

Building the Bridge:

Social Workers Are Needed for Transitional Work with Pediatric Renal Patients

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Recent communications with some pediatric-onset renal disease patients who are now under the care of internal medicine care providers have provided the following frustrations and discouragements about the transition from childhood to adulthood:

“I think that doctors do not do enough to prepare you for the realities of adulthood. I have been engaged for over three years and cannot get married because of insurance. Because of the enormous cost of my medical bills I have had to continue on my father’s insurance. I cannot afford to do anything else. I am 26 years old, cannot work, go to school or get married because of this disease. It has taken every part of what should be a normal life.”

“At the age of 15, I grew up fast learning that I would most likely only live to the age of 30; half my life was over. Emotional support was essential to my survival through high school and even now.”

“My disease was very difficult for me to understand, even as a college student. Liaisons that could have helped me to better understand my disease, what it meant to me, and how it would affect my life would have been invaluable”

“Whatever anybody thinks, any kind of help would improve transitions.”

The above quotes reflect the many psychosocial and societal issues children and young adults have as they grow up with chronic kidney disease. New technologies and better preventive care for both adults and children with chronic diseases have significantly prolonged life expectancy, meaning that more individuals are making the transition from childhood to adulthood with pediatric-onset diseases. Based on United States Renal Data System data, the vast majority of adolescents with chronic kidney disease (CKD) are expected to survive into adulthood, with a 10-year survival rate for transplant recipients of 85.6% and for those on dialysis of

66.9%.¹ With this expectation for patient survival, the period of transition from traditional, pediatric-focused medical care model to an adult-oriented, self-management care model requires specific attention. Beyond medical management, these adolescents and young adults are expected to transition to employment, to insurability independent of the parents, and hopefully to a living environment independent of their parents. This transitional phase is clearly a complex process, and failure to transition smoothly can result in serious consequences.

Recent national interest targets this transition for children with chronic medical conditions. In kidney disease populations, it is not clear how adolescents with chronic kidney disease (CKD) navigate the complex pathway to independence. Traditional, prospective registries of children and adolescents with CKD stop data collection at age 18 and, in many cases, issues of disease self-management, insurance, employment and housing are not assessed. Of 43 manuscripts focusing on transition published between 1982 and 2003, only one was based on a kidney disease population.² This study was composed of primarily Caucasian kidney transplant survivors in the Midwestern United States.³ In all disease categories, the most frequently cited criteria for transfer to internal medicine medical care was age over 16 years, which is an arbitrary means for assessing transition readiness. In terms of program implementation for transitional patients, a meta-analysis of transitional programs for adolescents with a variety of chronic diseases found that the majority of research that has been done is exploratory in nature and lacking in measured outcomes.²

Helping teenagers and young adults begin to navigate their way through the adult health care system is beneficial, but there are not research results showing which programs work best and can be reproduced effectively. Optimal preparation, timing and methods in support of transition to self-management are all unanswered questions. Outcome measurements of existing or new programs must take place in order to create valid and reliable “best practice” models for transition services, which are sorely needed to enhance social work research and practice. Renal social workers have the opportunity and the responsibility to participate in the

development of evidence-based models for transitional care to strengthen and measure outcomes of these programs and to contribute rigorous, evidence-based research in the field of social work.

Social workers have a unique position in the world of transitional patient care, as the core concepts listed in the NASW code of ethics deal with strengthening relationships and respecting a client's autonomy and self-determination. Children with chronic illnesses like kidney disease need these tools of empowerment much more than normally developing children, as their path to adulthood is often strewn with more obstacles and pitfalls. Social workers who deal with renal patients can help make sure an adolescent patient's voice is heard as they begin to enter the world of adult medical care.

Formal links between pediatric and adult health care systems have been identified as key components for a smooth transition.⁴ Families may also need assistance, particularly the parents in "letting go" and helping their child become more independent. Social workers have the ability to act as a "bridge" between youth and families and between adult and pediatric providers to ensure that the patient's rights and autonomy don't get lost in the shuffle. Psychosocial services to assist with referrals to health insurance agencies, education, training, employment, rehabilitation, and community resources in a developmentally-appropriate fashion, are additional components to optimal transitions that social workers are trained to provide.^{5,6} Further work and research in this area is needed.

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