Why We Need YOU!
Holly Archinal

You may have heard the terms ‘patient-centered research’ and ‘patient-centered outcomes’ - but what do they really mean? Patient-centered means focused on the patient. In healthcare, this means that treatment is based on what the patient thinks is most important.

What does this have to do with research? Patient-Centered Outcomes Research (PCOR) is built on the idea that—in order for research to be effective—it is important to know what patients want scientists to investigate. Outcomes research compares treatments, procedures, and interventions based on their outcomes. PCOR uses outcomes that matter to patients, such as quality of life, fatigue, or pain.

PCOR is fast becoming very popular, and this is because in the past, research did not always investigate things that help patients directly.

To put the patient at the center of research for PCOR, we need to know what patients care about the most, because what is interesting to the researcher may be less important to the patient or have less impact on patients’ daily lives.

For instance, do patients worry more about a cure for CKD or management of the condition? By engaging patients, their families and caretakers, and care providers like doctors and nurses in the research process, we can focus our research on finding information that will help make big decisions and daily choices easier for patients with CKD.

PCOR sets out to help patients, physicians, caregivers and others make decisions about the healthcare options that work best for each individual. We are dedicated to ensuring our research will improve the health and care of everyone living with CKD. To do this—we need you.
Home Dialysis in Delaware
William Murray

When kidneys start to fail, several options are available to patients to receive dialysis: center hemodialysis and home dialysis, which includes peritoneal dialysis and hemodialysis.

Home hemodialysis (HHD) can be done at the patient’s home with an adapted hemodialysis machine. A care partner is required as well as extensive training.

The patient and care partner are both trained on how to set up the machine, perform the HHD procedure, and troubleshoot any issues that may occur. One benefit of HHD is that it can be done on a convenient schedule for the patient and his or her care partner.

According to the United States Renal Disease System 2016 report, the use of home dialysis (peritoneal dialysis or home hemodialysis) among patients with end-stage renal disease (ESRD) has increased appreciably in recent years. Among home dialysis patients, the proportion using hemodialysis was over 2.5-fold higher in 2014 (15.6%) than in 2000 (6.2%).

References:


DIALYSIS SUPPORT GROUP

Dialysis patients interested in meeting with others can attend the Home Dialyzers Support Group. Group sessions consist of an educational portion followed by time for questions and answers to discuss issues with treatment, treatment options or just support.

The group is open to anyone in any stage of CKD and for any type of dialysis—peritoneal dialysis, home hemodialysis or in-center dialysis. Our goal is to take the fear and mystery out of performing dialysis at home so that more people can experience the freedom and results.

The support group is held monthly on the 4th Monday of each month from 5:30 to 7:00, at the North Quarter Creole, 837 N. Union Street, Wilmington.

For questions or to RSVP, contact Bill Murray at (302) 275-4665 or shmrckpl@comcast.net.

Support group sponsored by NxStage.
Community Forum Recap
Claudine Jurkovitz, MD, MPH

To strengthen our partnership and better understand each other, we organized a series of four town halls/open forums in early 2017.

The January meeting focused on Patient-Centered Outcomes Research (PCOR). Coordination of care between primary care physicians and specialists was selected as one of the most important topics for PCOR.

Patients pointed out that most of the time, they were in charge of keeping all their providers in the loop, and regretted that there was little direct communication between physicians. In many cases, faxing information from one practice to another is still used but is not a reliable method as paper can be lost and the information may not be entered into the electronic health record (EHR).

To improve communication between providers, everyone agreed that improving EHR system connectivity would be ideal, but other methods such as texting or emails could be used as long as the information was transmitted in a secure, confidential and reliable way. Many opportunities for research were discussed!

The March meeting focused on epidemiology and comparative effectiveness research. Dr. William Weintraub, former John H. Ammon Chair and Cardiology Section Chief at Christiana Care and an internationally recognized clinician-scientist with extensive leadership in clinical trials and comparative effectiveness studies, led the discussion by first explaining how the science of epidemiology began and giving some examples of famous epidemiologic studies such as the Framingham Heart Study which led to the identification of the major risk factors for cardiovascular disease and the British Doctors Study in the 1950’s that first showed the link between smoking and lung cancer. An animated discussion about comparative effectiveness science and how it could be applied to questions that matter to patients and other stakeholders followed.

Dr. John Goodill, Medical Director of the Palliative Care services at Christiana Care and Director of the

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Chronic Kidney Disease (CKD) and end stage renal disease (ESRD) are serious and costly diseases. CKD affects more than 20 million adults, and is seen most often in individuals over 60 years of age. Diabetes and hypertension are the most frequent causes of CKD in the United States.

We invite you to attend our second conference which is part of a two-year project to engage stakeholders as we address the impact and burden of CKD and ESRD in Delaware. Patients and their supporters, providers, payers, researchers, and policy makers are all encouraged to attend this event.

DATE: Friday, September 15th
TIME: 8:00 am to 1:00 pm (Registration opens at 7:30 am)
LOCATION: John H. Ammon Medical Education Center at Christiana Hospital

Please join us as we work together to address CKD and ESRD. Together, we will make a difference.

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Supportive and Palliative Care Education and Outreach was our guest speaker in April and led a thoughtful discussion on palliative care in the context of end-stage renal disease.

He defined palliative care and explained the difference between palliative care and hospice. He emphasized that palliative care was appropriate at any age and at any stage in a serious illness and could be provided along with curative treatment. He highlighted the importance of Advanced Care Planning and of documenting Advanced Directives and described the Delaware Medical Orders for Scope of Treatment program, which is designed to improve the quality of care people receive at the end of life by translating patient goals and preferences into medical orders (http://delawaremost.org).

We concluded our town hall/open forum series in May with a wonderful presentation from Anahi Santiago, the Chief Information Security Officer at Christiana Care, about confidentiality and safety of data. We learned that healthcare was the most attacked industry worldwide and in the US. She also emphasized that hackers target people not technology, and that they trick us into revealing passwords and personal identifiers. As one of the participant stated: “This was an eye-opening discussion”!