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DUNCAN Hi, everyone. My name is Duncan Johnstone. I'm the clinical director of the renal section here at University of
JOHNSTONE: Pittsburgh. Today I'm going to talk to you about home dialysis. The talk is going to be ESRD, No Place Like Home.

So goals for today, we're going to discuss both peritoneal home dialysis and home hemodialysis. We're going to go over some data on why we think home therapies are not the predominant form of dialysis among dialysis patients. We're going to discuss the advantages and disadvantages of home therapies over in-center center dialysis therapy and then discuss some of the practical considerations of home dialysis.

So my goal is to help you know enough that you can discuss with your patients a few basic things. So why should your patient and their nephrologist consider home therapy? And a lot of it is based on patient preference. So from surveys of patients who were asked to compare the advantages and disadvantages of in-center dialysis, many of the downsides that they mentioned are the length of the treatment, needle sticks, fatigue and weakness, which can be incredibly severe after dialysis, the cramping that occurs during and towards the end of dialysis. Because we're trying to condense all of a week's worth of kidney function into just four hours, three times a week.

So it's very intense, the frequency of treatment, and transportation to the unit, which can really take well over an hour each way and sometimes as much as three hours when they're in a group van. And dialysis is unpleasant enough that one of the largest patient sites is called I Hate Dialysis. It's for patients, by patients. Doctors aren't invited, and I think it's great that this site exists. But the fact that it is so named really tells us something about the burden of dialysis on people who really need it.

So for one quick example, imagine that you go to dialysis and then you try to go either to your work or go to home and see your family. It's hard. And the average time that patients report that they need to completely recover after dialysis is 4 hours. And for some, it's 13 hours. So they can't do a thing that whole day.

So I'm going to talk about the history of home dialysis based on the idea from Edmund Burke that those who don't know history are doomed to repeat it, which was a little bit butchered by Lemony Snicket. Dialysis is really created in the 1940s. But outpatient dialysis didn't start until the invention of the first long-term dialysis access, the Scribner shunt in 1960.

And in 1962, the first outpatient analysis unit opened in Seattle. Immediately, there was a high demand. And because the demand outstripped the supply of dialysis chairs, a selection board was created. And there's a fairly famous documentary that I watched when I was a medical school called, *Who Shall Live?* About those selection boards, I've included the link here.

And interestingly, in 1964, just two years after the selection boards were created, a 15 or 16-year-old girl in Seattle became the first home dialysis patient. And it was the daughter of one of Scribner's colleagues who was apparently turned down by the selection board. Because she was not an adult who was supporting a family. And Scribner helped the colleague make a home dialysis machine for her. And so for the next many years, this young woman and her mom did dialysis by themselves in their home. And it worked.

It worked so well that by 1973, the year that the ESRD Medicare Program was created and dialysis became a guaranteed medical service nationwide, in that year, 30% of the US population was actually on home hemodialysis. But then the popularity of home hemodialysis declined for the next 25 years really due to two reasons. The first was financial incentives that favored in-center and lack of training during fellowship for home therapy.

And we should quickly review the same history for peritoneal dialysis. In the late 1960s, the Tankoff Peritoneal Dialysis Catheter was invented. It wasn't immediately successful, because throughout the '70s and '80s, the rates of peritonitis were still very high. Clearance wasn't excellent. Sclerosing peritonitis, which is lethal, remained unacceptably high.

And so, in the mid-1980s a very prominent nephrologist announced that CAPD, which is Continuous Ambulatory Peritoneal Dialysis, is a second-class therapy for second-class patients by second-class doctors. And he didn't do it quietly. He did it as the title of his article.

But technical refinements for peritoneal dialysis at the time that article was being written were improving the treatment. So improved PD transfer sets to make it safer, better surgical techniques, and better prophylaxis, and some of those prophylaxis advances were done by Dr. Piraino here. And then from about 2000 to present, after all of those improvements, the outcomes of folks on peritoneal dialysis have really been at least comparable to hemodialysis. Financial incentives still favored in-center in this country.

But there is an effective public policy. And so, this is a busy slide looking at the rates of in-center hemodialysis, home hemodialysis, and home peritoneal dialysis around the world. And so, just to illustrate in a couple of ways how public policy can influence modality choice, Hong Kong many years ago decided that it would provide dialysis to everyone in the country. But that it would do so preferentially with peritoneal dialysis.

And so you can see that the majority of people in Hong Kong use PD as their modality of choice. And I worked with an absolutely fantastic nurse manager who trained for many years in Hong Kong who felt that every single patient can certainly try peritoneal dialysis. The only barrier, in her opinion, was if you didn't have two good working hands.

Thailand, within the last decade, made a similar choice. They made universal access to care a national policy but made peritoneal dialysis preferable. And so, they went from almost no PD patients to now between a quarter and a third of their patients on PD.

And lastly, the United States, so the financial incentives that I talked about that favored in-center dialysis are gradually being changed and with new rules that will be coming out of the next few years are actually going to favor home therapy. And so, still, a small fraction of folks are using home therapies really less than 10% total on home HD and home PD but that amount is increasing.

So why should your patient consider home therapy? And there are a couple of things that we can discuss. There are some data on hard outcomes, some data on survival, blood pressure, hospitalization rates, and cardiovascular events. There are also some data on soft outcomes, so quality of life measures of patients who have tried both, the ability to work, the ability to contribute to family life, the independence and empowerment that people feel when they're on home therapy, and the ability to travel.

So I'm going to start by talking about some of the hard data. Is one therapy better for survival? That data is very difficult to come by in what we would consider gold standard quality. And this slide goes over some of the problems with those data.

So there really aren't good randomized controlled trials of the two modalities. It's hard to recruit. In trials that have been done, the people recruited into those trials tend to be younger and overall fairly healthy. And as such, they don't represent the average patient on dialysis in this country. So it's not generalizable.

There's also a pretty big difference in the amount of dialysis you receive if you do home therapy compared to in-center. So that variability changes the outcome. There's also a lot of confounding. So as we'll discuss in the next couple of slides, the group that does home therapy tends to be younger and healthier. And there are also differences in location switch and selection bias that influence even retrospective data.

So location or modality switch is really common for folks on home therapy. And from one of the large studies of the United States Renal Data System, which looks at all patients on dialysis, all modalities within the US, 15% of home hemodialysis patients switched to in-center within the time of the study. 1% of home HD switches to peritoneal home dialysis. And of folks on peritoneal home dialysis, 44% switch to in-center and 25% switch to home HD. So it's a very fluid group.

And this has implications for how we compare outcomes, which I'll talk about, because this gives rise to difficulties analyzing retrospective data. So there are really compelling reasons that we all know about to analyze intention to treat in randomized controlled trials. But in a retrospective analysis, intention to treat really preserves the bias of patients who felt they were healthy enough and wanted certain things and felt they could do home dialysis.

There's also a selection bias from the doctors who choose those patients. And intention to treat is more difficult in retrospective studies when modality switch is so common. So we start people on home dialysis, but if they switch a month later, which is not that rare, then at the end of the observation time both these patients are considered home dialysis patients, even though one of them was on center.

And even if we change and say, we'll analyze retrospective data as treated, depending on how granular the information is, you can lose information on why a modality switch occurred. So in the very large Australia and New Zealand dialysis and transplant cohorts, and this is a big one for home therapy, because Australia New Zealand has a greater share of patients on home hemodialysis and home PD than any other country, the initial report that those who switched to in-center have increased mortality was on further analysis really dependent on why a modality switch occurred. Because PD patients who switched for social reasons and compliance, those folks did have an increase in mortality. But the PD patients who switched due to infection or ultrafiltration failure, their mortality risk was actually lower.

And the selection bias in these studies for deciding which therapy is better is really huge. So the same database had a different report saying that home hemodialysis had a significantly better patient survival than peritoneal dialysis and a very, very significant difference in five-year survival. But if you look at the difference in patient characteristics for between the two groups, so 706 patients on home hemo and over 10,000 on home peritoneal dialysis. The home hemodialysis patients were younger. And many more of them had polycystic kidney disease as the cause of their ESRD, which is associated with having fewer co-morbidities.

And conversely, in the peritoneal arm, more of the patients had higher risk categories for morbidity mortality like diabetes, COPD, coronary artery disease, and stroke. So the two groups really are not that comparable. And making a big decision on which treatment is better is fraught with bias problems.

So the USRDS has tried as best they can to adjust mortality. And the mortality for folks on home peritoneal dialysis might be lower than home hemodialysis after adjustment. It's certainly not higher.

And that's even true for the aged. And I noticed that as we keep doing talks that include age in it, the definition of elderly keeps going up and up depending on the age of the speaker. So I've just blanked out what age here is considered aged. Regardless, the mortality of folks who are above a certain age on peritoneal dialysis is lower than hemodialysis. So there's really no clear age cutoff.

And there are other benefits of home peritoneal dialysis that can be discussed. So the 24 hour a day, seven days a week therapy with PD, instead of the very intense four hours for just three days a week, really helps avoid the large fluid and electrolyte shifts that occur with in-center dialysis. And as such, residual renal function is preserved much longer with peritoneal dialysis. And residual renal function is really important. A GFR of 10 with dialysis, with good hemodialysis, is not the same as a GFR of 10 with native kidneys. Your own kidneys also help clear middle molecules much better and help change your inflammatory milieu. The tubules do things that dialysis simply can't do.

There are also higher scores on health quality of life surveys in folks who are on peritoneal dialysis compared to in-center dialysis. They have less cramping and fatigue. They have much greater dietary options and are happy with that. And they have much greater independence for work and travel.

We can also talk about the benefits of home hemodialysis. And instead of looking at charts of outcomes, I'm instead going to talk about one unit just as the start of an example, so the unit in Tassin, France, close to Leon. And this fairly famous paper among nephrology circles, the "Survival as an index of adequacy of dialysis." And in this unit, they had incredibly good survival with very long aggressive hemodialysis.

So their patients dialyzed for eight hours, three times a week for 24 hours a week, compared to the 9 to 12 hours that patients receive in most of the USA. And they had-- they list demographic factors. So maybe their patients were more healthy, but they did have 87% survival at five years, compared to an average of 33 in the US, 75% survival at 10 years, compared to 10% in the US. And if we just look at folks above the age of 65 in their study, their survival was still 59%.

The blood pressure in these dialysis patients was fantastic. So all anti-hypertensive medications were stopped within six months of starting them on this aggressive long dialysis treatment. Only seven of the 445 patients still needed medications to control their blood pressure.

And their serum phosphorous and renal osteodystrophy was all controlled without binders. And this is in a part of France not known for dieting. This is pretty good food.

And some of that fantastic outcome from aggressive dialysis was replicated in the frequent hemodialysis network trial, which is a consortium of US and Canadian dialysis centers, smaller number than the French group. The primary endpoints here were death or a change in left ventricular mass, which is a pretty good surrogate for heart attacks and other cardiovascular outcomes, or death and a composite of physical health on a score. And then the secondary endpoints include many, among which systolic blood pressure and the number of blood pressure medications were included.

And so, with aggressive six times a week dialysis, compared to three times a week, there is a significantly different and improved rate of death or size of left ventricular mass. And there was also a significant difference in death or this physical health composite score. So the aggressive, very frequent dialysis does seem to have benefits. It just becomes a matter of public policy, whether there is enough benefit to really double dialysis capacity in our whole country.

And secondary endpoints after this 12-month trial included decreased levels of serum phosphorous, decreased blood pressure, and a decreased number of medications going from about three pills to about two pills. So similar to the French group, more aggressive, more frequent dialysis seems to have benefits that are what we would call hard outcomes, easily measurable.

And so these parameters can really be mimicked with home hemodialysis and a motivated patient. So they can have a longer, slower dialysis. They can perform their dialysis more frequently than just three times a week. They can do it for five or six times a week. They can do it for shorter times also, if they choose.

As such, they can have better control of the blood pressure and volume with better surrogate cardiovascular outcomes. They can also time their dialysis for the end of the day, so the recovery time of being washed out after dialysis happens as they're sleeping and doesn't disrupt their activities during the day. This can help them go to work. It can help them participate more in family life also.

As such, they have greater independence for what they can do, including going back to work. They have greater dietary freedom. And this can even improve fertility. So the conventional treatment for patients who wish to carry out a pregnancy is to put them on in-center for six times a week, just like this, just more aggressive dialysis. And that significantly improves maternal fetal outcomes.

So the main downside of home hemodialysis is you do have to put your own needles in, and these are fairly large needles. So there are many patient hints on how to do this in the easiest way and lots of techniques that have been tried. So there are some practical considerations about choosing one of the two home therapies.

So you can ask, who is really appropriate for home peritoneal dialysis, and who isn't? You can ask the same thing about home hemodialysis. Some of these are, on occasion, billed as absolute contraindications. And most of them are just relative contraindications, things that can be overcome in many circumstances.

So obesity is not an absolute contraindication. It's a barrier. And in some cases, the sugar that we use with peritoneal dialysis can exacerbate weight gain. And if you have a very large pannus, it's possible that the normal exit site will be sort of on the dark side of the moon. So they have special extension sets that come all the way up to your upper abdomen, and that way a patient can actually see where the peritoneal dialysis catheter is and be able to perform all the manipulations they need, with everything in sight.

Diabetes is also discussed as a potential contraindication. But although the PD fluid can exacerbate hypoglycemia, it's treatable. And home peritoneal dialysis nurses are very used to adjusting insulin regimens to help with this treatment.

And there's also an idea that the elderly can't do it. And it's true that they might need assistance. My oldest peritoneal dialysis patient that I started on PD was either 82 or 83 when she started and 85 when she stopped and went to in-center dialysis. And she did great, was never hospitalized on peritoneal dialysis for five years.

So who is appropriate for home hemodialysis? Who isn't? I've heard some discuss that really it depends on how sharp they are. What's their education level? And that's a tricky one.

So it's often pretty surprising. I've had a full professor be unable to pass the home hemodialysis training. And I had a colleague have fantastic success on someone who never finished high school. But he became a car mechanic, and he was fantastic with troubleshooting and figuring how things work.

So I think instead of making a prejudgment, just let the patient try. And your home hemodialysis nurses are going to tell you if it works or not. The main thing is needle phobia. So some patients hate needles so much that if they want to do home therapy, that's when you would really encourage them to look into home peritoneal dialysis instead.

There are some absolute requirements for either form of home treatment. You really have to have a clean home. So most home centers will do a visit. No cats, if you're trying peritoneal dialysis, and an absence of unstable behaviors, like poorly controlled psychiatric disease or drug abuse.

It's incredibly helpful and sometimes needed, for many patients, that they have a very supportive family. And that family can overcome lots of these barriers listed above. And the patient just has to be motivated. For additional considerations, if there's someone who cannot tolerate large fluid shifts with in-center dialysis, such as with right heart failure, one of these two home therapies really have a compelling additional benefit.

And you can think about special situations. If I'm on peritoneal dialysis and I need a surgery, even cardiothoracic surgery, what's going to happen? Will I have to switch?

And there have been some papers published on this. And in centers where they looked at folks on peritoneal dialysis who underwent large cardiovascular surgeries, Kaiser Permanente compared those who stayed on peritoneal dialysis, even right after the surgery, to those who were on hemodialysis, matched for all other characteristics they could bench, age, years, on dialysis, the percent with diabetes, and a Charlson co-morbidity index. The PD patients were even maybe a little sicker. More of them had a CABG. But the PD patients really did equally well if not better.

So they had equal operative mortality, a shorter ICU stay, a trend towards a shorter hospital stay, a trend towards fewer infections. And these trends were not significant only because the trial's not huge. And two years later there Kaplan Mier survival curves are indistinguishable. So PD has flexibility and can be used both at home and in the hospital.

Now, there is a burden of either home therapy on both patients and caregivers that really needs good discussion at the outset. So the patients can sometimes perceive that they are being a burden to their family by doing home therapy. Many patients have fear and anxiety about the treatment itself and end up having more social isolation, especially if they're not working, than folks do when they go to in-center.

If the patient needs a lot of help from their family members, then there can be caregiver stress and burnout. And all of that really needs lengthy discussions at the outset. And that seems to be especially helpful if you have a transitional care unit. And we tried to include these topics at every monthly home dialysis patient meeting, which includes the nurses, the physicians, and very often the dialysis unit's social worker and nutritionist.

And you can think of interventions that can be done for these situations. In Toronto, for example, they have home assisted peritoneal dialysis where home peritoneal dialysis nurses will visit folks who are unable to do the therapies themselves anymore and help them get on the machine. Some centers use intermittent respite, so the family can have a week or two weeks off. And there has to be some flexibility in the dialysis prescription to allow both patients and caregivers to get all the benefits of home therapy with none of the stress.

So home therapy is definitely an upfront investment of effort and time. So from a study of home therapy in Europe, it took about three to four weeks to really train someone to be ready to go home and do the therapy themselves, between 10 to 25 teaching sessions of 1/2 to 2/3 of a day each. And so we do have to think about how long do we anticipate someone being on dialysis. So that this upfront investment is worth is worth their time. Someone who's about to have a transplant, or someone who's considering conservative care, probably isn't a good choice for this intense investment of time.

And now we should discuss that dialysis really is a huge expenditure. I think at the outset this was anticipated by Medicare to cost between \$1 and \$200 million to care for all the dialysis patients in the country. It's now about 50-fold, no, sorry, 500-fold higher. We're up to about \$50 billion and still rising based on data from the US RDS that went through 2016.

And so there are some aspects of public policy that go into the modalities of home therapy. So there's definitely a personal choice. We really want patients to choose the modality that they think will work best for them.

There are also societal costs. So home therapies are less expensive per year. Presently over 90% of working-age dialysis patients between about 18 and 55 are officially classified as disabled. And being on dialysis chronically is considered automatic for Social Security disability approval.

So if you go to a sort of John Rawls conception of what justice is, you could include this in a good public policy and think about comprehensive costs. What are the actual costs of dialysis that we're talking about here, but also the costs and rates of hospitalization between different home therapies and in-center center therapy, and a benefit of return to productive work for those who can do it and want to? And then improvements in mental health, if home therapies help with that.

So why should your patient consider home therapy again? We've talked about a number of the hard outcomes, the fact that the data aren't great here, but that when we look at them, the survival and surrogate outcomes for cardiovascular events on home therapy really are comparable or better than in-center therapy. We've looked at softer outcomes, like quality of life and the ability to work, which are also better on home therapies than they are in in-center.

And then there's the consideration of public policy, the comprehensive cost-benefit analysis. And then, let's go to patient surveys. I've said that public policy sort of incentivized in-center dialysis for many, many years. Why do patients say that they didn't pick a home therapy? And the main reason is that no one ever told them about it.

And so a lot of the current effort is being spent on trying to make sure that we give patients the opportunity to learn about these modalities, so they can choose what's best for them. So there is the question I've heard about among patients on home therapy, what's better is peritoneal dialysis better than home hemodialysis? And really, we were going into the weeds to try to find out what's better down here between in-center, home hemo, and home peritoneal dialysis. But this really all does not compare with kidney transplantation. So that's still the focus on folks who lose kidney function is to try to increase access to kidney transplantation for better survival and better quality of life.

So in the end, we'd like to start dialysis as late as possible. I'd like to think that when I see a patient early enough, I can really make a big difference on the trajectory of their CKD and can delay their need to start dialysis. Secondly, we want to help patients learn about home dialysis options, so they get to choose the treatment that works best for them. We also need to use dialysis as a bridge to transplantation whenever possible. And then, think about other ways we can change public policy to encourage home options if we keep finding that those seem to be the best.

And lastly, I included some testimonials from patients. These are sometimes the most effective peer-to-peer education. And this gentleman discusses that he was an incredibly non-compliant patient. He hated in-center dialysis. And he really wanted to be back at work as an assistant football coach for his high school. And so he changed to home hemodialysis. And he's now happy and delighted to be working with his football players again. And his family life is much better because he's not washed out.

A wonderful testimony on a home peritoneal dialysis from another professional who wanted to do a gentle therapy so that she was never washed out and could think and function and maybe do a quick exchange during the working day but then do everything else at home. And then multiple patients talking about the same things from Canada where home therapy is a little bit more common, especially in the provinces. And then an interesting video from a patient on home hemodialysis trying to give as many tips as she can on, this is how to place dialysis needles yourself, solo.

And these are the kind of videos by patients for patients that I think are really helpful to show patients what options they have and show providers that there's really not just one form, one way, to do hemodialysis. We can give patients some flexibility. All right. Thank you.