

Patient-Centered Insights on Treatment Adherence and Social Determinants of Health in Patients with Autosomal Dominant Polycystic Kidney Disease

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Background

The Polycystic Kidney Disease (PKD) Foundation advocates, educates, and funds research for PKD, the most common genetic kidney disease in the United States (U.S.). PKD affects approximately 600,000 individuals¹. This study explores **patient treatment adherence among patients within the autosomal dominant polycystic kidney disease (ADPKD) population, while examining the influence of social determinants of health (SDOH)**. Understanding these factors is essential for creating effective treatment strategies, aligning with Healthy People 2030’s recognition of SDOH’s impact on health outcomes².

Methods

The study, conducted online via an online survey and the ADPKD Registry, used an **SDOH framework to investigate factors affecting treatment adherence among individuals diagnosed with ADPKD**. Approved by an Institutional Review Board (IRB), this study includes U.S. residents with an ADPKD diagnosis and self-reported engagement in various treatment(s) such as diet and lifestyle interventions, non-kidney related medications, kidney related medications, dialysis, etc.

Conclusions

The study, comprised of primarily non-Hispanic, white, female, and pre-transplant participants, **identified key treatments that the ADPKD population engages in** such as diet and lifestyle interventions, and medications for kidney and non-kidney related conditions. 23% of the study participants cited experiencing **at least somewhat of an economic burden** from PKD-related medical costs. The findings emphasize the importance of the **SDOH framework** and **affordable healthcare** to enhance care for individuals diagnosed with ADPKD.

References

1. PKD Foundation 2. Office of Disease Prevention and Health Promotion. Social Determinants of Health. Social Determinants of Health - Healthy People 2030.

Data

Table 1: Cohort demographics

	Full Cohort n=396	% of Full Cohort
Age (avg)	55.85	
Gender		
Male	98	25%
Female	292	74%
Non-binary	4	1%
Transgender male	2	1%
Transgender female	0	0%
Race		
Caucasian	374	94%
Black or African American	6	2%
American Indian or Alaska Native	3	1%
Native Hawaiian or other Pacific Islander	0	0%
Asian	10	3%
Prefer not to answer/ Unknown	10	3%
Ethnicity - Hispanic or Latino		
Yes	23	6%
No	373	94%
Kidney Transplant		
Yes	110	28%
No	284	72%
Unknown	2	1%

Figure 1: Are you currently being treated by a physician for PKD? If so, where?

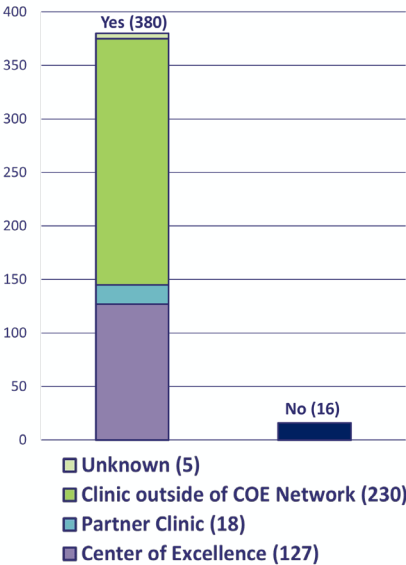


Figure 2: Do you take part in any of the following treatments for your PKD (select all that apply)?

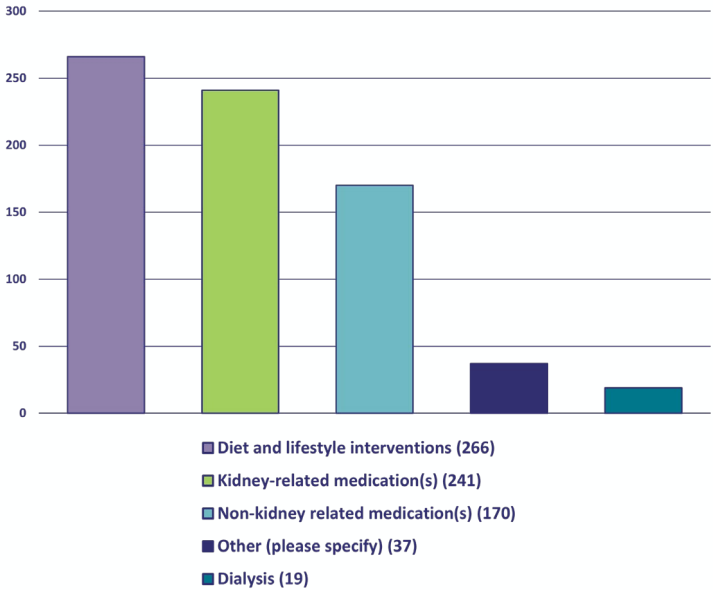


Figure 3: Have you ever been told by your doctor that you have any of the following extrarenal manifestations (select all that apply)?

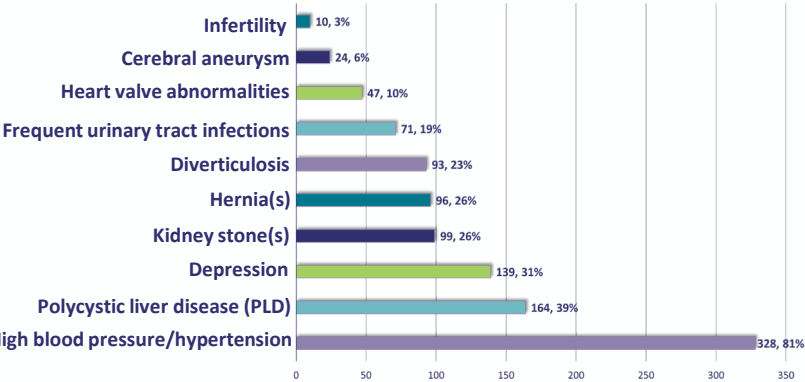


Figure 4: Have your PKD-related medical costs been an economic burden to you over the past year?

