning and this distinction hopefully will disappear in the future, and we will simply look at the urine albumin excretion as a continuous variable and a continuous risk factor.

The second issue which really has confused providers is the importance of repeated measurements of urine albumin. Many providers will say, well, I screened the patients for urine albumin, it was positive, I put them on an ACE inhibitor, why do I need to recheck it? It's important to monitor the urine albumin for number of reasons. One, it's a very strong predictor of outcome and response to treatment also may predict prognosis. This slide shows the relationship between reduction in albuminuria following initiation of angiotensin receptor blocker and the risk of end-stage renal disease or a renal endpoint. Renal endpoint includes end-stage renal disease, loss of half of kidney function or death. And you can see as albumin reduction in response to treatment increases the risk of progression decreases. So it's important not only to identify people with urine albumin excretion, which is abnormal but to monitor it for response.

The final issue on laboratory measurement includes the Staging Algorithm. The conventional Staging Algorithm, which has been widely used is described here with stages one through five based simply on GFR. There are a lot of difficulties in using this algorithm, one is that the MDRD equation, which is the most widely used estimating equation for a GFR is not accurate above 60, so therefore it's impossible to distinguish between stages one and two.

Many patients who meet damage criteria, which is usually proteinuria have GFRs greater than 60, and it's not clear what the prognostic meaning of that is, many of those patients will not progress. Many patients have what appears to be age-related decreases in GFR and it's not clear that those patients should be given a stage of chronic kidney disease. The age-related decline makes up much of stage 3 as I showed you in the numbers from the Kaiser Permanente population, many of them do not progress, and we clearly would want to focus our efforts on patients at risk of progression.

eGFR is probably too narrow a basis on which to make a diagnosis and prognosis. And it's likely that as we move into the future that staging and identification of people with CKD will be based on a multifactor scoring algorithm similar to the Framingham Study algorithm for cardiovascular disease. It's likely that any algorithm would include estimated GFR, urine albumin, diabetes status and perhaps blood pressure as well as other markers, some of which are not currently in routine use.

Again, it's very important to remember that proteinuria is as important as estimated GFR in identifying risk for progression. This JAMA study which is stated on this slide showed that at any given level with eGFR risk for mortality, cardiovascular disease, and kidney disease progression were independently associated with increased levels of proteinuria.

Tools for Improving CKD Outcomes

Finally, I'd like to describe some of the materials that have been developed by the National Kidney Disease Education Program for educating providers and patients. This first quick reference on urine albumin, creatinine ratio and estimate GFR is designed for providers and provides a one-page explanation of the urine albumin/creatinine ratio, and on the reverse side a one-page explanation of estimated GFR.

If providers don't understand these two tests, they can't interpret the results for patients and they can't explain to the patients their disease and how they are responding to therapy.

We've also developed a GFR urine albumin tear-pad, and this is a pad of sheets, which are meant to be given to the patient and it's meant to convey to the patient what their estimated GFR and urine albumin result is. And there is an explanation of eGFR and urine albumin at the fourth to sixth grade level along with graphics which we hope are useful. On the back of this sheet, which is can be torn-off, are some general recommendations on how to protect your kidneys and these should be applicable to virtually all patients.

On the cardboard backing to this tear-off sheet, for providers, there is a list of four basic points to address with patients. And the idea is that these are concepts which could be discussed in 60 to 90 seconds and are actually the kinds of things that could be done during a routine visit without unduly prolonging it. Patient education and promotion of self-management obviously is really important, but if we recommend something that requires adding 15 or 20 minutes to each visit it's not going to be feasible to implement that.

So these are very simple points, which can be conveyed and we've actually given a few sentences that you could use if you aren't sure exactly how to convey these points, and over time, I think if you use this or you could develop your own way of saying this.

For example, the first one is to talk the patients about their kidneys and their risk, and that includes answering the question what is CKD, and providing the patients with a

simple definition how can they lower their risk for CKD, and answering that through explaining that they can manage their diabetes, high blood pressure and stop smoking.

The second key point is to communicate the importance of testing and how CKD is diagnosed, so you need to explain the patients that most patients have no symptoms, and so the laboratory tests are very important, and what the two tests and what their results are.

The third point is to talk about the progressive nature of CKD and the basics of treatment. Patients need to understand that even if they do everything you want them to do, their kidney disease will not likely be arrested. It is likely they'll progress, but they'll progress much more slowly. They are not going to be able to improve their eGFR the way that might be able to improve the hemoglobin A1c.

The fourth point is to address the idea of dialysis and transplantation. If you mention the words 'kidney disease' to patients, they will assume that you mean dialysis even if they merely have their earliest signs of kidney injury. I think that it's important to explain that, that may not be an issue right now and it may be reasonable to say, when there is severe injury those are issues we'll have to address.

For people who are likely to progress, again it's certainly useful to at least give some general information on dialysis and transplant. It takes quite a while for patients to come to terms with this and you can never make this something that is easily acceptable to patients but by mentioning it early you can give people time to come to terms with it.

We have a CKD brochure, which is a eight-page document, which is meant to explain to patients what it means if they have CKD after you've told them they have kidney disease. This is something you could give to them and they can take home and try to understand it, and it will clarify for them and their family some of the basic issues. And may be help them understand more about it and help them ask questions in the future.

This booklet includes some basic information on what the kidneys do, what it means to have kidney injury, the fact that it's progressive, what the tests are, and how your provider knows that you have kidney disease, what causes it, which medications are used, that there are some drug interactions and drug issues they need to be aware of that may affect other aspects of their health, and if they may have complications of chronic kidney disease, that they can track their chronic kidney disease by following their blood pressure, an eGFR, and urine albumin.

Virtually everyone will say, will I ever have to go on dialysis, and so this addresses that in a very general way. It addresses very briefly the idea of kidney transplant, and finally it talks about dietary changes and answers some really common questions including, do I need to drink more water, what about juice, cranberry juice, and smoking's bad. And finally it has some instructions on how to track your own test results, and a small card for writing down those test results and the key tests would be blood pressure, GFR, urine albumin and hemoglobin A1c.

We have a kidney test result report card, which is modeled after a tool that's often used in dialysis units. This is something that can be given to the patients to take home, as they have more advanced kidney disease, you'll be talking about these test results. It gives them their result, it defines what that result means and it explains why it's important. Patients really tend to look at these and be quite attentive to it because they tend to worry if they have kidney disease.
We've developed a management guide for dietitians and for health providers who are trying to advise patients on diet when there is no dietitian present. And this is a brief document again, not like some of the documents that are available and this guide is really based on providing the health professional with the information they need to use that kidney test result report card with the patient. There is some basic information about CKD in its definition and then it goes test-by-test through all the tests that are on the report card including the measurements of kidney function and damage, providing detail and references on estimated GFR, urine albumin; then moves on to the importance of blood pressure and reducing albuminuria and managing diabetes in the results that are important to that. And then it discusses the complications, the tests related to that albumin, bicarbonate, potassium, calcium, phosphorus, PTH if you are getting that, vitamin D levels, hemoglobin, and cholesterol.

Finally, we have a patient and parent pamphlet to help ensure that children who need a urinalysis, get one. The American Academy of Pediatrics no longer recommends routine urinalysis in well-child care. Unfortunately, some children who really should get urinalysis are not getting it because it's not routinely recommended. This brochure describes for patients and their parents those kids that really should have a urine test and there is a poster to go along with that which may be useful for your waiting room.

Nephrology Referrals

So if you want to implement improved care, there are some performance measures are listed on this slide and I mentioned them earlier in the talk. But those would be: one, a yearly eGFR and urine albumin/creatinine ratio in all diabetics; a second one is blood pressure control and use of ACE and ARBs; those two measures are actually routine diabetes care now. The third one really is screening for complications. Again that just means getting SMA-7, calcium, phosphorus, and albumin and the CBC in all patients yearly, which is not that different from what most people are doing and finally to document some education on CKD.

One final issue is how to collaborate with a nephrologist, many primary providers have a difficult time collaborating with nephrologists and nephrologists have a difficult time collaborating with primary providers. There is a lot of emphasis in the kidney community on routine referral specific eGFR often 30 or some cases it's higher than that. I don't urge an arbitrary eGFR cut-off for referral. Some patients need to be referred early in the course of their disease, if they are younger or have unclear diagnosis. Other patients who have been very stable, or are elderly, or who don't have complications may not require nephrology referral even with fairly advanced kidney disease.

Oftentimes, it's recommended, refer patient if there is a diagnostic challenge. Often the decision whether to biopsy or not, if there is a therapeutic challenge such as difficult to control blood pressure, if the patients are progressing unusually rapidly. Most patients with primary kidney disease especially glomerulonephritis are managed primarily by nephrologists. And preparation for renal replacement therapy is done in collaboration with a nephrologist, but you shouldn't wait to start that process until referral. It's perfectly okay to bring up the eventual need for dialysis and vascular access with patients when you are seeing them. This is difficult information for them to hear and it may be easier for them to hear it from a familiar person, rather than from a nephrologist whom they are just meeting.

Again, many guidelines have an estimated GFR at which they recommend routine referral and you may choose to follow this guideline. The question is though does early intervention equal early referral, and because of the lack of success the implementing population based approaches to chronic kidney disease, much of the conventional wisdom in the kidney community is that early intervention equals early referral. If you have been able to review this presentation up to this point you realize that most of the interventions are therapeutic interventions that can be implemented by and are implemented by primary providers - blood pressure control, use of ACE and ARBs, screening for complications, patient education.

Although, many of these things have not been done by primary providers, it doesn't mean that they shouldn't be. I don't recommend routine referral at any specific estimated GFR, but I would say that if you are going to work in collaboration with a nephrologist it's very important that you obtain as much information as possible prior to the referral and to convey that information to the consulting nephrologist. It may be useful for you to obtain some preliminary evaluation to rule out non-diabetic causes of CKD, and although there has never been an evidence-based evaluation of the screening workup, there are some routine tests, which may be helpful.

It's also important to provide the consultant with as much patient history as you can. including serial measurements of kidney function. The rate at which kidney disease has progressed in the past will often predict how it will progress in the future, and that's very useful information for the nephrologist to know in managing the patient and to help the patient understand what the future holds.

It's also important to talk to the nephrologist about what things you want to keep managing and what aspects of the patient care rather would relinquish to his or her management. This shows a form, which is available on the web, which is a pdf fillable form, one page which you may find helpful in communicating with your nephrology consultant. On the top it includes identifying information and reason for referral, and then information on the history of the patient's diabetes if the patient is a diabetic. It's important to let the consultant know if the patient has retinopathy and other complications because they are often associated with kidney disease, and if they are absent it may raise question as to other etiology.

It's important to let the consultant know how much albuminuria the patient has, how long it's been present. Also whether the patient has in the history of hematuria or an active urine sediment, which would reflect inflammatory process, providing some serial measurements of eGFR would be very helpful, blood pressure control and then some laboratory evaluation, which – there's never been a rigorous examination of the cost-effectiveness of any particular evaluation - but these are some tests which are routinely obtained. As you work with a specific Nephrology Consultant, you will understand what screening tests he or she really may feel it most important, but here are some suggestions. If you can convey family history that would be helpful, some kidney diseases are familial, but also the risk of progression also appears to be familial.

Medication list is helpful and it's also very important to convey to the consultant whether the patient knows that they have kidney disease, whether they know the severity, and whether they know or not whether they are likely to progress in the dialysis or transplant.

Summary

So many of these approaches have been implemented in Indian Health Service, and the key messages that we've learned are that CKD should be part of primary care. To improve care you've got to change the system and the diabetes program in the Indian Health Services is sort of a model of a systemic approach to chronic disease, which includes team management and includes treatment algorithms, includes an excellent data system for monitoring outcomes and identifying areas that are needed for improvement.

Much of the improvement in care has resulted from changes that have been implemented by the non-physician members of the healthcare team, most physicians are very supportable change, but are often overwhelmed by clinical responsibilities from actually implementing change. And in Indian Health Service it's often the non-physician health professionals who provide the most continuity.

A very important lesson learned in Indian Health Service, which I think could serve the general healthcare system well is that the best way to implement improvement in care of chronic kidney disease is to do so through the existing diabetes care delivery system. And perhaps establishing special renal clinics is not the way to go, and instead since such a high proportion of people with chronic kidney disease have diabetes to address chronic kidney disease within diabetes care, the same way the cardiovascular risk and peripheral vascular disease is addressed.

Finally, I think an important message is that the emphasis should be on ensuring that the patient receive the care they need from someone who is competent and able to do that. Referral is important, but the focus should not be on referring at a certain point. If the focus is on referring at a certain point, it almost gives the provider permission to do nothing up to that point, and if they then refer then they can consider they've done a good job. Well, by the time, most people get referred to a nephrologist most of the damage is done, and many of the opportunities for prevention have been lost. So it's

important that providers see managing kidney disease as part of managing the whole patient in the primary care setting.

So what are the outcomes of changing how we do this? Well, many of the things that we look at are process measures, whether or not you get a test, whether or not you have documented education, those were all process measures and do they actually make any difference? Well the outcome measure that we often look at is the rate at which people start dialysis. And this is national data which shows that the rate of American Indian people starting dialysis due to diabetic kidney disease has decreased significantly over the last ten years, from approximately 500 per million to about 330 per million.

So that is a significant improvement not all those patients are managed within Indian Health Service, but a significant proportion are. And although this is simply an observation that doesn't prove anything, it's highly suggestive that the kind of coherent comprehensive approach to diabetes including the kidney complications of diabetes, which exists within Indian Health Service, has had a significant impact on the ESRD burden among American Indians.

Now remember these are rates and because the population is increasing you may not have seen a similar decline in the number of people in the community that you are serving on dialysis, but the rate has decreased and eventually we hope to see a decrease in the absolute numbers.

So improving chronic kidney disease care requires that we change clinical practice in settings where high-risk populations are served like Indian Health Service; that it's hard to get providers to change, but presumably all healthcare professionals have science-based education and will change what they do based on scientific evidence and the expectations of their patients, so the more that the patients know, the more that they are asking for information, the more likely it is that care will change.

Then it's very important to improve care of patients prior to referral to nephrologist in order for the nephrologists to provide the optimal care and that part of achieving this goal includes facilitating a better and more functional relationship between primary care professionals and nephrologists.

The bottom line of all of this is really can be summarized in three simple points. You should follow the estimated GFR and albumin/creatinine ratio on all your diabetic patients at least yearly. You should control blood pressure as well as you can and as safely as you can in any individual. And you should talk to the patient about CKD, don't be afraid of talking to them about it, whatever you tell them will be helpful.