

Treatment Adherence in Young Adults Receiving Kidney Replacement Therapy

A Caregiver Perspective

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Introduction

We commend the authors of the recent *Clinical Journal of the American Society of Nephrology* publication entitled “Associations with wellbeing and medication adherence in young adults receiving kidney replacement therapy” (1) for examining the challenges of young adults (ages 16–30 years old) as they navigate typical teenage struggles as well as the stresses of early career environments with the extraordinary added burden of dialysis or kidney transplant management. Psychosocial wellbeing of young adults struggling with ESKD is grossly ignored in the frenetic setting of nephrology clinical care. Fostering this understanding among all parties involved in patient care is paramount in addressing the epidemic of medication nonadherence.

Children younger than 16 years old with those same hardships are tasked with handling physical and social growth without any baseline understanding of normalcy. As caregivers to children who presented with ESKD as toddlers, enduring several hundred hospitalizations and therapies and culminating in live donor kidney transplants, we offer a unique perspective on psychosocial factors in children receiving kidney replacement therapy. Past psychosocial studies propose that personality and behavioral traits are developed during the early years of childhood (2). We suspect that children who have experienced prolonged medical trauma may be at increased risk of struggling with medication adherence as they mature. In this study, however, those diagnosed as children had higher acceptance rates of their condition, which translated into lower nonadherence rates. We suggest that longitudinal research of these younger patients (albeit, a small population) may also show decreased medication adherence over time.

An observation that we noted in this study’s theoretical model of factors associated with medication adherence was the lack of consideration that some of the medications themselves could cause difficulty in adherence. Some frequently prescribed antirejection medications result in a host of other side effects. These include the very real potential for severe neurotoxicity and a cognitive “fog.” We have directly

observed changes in behavior and intellectual abilities of young patients with kidney disease as new medications were introduced and suspect that these may negatively affect patients’ ability to comply with their complicated treatment regimen over time.

As this research suggests, many psychosocial factors play a role in each patients’ wellbeing and medical adherence. Therefore, clinics must create an environment where psychological health is consistently monitored and addressed and where patients and their caregivers are given tools to advocate for themselves. This study is a wonderful start and can be used as a stepping stone to further understand how patient environment effects future care.

About the Authors

P.D. is mother to Lindsey (age 16 years old). Lindsey’s kidney journey began “out of the blue” at age 2 years old with proteinuria, edema, and an initial diagnosis of minimal change with mesangial proliferation. Over the course of 8 years, Lindsey experienced 172 hospitalizations and countless toxic medication combinations with side effects resulting in lumbar compression and the need for a wheelchair. Her third biopsy confirmed idiopathic FSGS. At age 8 years old, Lindsey was enrolled in a National Institutes of Health study as a final effort to save her native kidneys. Lindsey underwent 14 infusions of rituximab over 13 months. After continuous relapses when B cells would repopulate, it became apparent that her kidneys were too scarred, and she proceeded to a bilateral nephrectomy. Subsequently, she experienced hemodialysis followed by peritoneal dialysis for 1 year. In 2012, Lindsey received a live donor kidney from her father, and gratefully, the FSGS did not recur. She has become an ardent advocate for children with CKD and pediatric transplant needs. P.D. is currently employed by The Johns Hopkins Hospital Comprehensive Transplant Center and serves on the Patient Family Partnership Council of the Kidney Health Initiative (a public/private partnership to advance scientific understanding of kidney health and foster development of kidney therapies).

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K.H. is mother to Macy (age 12 years old), whose journey with FSGS began at age 3 years old when she presented with severe edema. Macy was initially steroid dependent, but after months of high doses, she became steroid toxic and did not respond to any second-line therapies. ESKD came quickly, with an average protein-to-creatinine ratio of 45 and daily albumin infusions. At the age of 5 years old, Macy received a bilateral nephrectomy, began peritoneal dialysis, and received a living donor transplant. Unfortunately, FSGS recurred within hours of transplant, but she was able to obtain remission about 1 year post-transplant. Macy continues her battle with a fighting spirit and an incredibly strong kidney. Despite chronic pyelonephritis, frequent hospital stays, and 18 daily medications, her transplanted kidney still has 40% function after 7 years! Kelly is currently employed by NephCure Kidney International, where she serves as the Manager of Patient Engagement and supports patients and caretakers living with nephrotic syndrome.

Disclosures

None.

References

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See related Patient Voice editorial, "Treatment Adherence in Young Adults Receiving Kidney Replacement Therapy: A Patient Perspective," and article, "Associations with Wellbeing and Medication Adherence in Young Adults Receiving Kidney Replacement Therapy," on pages 1613–1614 and 1669–1679, respectively.