

# Treatment Adherence in Young Adults Receiving Kidney Replacement Therapy

## A Patient Perspective

Amanda Grandinetti

*Clin J Am Soc Nephrol* 13: 1613–1614, 2018. doi: <https://doi.org/10.2215/CJN.11230918>

### Introduction

The care of the young adult and adolescent population of patients on kidney replacement therapies remains a large gap in care in nephrology. Young adults and adolescents experience changing social roles, self-identify, and biology (1). These changes can provide a unique set of challenges for the nephrology care team and patient. The set of particular challenges can be even greater in young adults and adolescents undergoing dialysis or with kidney transplant, because these modalities require many change-in-life patterns. Support services for the young adults and adolescents population are critical, because these patterns often manifest themselves into how patients will take care of themselves in the future. It is also a must to provide age-appropriate care and effective intervention (2). Often times, young adults and adolescents receive the same care as middle age or older adult patients.

I was 14 years old when I was diagnosed with FSGS. It was my first year of high school. I experienced a multiyear long and difficult road to get into remission. It was during this time that I realized that young adults and adolescents are treated in the same fashion as adults. No one ever talked to me about what my disease meant. Was I going to die? Would I be able to go to college? Would it ever get better? At 14 years old, I was just discovering myself and figuring out who I was. Navigating an extremely difficult disease was not part of my plan, but I had to make it part of my life if I ever wanted to be healthy. My kidneys failed at 22 years old during my last semester of my undergraduate degree, and I was placed on hemodialysis. It shook my entire world. Adjusting was incredibly difficult. I had to change all of my classes, take a break from my job, live at home, shower differently, and see my friends less (to name just a few!). I realized during my time at the hemodialysis clinic that I was being treated exactly the same as the woman who sat to my left who suffered from a stroke and was completely bedridden and the same as the man in front of me who was 65 years old with grandchildren. Why was I there? There were things I wanted to do, and I had a life that I wanted to live. I sat miserable in the clinic until I switched to peritoneal

dialysis. Peritoneal dialysis changed my entire life. Although it was not easy, I had more freedom to live the life that I wanted. I was able to go to graduate school for public health, go out later with friends, eat and drink more, and shower like a “normal” person. I wanted to take care of myself by myself. I did not want anyone touching my catheter or connecting me to a machine. Taking charge of dialysis was one of the most important decisions that I ever made. I was a much happier person, and my quality of life increased dramatically, despite needing more surgeries and having a longer dialysis treatment. The cost of taking care into my own hands was invaluable. Eventually, in 2014, I received a living kidney transplant from my best friend. My kidney has worked at 100% since, and the FSGS has never returned.

Hamilton *et al.* (3) sought to discover psychosocial behaviors correlated with treatment adherence in young adults and adolescents requiring kidney replacement therapies. The study design was a cross-sectional online survey with validated questions from the Warwick–Edinburgh Mental Wellbeing Scale and the Morisky Medication Adherence Scale. The study included 417 patients between the ages of 16 and 31 years old. Among these, 417 had transplants, and 173 required dialysis. Worse outcomes were associated with psychologic morbidity, comorbidity, Asian and black ethnicities, being on dialysis, and finishing full-time education at a younger age. Improved outcomes were associated with social support, living with parents, conscientiousness, greater access to the care team, patient activation, being a boy/man, and being 16–21 years old.

There were many strengths of the publication by Hamilton *et al.* (3). The study was multicenter and included the use of scales to gather data on psychosocial aspects in a gap of care population. Additionally, interoperability between study data and a registry eliminated potential bias and further validated the data. The study included sufficient power. A limitation was that the cross-sectional design cannot establish pathways of outcomes. Other limitations were that the two populations were not comparable in size. The transplanted population was significantly larger than the dialysis population. Establishing a larger group of young patients on

### Correspondence:

Amanda Grandinetti,  
MPH, Elmhurst, IL.  
Email: [grandinetti@gmail.com](mailto:grandinetti@gmail.com)

dialysis will facilitate the opportunity of finding age- and goal-appropriate dialysis modalities in this population.

### Discussion on Clinical Implications

It is important to continue establishing correlations between psychosocial factors and treatment adherence in young adults and adolescents, because they can lead to a greater quality of life in this population. Understanding the challenges faced by young adults and adolescents can increase graft survival and decrease dialysis morbidity and mortality.

### Transition of Care Centers

The data discovered in this study should be used consciously when evaluating young adults and adolescents in clinical practice. Further research on psychosocial factors should be conducted so that data can be implemented into the increased development of transition care centers for young adults and adolescents. Transition centers may decrease the apparent health disparity in this population. Transition of care programs promote care collaboration networks within the nephrology department and other specialties that work with young adults and adolescents on many aspects of transferring their health care from the caretaker to themselves. These programs should address biologic and psychologic aspects of care and ideally, take several years to help the patients adjust their care. The transition should begin slowly and move gradually until the patients are ready to entirely take care of themselves.

Young adults and adolescents experience a unique set of challenges that may be hard to navigate. The use of transition of care facilities should be implemented to provide a smooth transition to self-care. Research in the young adults and adolescents population and the use of transition of care for kidney disease has become promising in recent years (4).

The creation, implementation, and evaluation of young adults and adolescents care transition centers need to be further executed into a standard of care, because they provide an important introduction to self-care. Further evaluation of care transition centers is imperative to increasing better outcomes and health care satisfaction in young adults and adolescents.

### Fostering Patient Activation and Care Satisfaction

It is important for the physician to develop an individualized relationship with young adults and adolescents. Social support and living with family were associated with better outcomes in the study. Building rapport between the physician and patient will foster the trust and communication pathway. Communication information should be given to the young adults and adolescents after the care transition has begun. This information should include direct lines to the clinic and if possible, any information technology platforms, such as phone applications (MyChart, etc.). Providing a media platform that can be accessed *via* phone may encourage newly transitioned patients to communicate more often with and directly to the care team.

Honest conversation regarding the disease state should be a required discussion during the outpatient visit. Patient beliefs can manifest into how patients care for themselves. It is imperative for patients to understand their disease state so that they may choose an effective intervention. A young adult or adolescent who is starting his or her own family may choose to have a different treatment modality than a young adult or adolescent who is just beginning high school. Understanding the patient's goal will increase satisfaction and treatment adherence.

### Social and Familial Support

The transition program should include information in which the young adults or adolescents can communicate together with their former caretakers. A clearly defined role of the caretaker in the transition program should be included. The habits of the caretaker are changing alongside the habits of young adults and adolescents, and this should be addressed. Caretakers may experience anxiety or other fears after the implementation of care is placed onto the patient, which may cause stress or lack of adherence to the patient.

### Psychologic Wellbeing

Psychologic morbidity was an important outcome in the study. Young adults or adolescents should be regularly screened for psychologic morbidity, because these conditions are treatable with cognitive behavioral therapies and/or medication. Cognitive behavioral therapy can also facilitate the creation of healthy habits and conscientiousness, which further medication adherence. Conscientiousness was also an important outcome in the study.

### Conclusions

Differentiation of the nephrology care that young adults or adolescents receive from that of the adult population is critical. The adolescence and young adulthood time period is a crucial stage in development of the self. The habits formed during this time period may create habits that last a lifetime. Patient goals further activate the patient, which will increase treatment adherence and quality of life.

### Acknowledgments

A.G. is a member of the Kidney Health Initiative's Patient and Family Partnership Council.

### Disclosures

None.

### References

1. Kreuzer M, Prüfe J, Tönshoff B, Pape L: Survey on management of transition and transfer from pediatric- to adult- based care in pediatric kidney transplant recipients in Europe. *Transplant Direct* 4: e361, 2018
2. Javalkar K, Fenton N, Cohen S, Ferris M: Socioecologic factors as predictors of readiness for self-management and transition, medication adherence, and health care utilization among adolescents and young adults with chronic kidney disease. *Prev Chronic Dis* 11: E117, 2014
3. Hamilton, AJ, Caskey FJ, Casula A, Inward CD, Ben-Shlomo Y: Associations with wellbeing and medication adherence in young adults receiving kidney replacement therapy. *Clin J Am Soc Nephrol* 13: 1669–1679, 2018
4. Kreuzer M, Prüfe J, Oldhafer M, Bethe D, Dierks ML, Mütter S, Thumfart J, Hoppe B, Büscher A, Rascher W, Hansen M, Pohl M, Kemper MJ, Drube J, Rieger S, John U, Taylan C, Dittrich K, Hollenbach S, Klaus G, Fehrenbach H, Kranz B, Montoya C, Lange-Sperandio B, Ruckbrodt B, Billing H, Staude H, Heindl-Rusai K, Brunkhorst R, Pape L: Transitional care and adherence of adolescents and young adults after kidney transplantation in Germany and Austria: A binational observational census within the TRANSNephro trial. *Medicine (Baltimore)* 94: e2196, 2015

Published online ahead of print. Publication date available at [www.cjasn.org](http://www.cjasn.org).

See related Patient Voice editorial "Treatment Adherence in Young Adults Receiving Kidney Replacement Therapy: A Caregiver Perspective," and article, "Associations with Wellbeing and Medication Adherence in Young Adults Receiving Kidney Replacement Therapy," on pages 1615–1616 and 1669–1679, respectively.