

How can we empower individuals choosing between dialysis modalities?

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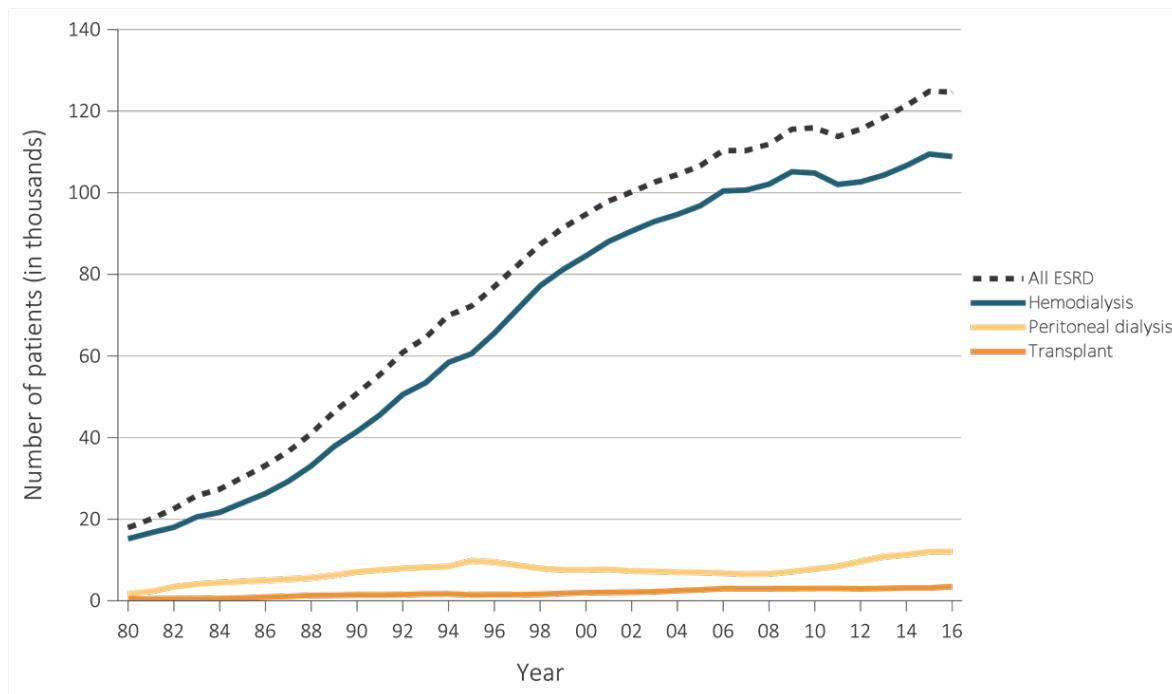
Erica Perry, LSW

Executive Order 2019

Goal:

By 2025, 80% of patients newly diagnosed with end-stage kidney disease should receive home dialysis or kidney transplants

Trends in the annual number of ESRD incident cases, by modality, in the US population, 1980-2016

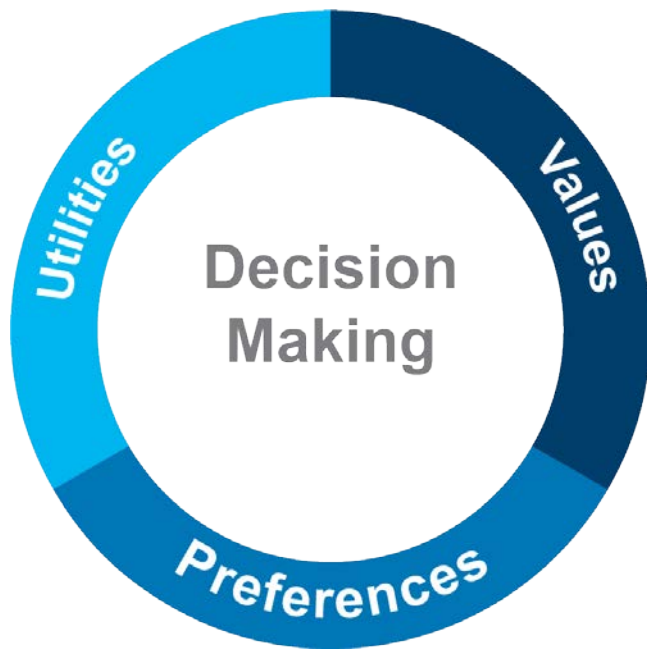




Choice of Dialysis Modality

- Individuals with kidney failure require replacement therapy
- The most common decision is between in-center hemodialysis and peritoneal dialysis
- This is a difficult decision; patients often do not feel well informed or supported

Factors that Influence Decisions

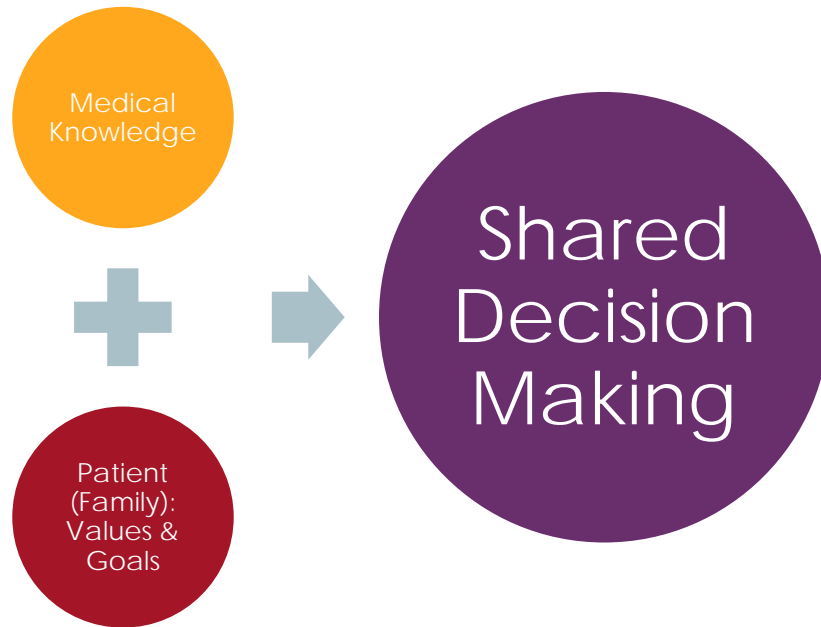


Shared Decision Making

- Usually in situation of clinical equipoise
- Steps:
 - Review best medical evidence
 - Solicit patient preferences and values
 - Address potential outcomes

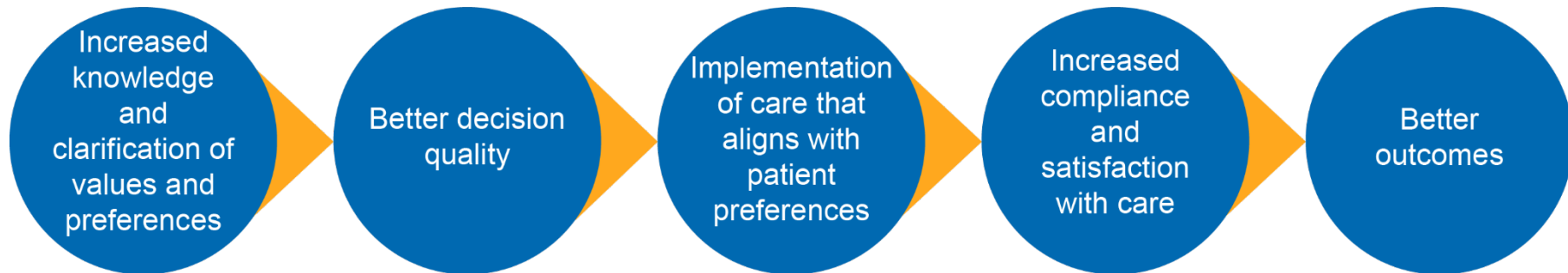


Collaborative Approach

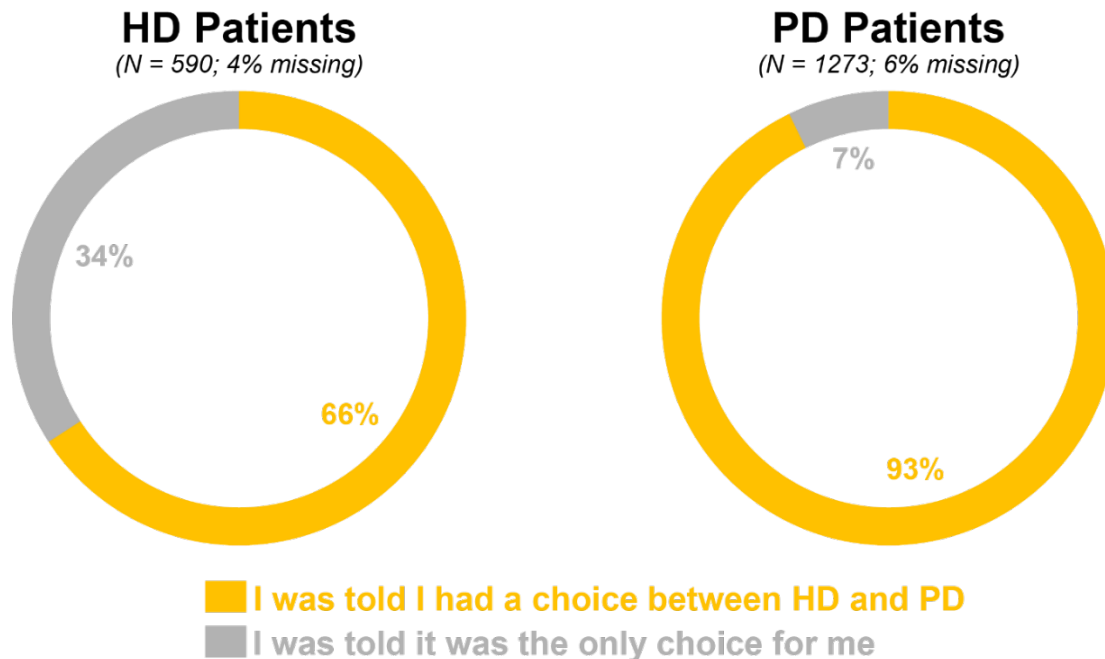


Shared Decision Making: Benefits

Shared Decision Making



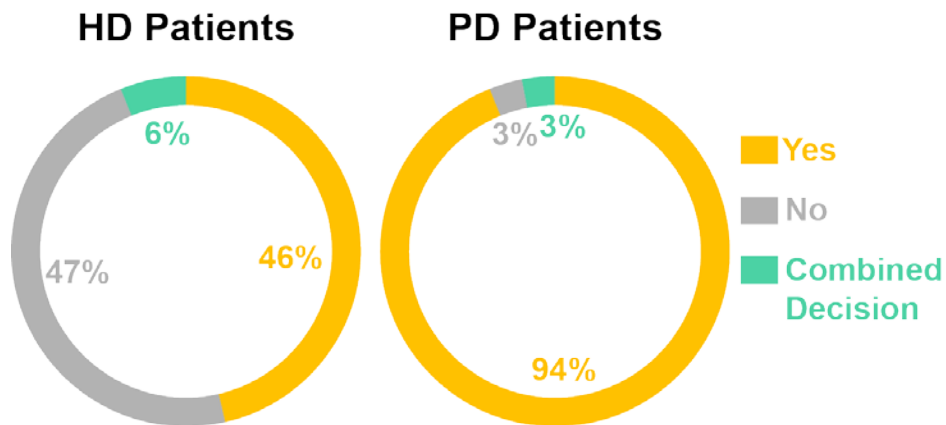
Which of the following happened when you started HD/PD?



* $P < 0.05$ for PD vs. HD comparison, adjusting for age, gender, diabetes, vintage, race, and platform.
Preliminary results as of October, 2015

Do you feel that the decision to go on HD/PD was largely *your* choice?

Quotes from patient interviews



- **No:** “My kidney doctor just walked in and said it.” (*HD pt*)
- **“Weak” Yes:** “[PD] was not an option. Because of surgery that I’ve had...the cancer in my abdomen...So...it...couldn’t be done. Not an option.” (*HD pt*)
- **“Strong” Yes:** “It was 100% my choice. They explained the peritoneal, the hemodialysis and the peritoneal where you’re on the cyclor at night....and this just made the most sense to me.” (*PD pt*)

Decision Aids

Basic information about the health condition

Recognize the need to make a treatment decision

**Describe
Treatment Options**

**Benefits
&
Harms**

**Values
Clarification**

**Other Patients
Experiences**
(optional)

Guidance in next steps of decision making



EPOCH - RRT

Empowering Patients on Choices for Renal Replacement Therapy

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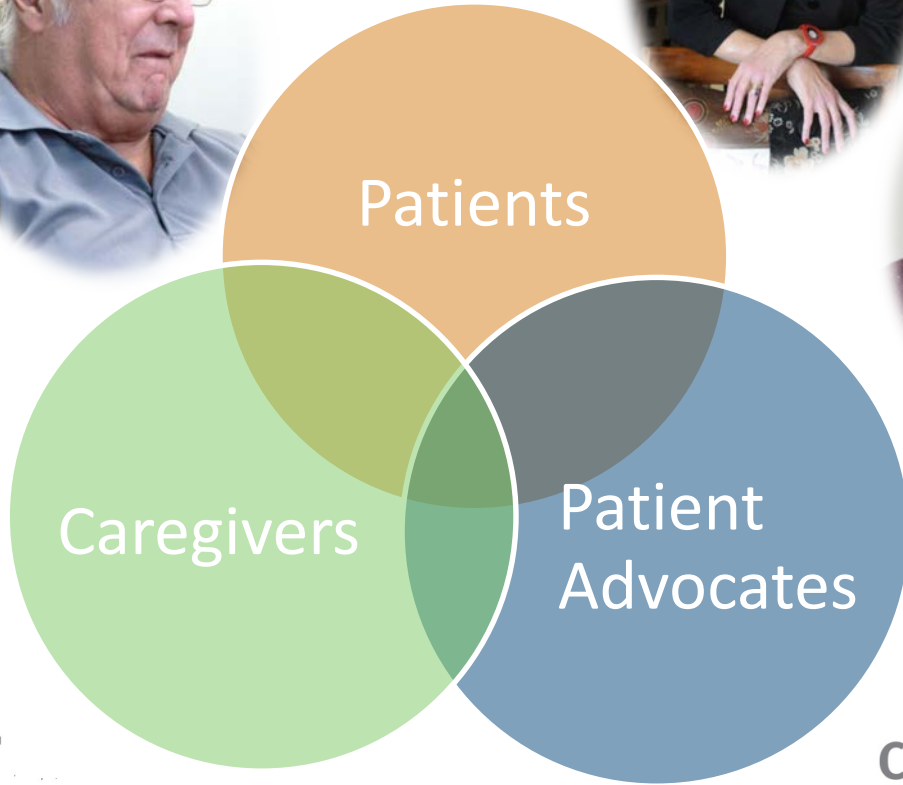
PCORI award # 1109_2013051

Tentori PI

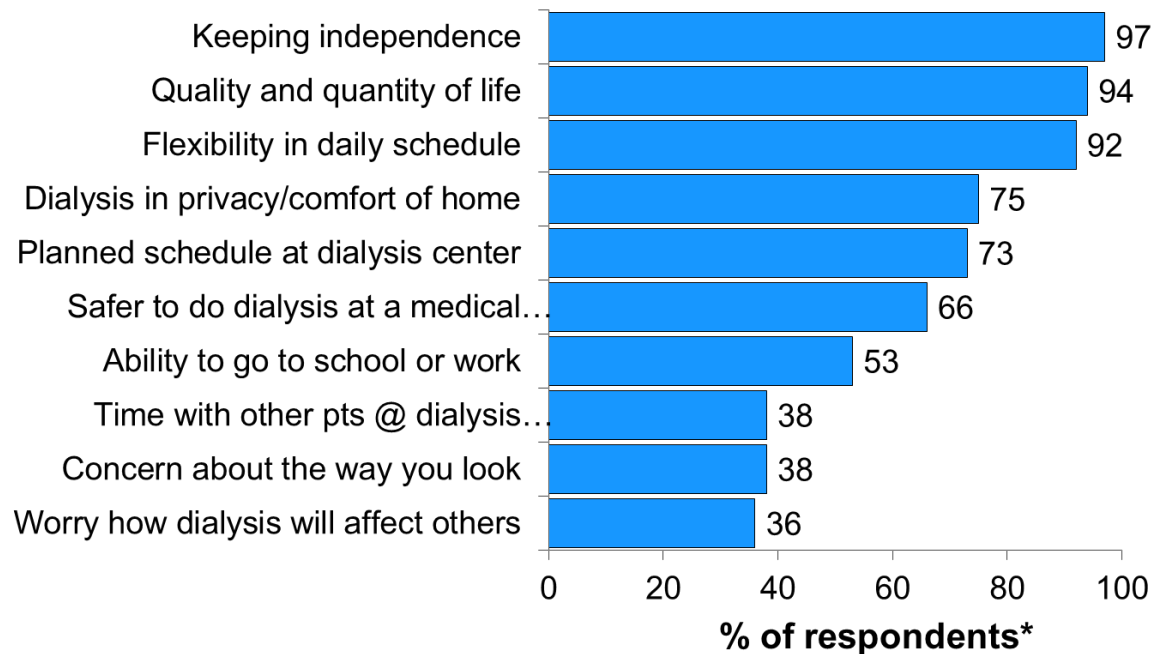


EPOCH-RRT

ChoosingDialysis.org



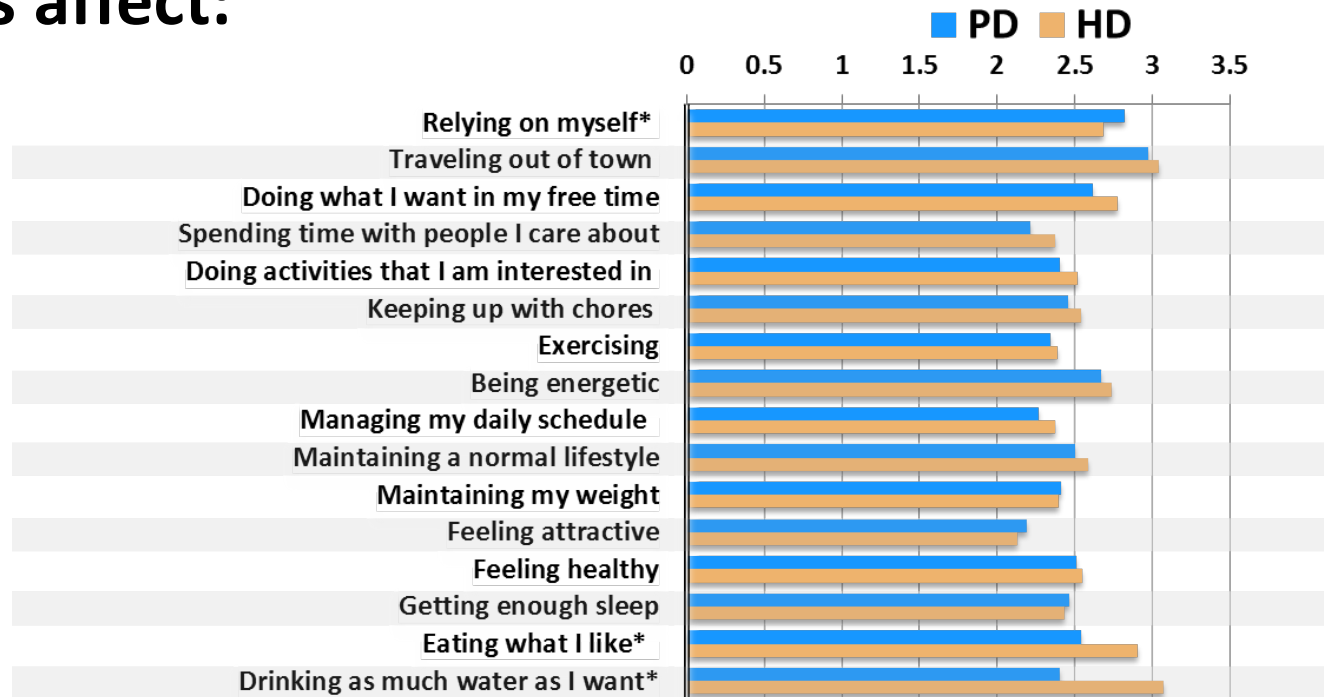
Factors Identified as Most Important



* Not everyone was asked every probe and some who were asked did not answer, this includes 'yes', 'no', and 'don't know' responses. N for each probe ranged from 88 to 166.



Compared with before starting dialysis, how does dialysis affect:



Scale: 1: Not at all → 5: Extremely; mean scores are presented

* $P < 0.05$ for PD vs. HD comparison, adjusting for age, gender, diabetes, vintage, race, and platform. Preliminary results as of Oct 2015.



ChoosingDialysis

Empowering Patients On Choices for Renal Replacement Therapy

[HOME](#)[YOUR KIDNEY HEALTH](#)[LEARN ABOUT DIALYSIS](#)[DECISION TOOL](#)[FOR LOVED ONES](#)[RESEARCH](#)

Get the facts you need about dialysis from people who have experienced it.

We will help you learn about the factors that matter most so that you can choose the best care for your needs.

Get started: Why it is important to think about dialysis now.

- [Compare the two most common types of dialysis.](#)
- [Get to know your care team.](#)
- [Find tips for caregivers and loved ones.](#)
- [Use our decision tool to weigh the factors that matter to you.](#)



"I may have kidney disease, but it doesn't have me." -Margie

In the United States, more than 96% of people with kidney failure start either in-center hemodialysis (HD) or peritoneal dialysis (PD). We focus on these two types of dialysis on this site because they are the most common. However, keep in mind that there are other options. For more information, see [Additional Resources](#).

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ChoosingDialysis.org

Navigation bar
follows decision
making process



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HOME * YOUR KIDNEY HEALTH * COMMON DIALYSIS TYPES * DECISION TOOL FOR LOVED ONES RESEARCH HOME HEMODIALYSIS

On this page: Understanding Your Choices

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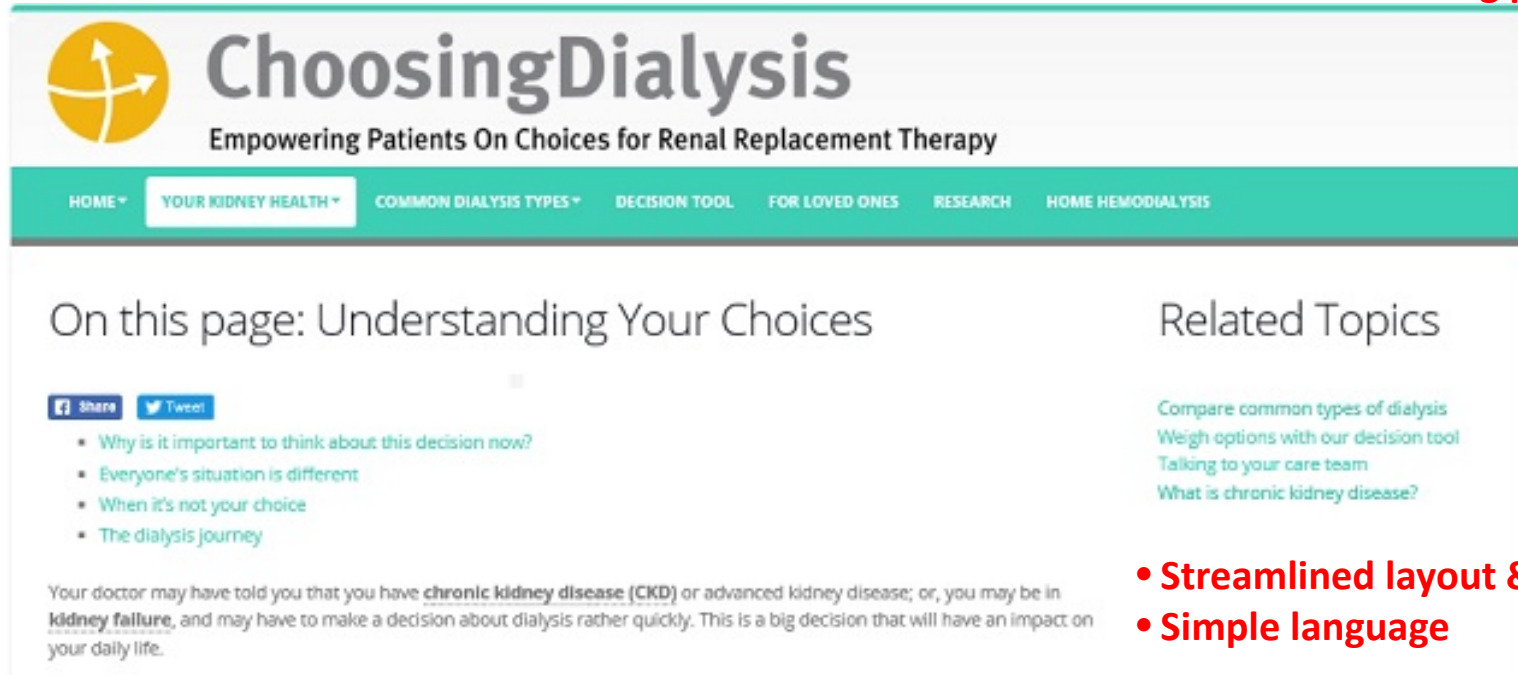
- Why is it important to think about this decision now?
- Everyone's situation is different
- When it's not your choice
- The dialysis journey

Your doctor may have told you that you have **chronic kidney disease (CKD)** or advanced kidney disease; or, you may be in **kidney failure**, and may have to make a decision about dialysis rather quickly. This is a big decision that will have an impact on your daily life.

Related Topics

- Compare common types of dialysis
- Weigh options with our decision tool
- Talking to your care team
- What is chronic kidney disease?

Navigation bar
follows decision
making process



The screenshot shows the homepage of the ChoosingDialysis website. At the top is a teal navigation bar with a logo on the left and several menu items. Below the navigation bar is a main content area with a large heading, social sharing buttons, a list of topics, and a paragraph of text. To the right of the main content is a 'Related Topics' section with three links. The website has a clean, modern design with a teal and white color scheme.

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Related Topics

- [Compare common types of dialysis](#)
- [Weigh options with our decision tool](#)
- [Talking to your care team](#)
- [What is chronic kidney disease?](#)

- Streamlined layout & navigation
- Simple language

Navigation bar
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Pictures & Graphics




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- [Compare in-center HD and PD](#)

What is dialysis?

Dialysis is one of the treatments that are available when kidneys have almost stopped working. Other options include kidney transplant and conservative management. Dialysis does not do everything that healthy kidneys normally do, but it cleans the blood and filters out harmful wastes and excess fluids. Most people who start dialysis remain on dialysis for the rest of their lives, or until they receive a kidney transplant.

What are the most common types of dialysis?

In-center Hemodialysis (HD)



Peritoneal Dialysis (PD)



This website focuses on the two types of dialysis that are used by the majority of patients with kidney failure: in-center HD and PD. Since these treatments are very different, we want to help you understand how each might fit your preferences and lifestyle.

[Common Dialysis Types](#)[Dialysis Schedule](#)[Side Effects](#)[Daily Life](#)[Lifestyle Changes](#)[Your Care Team](#)[Summary of In-center HD and PD](#)

- **Focus on the two most common dialysis types**
- **Resources on home HD and transplant are provided**





- Compare in-center HD and PD

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- Focus on the two most common dialysis types
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Tables comparing HD and PD

	Hemodialysis (HD)	Peritoneal Dialysis (PD)
How does it change everyday life?	<ul style="list-style-type: none"> Transportation to the center Travel considerations 	<ul style="list-style-type: none"> Clean environment Space for supplies Travel considerations



Move the sliders to show how much or how little each of these things matter to you.

What matters to me for this decision



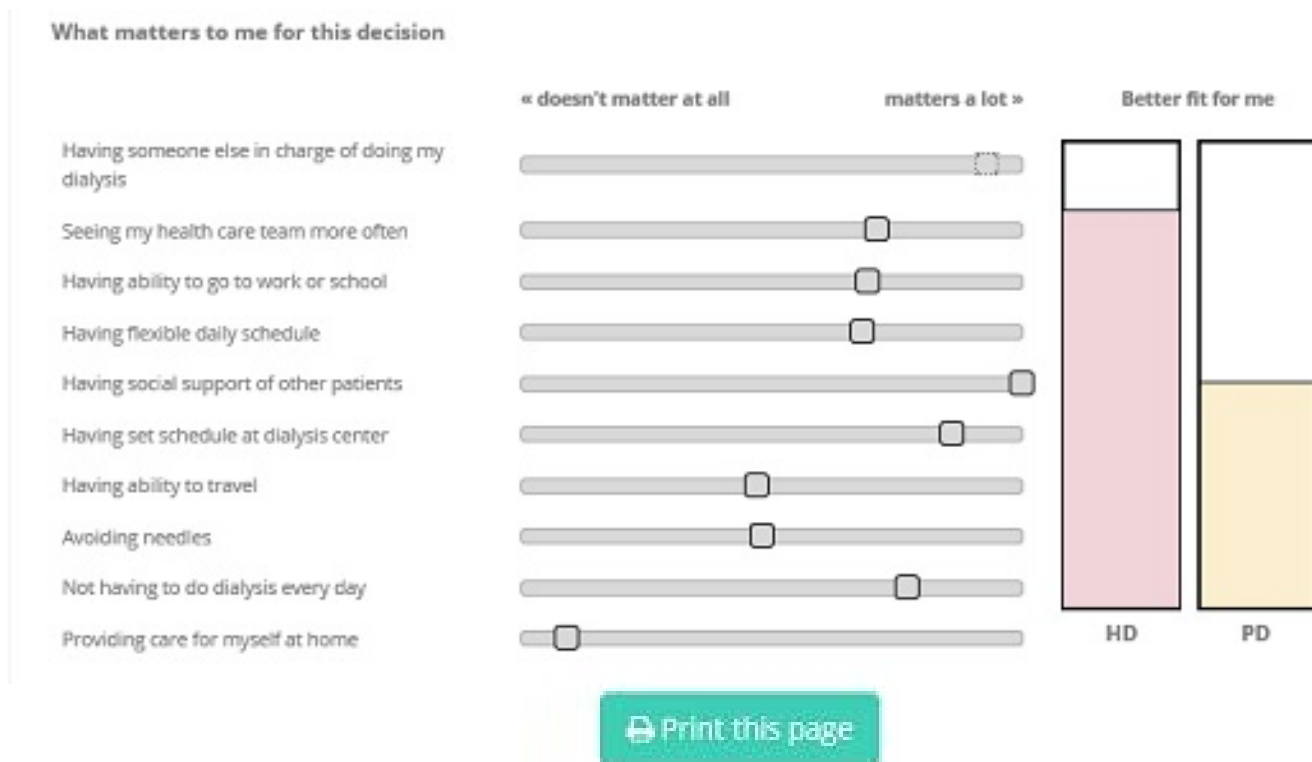
Patient A: PD may be a better fit

What matters to me for this decision



 Print this page

Patient B: HD may be a better fit



IMPORTANT!!!

- Results from the decision aid do not indicate what is the “right” modality for that patient
- Intended as a tool to help patient clarify his/her wishes and share them with care team

Talking with your care team

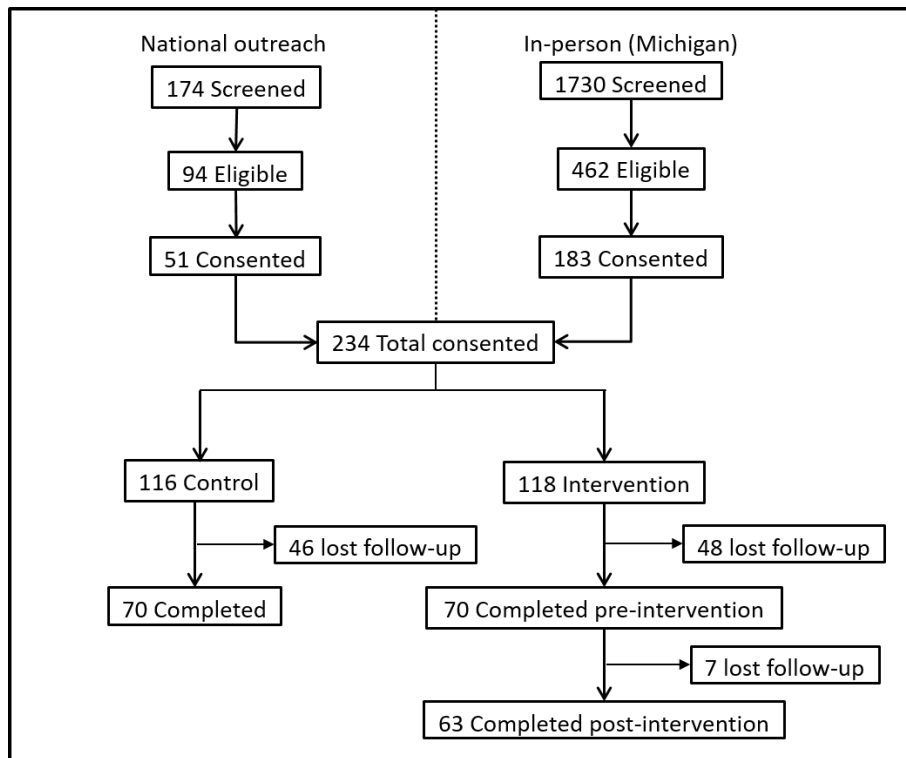
Here are some suggestions to keep in mind when you meet with your health care team:

Health Tips

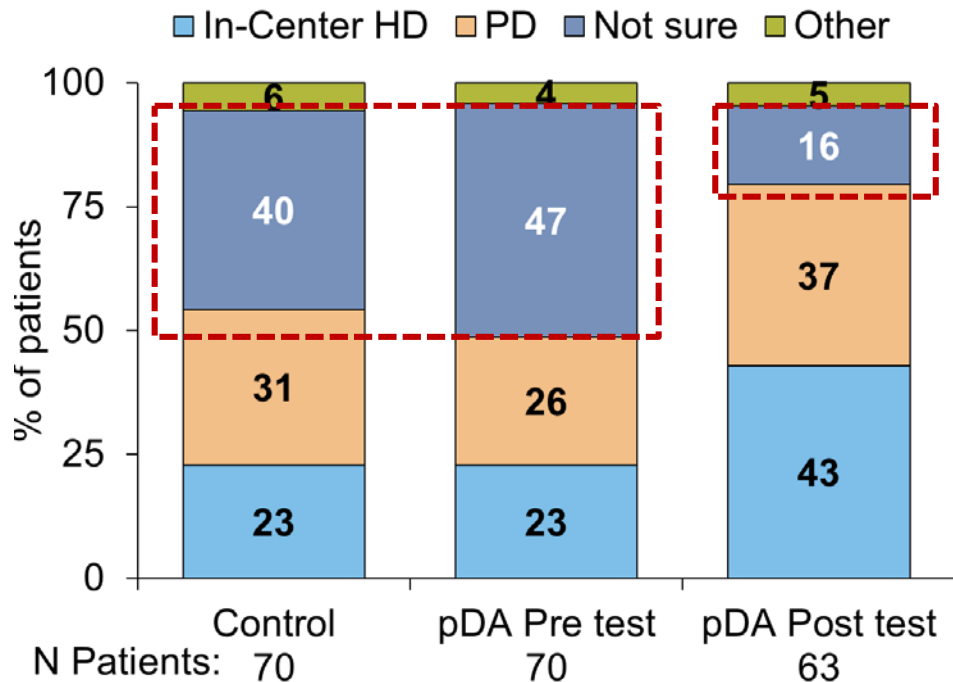
- ✓ Talk with your social worker about a special type of Medicare that is available to people with kidney disease and additional co-insurance that will help you get the best coverage for your dialysis care.
- ✓ To help you remember the details, bring pen and paper to take notes.
- ✓ Think of questions you have, write them down, and bring this list to your appointment.
- ✓ Bring a loved one with you. They can help remember some of the details and ask questions.
- ✓ Discuss your wishes with your loved ones and make them known to your health care team.
- ✓ Tell your health care team what's important in your life, and ask them about the symptoms or side effects you care most about.
- ✓ If you have a dialysis treatment preference, let your health care team know. Sometimes, they may have medical reasons for recommending one dialysis treatment over the other, but it's important to know what these reasons are.
- ✓ Print out the results of the exercise on the "Decision Tool" page, and share these with your health care team.

**Tips from real-life patients,
families and health care
providers**

Trial of decision aid to measure decision-making outcomes



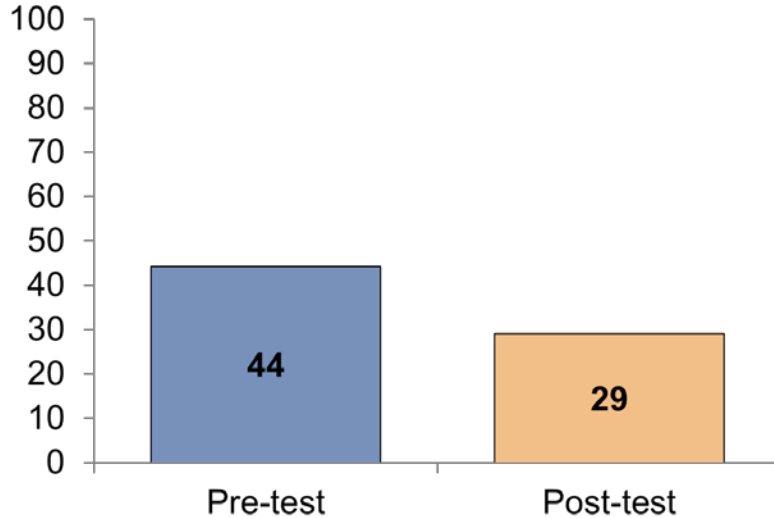
Which type of dialysis do you think you might choose when you need to start dialysis treatment?



Subramanian 2019 AJKD

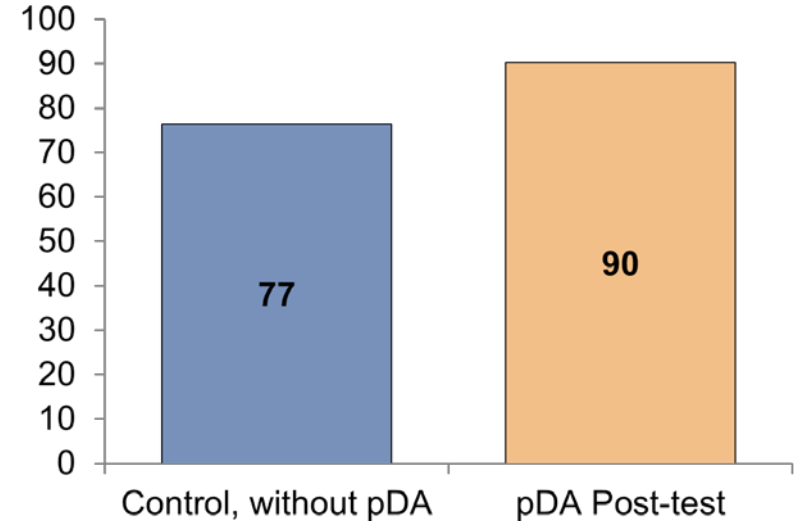
DECISIONAL CONFLICT

Before and After Decision Aid



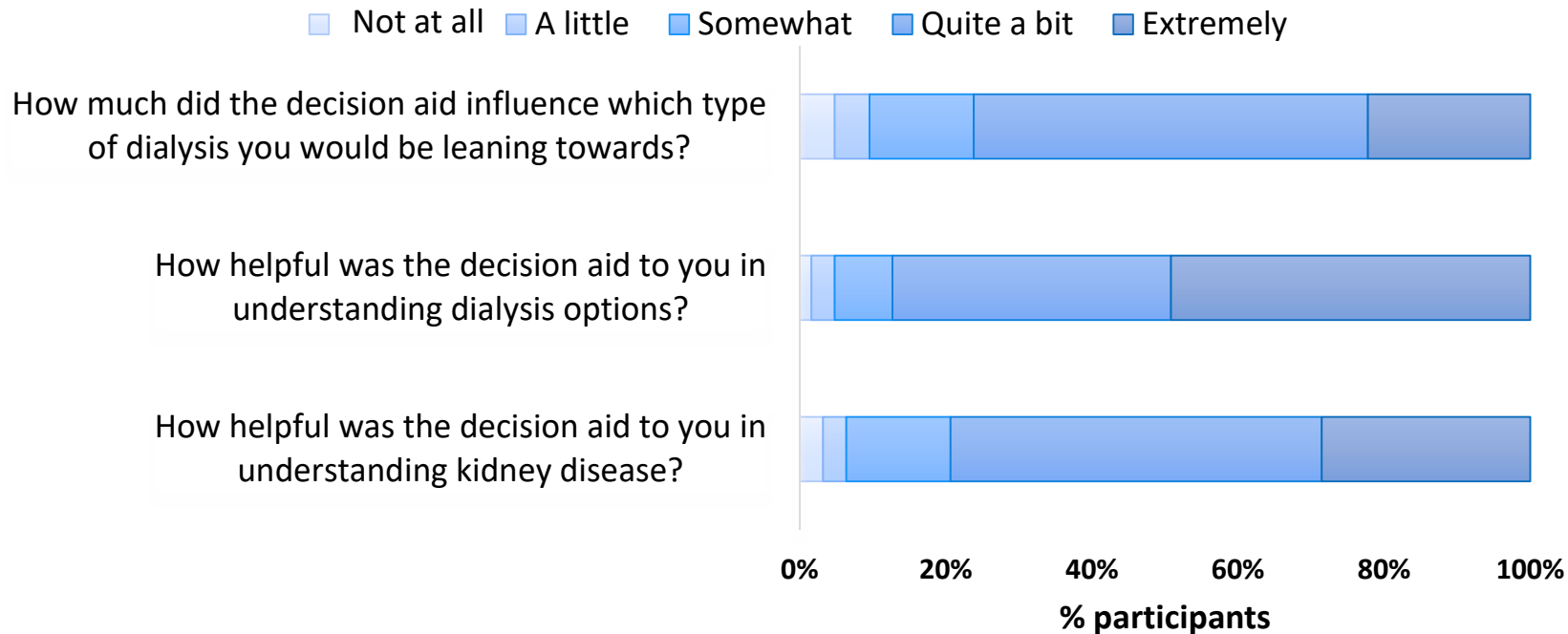
KNOWLEDGE

Controls vs. Intervention



Subramanian 2019 AJKD

Opinions on the EPOCH-RRT decision aid



Subramanian 2019 AJKD

NKF Mission Award

March 2020

Recognizing research published in AJKD that has great promise to enhance the lives of those affected by kidney disease

awarded to

Lalita Subramanian, Junhui Zhao, Jarcy Zee, Megan Knaus, Angela Fagerlin, Erica Perry, June Swartz, Margie McCall, Nicole Bryant, and Francesca Tentori

for their article:

“Use of a Decision Aid for Patients Considering Peritoneal Dialysis and In-Center Hemodialysis: A Randomized Controlled Trial”

Kerry Willis

Kerry Willis, PhD
Chief Scientific Officer, NKF

Harold I. Feldman

Harold I. Feldman, MD
Editor-in-Chief, AJKD



EPOCH-RR



**NATIONAL KIDNEY
FOUNDATION®**

ChoosingDialysis.org



Challenges to Shared Decision Making

PATIENT

- Knowledge
- Values awareness
- SDM skills



CLINICIANS

- Time
- SDM importance
- SDM skills

How to Support Ideal Process

Patient/Loved Ones

- **Timing**
 - Reminders
 - Time
- **Tips for better communicating**
 - How to let your doctor know when you don't understand
 - Taking notes / record
 - Having loved ones attend the appointment

Clinicians

- **Educate on value**
- **Provide specific tips**
 - empathy
- **Ensure enough time is made available**

Summary

- The choice of dialysis modality is a very difficult experience, and often patients needs are currently not being met.
- Nephrology teams need to get better at listening, communicating, and eliciting questions.
- New tools such as decision aids should be considered.
- Improved understanding may result in improved fit between each patient and the dialysis modality that best fits his/her lifestyle.

The EPOCH-RRT decision aid is
publically available

www.choosingdialysis.org

