Myths and Realities about Treatment Options

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Speakers

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Agenda

Introduction

Myths and Reality about Home Dialysis
- Why a kidney patient should consider Home Dialysis
- Educational Resources to address Home Dialysis Myths

Myths and Reality about Kidney Transplant
- Why a kidney patient should consider Kidney Transplant
- Educational Resources to address Kidney Transplant Myths

Closing Remarks
Introduction

• This recorded webinar is appropriate for both providers and patients.
• The ESRD Network has identified that some perceived challenges towards kidney transplantation and/or home dialysis utilization are based on myths.
• Myths are a widely held ideas that is based on stories. They tend to be false or partially false.
• During the following slides you will review varying myths regarding renal treatment options, and the reality or fact that addresses these misguided beliefs.
• If you are a provider, you may print the accompanied slides and share with patients as a handout or a collection of prints through your facility or bulletin board. You may also use this presentation to address these patient myths through education.
• If you are a patient, we hope that these facts help you make informed decisions about your health. You can also be a patient leader by educating other patients on the facts, especially when you hear these myths from your peers.
Treatment Options Overview
Treatment Options Overview

In-center Dialysis

Home Hemodialysis (HHD)
- Conventional
- Short daily
- Nocturnal

Peritoneal Dialysis (PD)
- CAPD – Continuous Ambulatory Peritoneal Dialysis
- CCPD – Continuous Cycling Peritoneal Dialysis

Transplant

No Dialysis
Myth vs. Reality – Home Dialysis
HHD Myth vs. Reality

Myth
A kidney patient can’t do home hemodialysis if they are afraid to insert their own needles.

Reality
Many patients have learned how to self-cannulate (insert their own needles) both for in-center and home dialysis. It can preserve the fistula, hurt less, and result in fewer complications.
PD Myth vs. Reality

**Myth**
A kidney patient shouldn’t consider PD as an option because they will get an infection!

**Reality**
Peritonitis (an infection of the abdomen) can be prevented. It rarely occurs in good peritoneal dialysis (PD) clinics (about once every seven years).
HHD Myth vs. Reality

**Myth**
A home patient won’t have any experts in the home to help them out.

**Reality**
The patient and/or their care partner will learn to be an expert, and the facility will provide 24/7 phone support. Help will always be nearby.
PD Myth vs. Reality

**Myth**
If a person is overweight, they can’t do PD.

**Reality**
A catheter placed differently into the abdominal cavity may be a better option. PD can still be done.
HHD Myth vs. Reality

Myth
Home HD is a huge burden for a care partner.

Reality
It is best if the patient performs as much of their treatments as possible. Some people perform home HD without a care partner.
PD Myth vs. Reality

**Myth**
A kidney patient needs to have some kidney function in order to do PD.

**Reality**
Kidney function will always be checked, but PD can be done without any kidney function.
HHD Myth vs. Reality

Myth
A person could bleed to death very quickly at home while receiving dialysis.

Reality
No one has ever bled to death on home hemodialysis. Machine alarms alert you to the detection of just one drop of blood out of place. You will have time to react and fix the problem.
HHD Myth vs. Reality

Myth
If a person decides to do HHD, they must follow the same scheduled days of the week.

Reality
Many different schedules are available and can be arranged at home. There is short daily and nocturnal dialysis if you’re interested in dialyzing while you sleep. The purpose of home dialysis is to set your own schedule.
General Information - Myth vs. Reality

**Myth**
Home dialysis, will cost more than at the dialysis unit.

**Reality**
No, not at all. Both Medicare and private insurance cover the cost of home dialysis.
Myth
A kidney patient will have to get rid of their pets to do dialysis at home.

Reality
Lots of people dialyze at home and still have pets. Clean well and ensure your pets stay out of the room when you connect or disconnect.
General Information - Myth vs. Reality

**Myth**
When a person dialyzes at home, they can eat and drink whatever they want.

**Reality**
Dietary and fluid intake limitations remain in place, but you may have a bit more flexibility with your limits and choices. Always check with your medical team when changing your renal diet.
Myth
A lot of space is needed in a person’s home to do HHD or PD.

Reality
Home dialysis will require some space for supplies, but many people who live in efficiency apartments, mobile homes, and other small spaces find a way to make PD work.
General Information - Myth vs. Reality

Myth
If a person does dialysis at home, they won’t be able to change dialysis types or be a candidate for transplant.

Reality
Not at all. You can always switch to another home modality or decide you’d like to go to in-center hemodialysis. Also, doing home dialysis does not make you less likely to receive a transplant.
Home Dialysis Considerations

- More flexibility in dialysis and daily life schedules
- More normal diet with less restrictions
- May be able to reduce medications
- Less recovery time after treatment
- Reduced transportation hassles getting to and from the clinic
- Ability to travel more (depending on your capability with bringing the machine and supplies)
- More energy, both mentally and physically
- Better control of blood pressure
- Less stress on the heart
What type of support would be provided by the dialysis facility?

• Dialysis providers are required to educate about home dialysis treatment options and assess patient interest.

• The healthcare team can help in referring a patient to a home program.

• Home nurse will provide one on one training until a person is comfortable with dialyzing at home.

• A home nurse will assist in organizing your home with supplies needed for dialysis.

• A kidney patient will still have visits to the dialysis unit for monthly labs and evaluations.

• Remember, the dialysis unit staff will be available to you 24/7 either in the facility or by phone.
Uncovering Myths About Home Dialysis

Myth vs. Reality

My Choice, Home Hemodialysis (HD)

Myths vs. Reality

You won't have any experts at home to help you out.

You could bleed to death very quickly.

Home HD is a huge burden for a care partner.

A home HD care partner needs to have a medical background.

You can't do Home HD with a dialysis catheter.

Your house has to be perfectly clean at all times.

You'll get an infection!

You'll have to get rid of your pets to do PD at home.

If you've had previous abdominal surgery, you can't do PD.

If you have vision or hearing problems you can't do PD.

If you are overweight, you can't do PD.

Peritonitis (an infection of the abdomen) can be prevented. It rarely occurs in good peritoneal dialysis (PD) clinics (about once every seven years). An infection from an hemodialysis access is more common and more likely to be fatal.

Lots of people do PD at home and still have pets. Clean well, and keep pets out of the room when you connect and disconnect.

Routine abdominal surgeries (like hernia repairs, C-sections, and some transplants) do not prevent you from doing PD.

There are assist devices available to help with most tasks involved with doing PD.

Kidney function will always be checked, but PD can be done without any kidney function.

PD can still be done. The surgeon will evaluate the best placement of the catheter based on your shape and size.
Myth vs. Reality Resource Links


Myth and Reality – Kidney Transplant
Transplant Myth vs. Reality

**Myth**
A person receiving dialysis who would like to receive a living donor kidney transplant must have a **blood-related family member** who is willing to donate a kidney to them.

**Reality**
A donor can be a family member, friend or stranger as long as they are a compatible match for the recipient.
Myth
Kidney transplants can only be done if the recipient is under 70 years old.

Reality
Many transplant centers in the nation do not have an age cut off, but rather assess the overall health status of the person needing a kidney transplant.
Myth
A transplanted kidney will not last a long time.

Reality
The average life of a kidney transplant depends on the donor type. Deceased kidneys last about 15 years; while living donor kidneys last about 15-20 years on average. Although kidney transplantation is not a cure, it can mean many years of freedom from dialysis treatments.
Myth
A person interested in a kidney transplant needs private insurance to pay for the procedure and anti-rejection medications.

Reality
A private health insurance is not required to receive a kidney transplant. In fact, Medicare covers kidney transplant costs for the recipient (and medical costs for a living donor, if involved).
Transplant Myth vs. Reality

**Myth**
A person **needs to be on dialysis** to be referred for a kidney transplant.

**Reality**
Pre-emptive transplant can be offered to people diagnosed with Chronic Kidney Disease (CKD) and GFR less than 20 even before starting dialysis. A referral can be made once the GFR reaches 30. Some people never undergo dialysis treatments before getting their kidney transplant.
Transplant Myth vs. Reality

Myth
If a living donor is not a direct match, then the recipient is out of options to receive a living donor kidney transplant.

Reality
If a living donor is not a direct match to the recipient, then both parties can enter a pair exchange program (also known as a kidney swap).
Myth
Kidney transplant as a treatment option, is only a choice for the **wealthy**.

Reality
Kidney transplants are available to any eligible patient regardless of financial or social status. Transplant centers have financial coordinators that will evaluate the patient’s situation to assure that can afford the costs related to the work-up process, surgery and care after the transplant, such as medications.
Myth
Kidney transplants are offered mostly to Caucasian kidney patients.

Reality
The Kidney Allocation System (KAS) makes the distribution of organs a fair and equitable process that does not discriminate against race or ethnicity.
Transplant Myth vs. Reality

**Myth**
If a person receives a kidney from a **Hepatitis C** positive donor they would develop the disease, which will lead to liver failure.

**Reality**
Some transplant centers have a program that offers the option to transplant a Hepatitis C positive kidney. After transplantation, the recipient is treated with antiviral medications to treat and cure the Hepatitis C.
Myth
A person with kidney failure can be referred to a transplant center only when they have been on dialysis for at least a year.

Reality
Although the time on dialysis is considered when allocating an available kidney from a donor, referral to the transplant center can be done at any time. No specific amount of time on dialysis is needed to start the process!
Myth
After a kidney transplant, all kidney medications will stop.

Reality
Although some medications related to dialysis can be discontinued, patients must take a daily anti-rejection medication to prevent the body from attacking or rejecting the transplanted kidney.
Transplant Myth vs. Reality

Myth
If a transplant center determines a patient is not eligible for a transplant, this means that a person will never be able to receive a kidney transplant.

Reality
A dialysis patient who has been determined as ineligible for a kidney transplant, can be referred and evaluated at another transplant center that has different criteria and/or try again at a later time when the patient meets the criteria at the original transplant center where he/she was not eligible.
Myth
The first visit to the transplant center, means that a patient has been added to the transplant waitlist and is now waiting for a kidney transplant.

Reality
On the first visit to the transplant center, a patient receives general education and may begin the assessment process with the healthcare team. Once the transplant center has determined the patient meets their criteria, then a patient would be added to the transplant waitlist. Once a kidney becomes available that matches the patient, they will be called to get a kidney transplanted through surgery.
Transplant Myth vs. Reality

**Myth**
A patient must be referred to a transplant center by their kidney doctor or healthcare professional only.

**Reality**
Many transplant centers will accept self-referrals, meaning that the patient can refer themselves for a transplant center evaluation.
Transplant Myth vs. Reality

Myth
Being multi-listed with more than one transplant center is duplication of efforts.

Reality
When patients are multi-listed with two or more transplant centers located in different Donor Service Areas, the chances of receiving a kidney transplant sooner increases.
Transplant Considerations

- More flexibility in life and freedom from dialysis treatments
- Reduced transportation challenges getting to and from a clinic
- Flexibilities of going back to work or school
- Ability to travel with less hassle
- Less dietary restrictions, if any
- The new kidney works 24/7 cleaning your blood
- More energy, both mentally and physically
- It’s considered the best treatment option for both clinical and quality of life outcomes for kidney patients
What type of support would be provided by my dialysis facility?

- Dialysis providers must **educate** about kidney transplant as a treatment option and assess patient interest.
- The healthcare team can help in **referring** a patient to the transplant center.
- The healthcare team might assist providing required **paperwork** such as H&P, insurance, 2744 and other forms.
- The healthcare team can assist in reminding of upcoming **appointments** to the transplant center and/or related tests or procedures.
- The Social Worker might assist in coordinating **transportation** for such appointments.
- **Communication** between dialysis providers, transplant center and patient are crucial during this process.
Turning Negatives into Positives

• Address negative misconceptions with positive reinforcements about transplant
• Negative ideas about transplant can develop myths or false statements
• Facts can be presented in a positive light that motivate kidney patients to pursue a kidney transplant

https://www.esrdncc.org/globalassets/negpostransplantflyerfinal508.pdf
Treatment Options
Additional Resources

• Home Dialysis Central: https://homedialysis.org/home-dialysis-basics
• Home Dialyzors United: https://www.homedialyzorsunited.org/
• Explore Transplant: https://exploretransplant.org/
• National Kidney Foundation: https://www.kidney.org/treatment-support
• My Life, My Dialysis Choice: https://mydialysischoice.org/
• AAKP: https://aakp.org/center-for-patient-research-and-education/dialysis-education/
• Life Options: https://lifeoptions.org/living-with-kidney-failure/options-for-dialysis/
Thank You!

For more information:

Website: https://esrd.ipro.org/