

Mini Review

Transition of Care for Adolescent Kidney Transplant Recipients

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Abstract

Successfully transitioning the care of adolescents with chronic illness to adult providers is an important, yet often challenging, aspect in the care of these patients. In renal transplant recipients in particular, there is concern that the transfer of care of adolescents might increase rejection rates in a population that is already known to have an increased risk of non-adherence to medical therapy. The purpose of this brief review is to provide a definition of transition, to determine some of the potential risks associated with the transfer of care, and lastly to discuss important aspects of a successful transition process.

INTRODUCTION

Taking care of adolescents is recognized as a challenging area in pediatrics. As the transition is made from childhood to adulthood, adolescents are expected to develop autonomy and decision-making capabilities at a level sufficient to carry out the responsibilities for their own health. The transition from childhood to adulthood is especially challenging for children with chronic illness, and they may experience difficulty and anxiety related to leaving their familiar pediatric medical home, often equipped with extensive support services, to enter a strange and anonymous world where they suddenly assume much more responsibility for their wellbeing. At the same time, guardians and physicians who have long-cared for these patients are faced with the anxiety of having to let go, exacerbated by the knowledge of potential risks associated with the transition period. Pediatric nephrologists specifically worry about the risk of non-adherence in patients not ready to assume responsibility for their own care, as this may result in allograft rejection or failure. In order to give patients the best chance of successfully managing their illness in the long-term, providers of adolescents with chronic disease are obligated to transition them to adult-centered care in a gradual and supportive fashion. This brief review will go over the definition of transition; address risks associated with the transition period for kidney transplant recipients; and discuss methods that may overcome some of the obstacles, recognizing that the optimal approach to transition of care remains to be determined.

Definition

The concept of transition is defined as the "purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented

health care system" [1]. A consensus policy statement on health care transition approved by the boards of the American Academy of Pediatrics, the American Academy of Family Physicians and the American College of Physicians-American Society of Internal Medicine defined the goal of transition "as is to maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood" [2].

As the rate of pediatric kidney transplantation is steadily rising, an increasingly larger number of adolescents will make the transition from pediatric to adult nephrology clinical care after transplant. The goal of transition for pediatric renal transplant recipients is to provide supportive care appropriate to the individual patient in order to maximize the potential longevity of their renal allograft.

Adherence-related Issues in Adolescent Renal Transplant Recipients

Renal allograft survival has improved markedly with the use of more potent immunosuppressive therapy, however much of the success is in short-term survival and improvements in long-term survival remain challenging [3,4]. Non-adherence to medication regimens plays an important role in poor outcomes [5]. Adolescents have higher prevalence of immunosuppressive medication non-adherence than young children and adults, with an estimated prevalence of 32% in adolescent renal transplant recipients [6]. Many factors have been identified that are associated with increased rates of non-adherence in this population. These include socio-economic factors, such as low socioeconomic status and family instability; psychological factors including psychological distress, risk taking behavior and

poor understanding of disease and reasons for medications; and treatment-related factors including the side effect profile of the medications [6-8]. The healthcare team should be cognizant of modifiable factors that are associated with improved adherence, such as knowledge of medication regimen, so that education is incorporated into the clinical visits [8]. Pertinently, the healthcare setting and the relationship between the health care provider and the patient is a critical factor in medication adherence [6]. As such, it would seem that without a transitional process in place, the transfer to adult care would increase the risk of non-adherence in adolescents.

Potential for improved outcomes with a transition system

Whether the transfer process itself leads to decreased allograft survival is not clearly supported by the existing literature, and discrepancies may have to do with variability surrounding transfer of care at individual institutions. Watson et al reported a high rate of unexpected graft loss within 36 months of transfer from a pediatric to adult unit [9]. However, Kiberd et al examined allograft survival in pediatric patients transferred to an adult center at age 18 as compared to young adults (18-<25 years) and adults (25-35 years) who were both transplanted and followed at an adult center. The cohort transitioned to the adult center had similar allograft survival to the young adult group, but survival of both groups was inferior to the adults. As the authors point out, missing from this study is a comparison to pediatric patients above 18 years of age who remain at a pediatric center for care [10]. Similarly, Koshy et al, in a single center retrospective cohort study of pediatric renal transplant recipients, did not find increased allograft failure during the ages where patients were transitioned [11]. Despite the variability in the above reports, there is room for improvement in the transition process. In a prospective analysis of renal transplant recipients transitioned at a single center in British Columbia, patients who attended transitional clinics had improved allograft and patient survival compared to historical controls [12]. Transitional clinics were further found to be economically feasible in this study.

Important aspects of transition

Ideally, transition represents a stepwise process that involves close collaboration between pediatric and adult physicians. It is important that a transition plan be in place that the patient is made aware of well in advance and that there be a clinician lead for transition in both the pediatric and adult clinics [13]. During the transition, adolescents' educational/ vocational, social, and psychological needs should be explored and addressed.

Assessment for readiness for transition is critical. The timing of transfer should be individualized rather than based strictly on chronological age [14]. Depending on the readiness of the individual, the preparation should start in pre-adolescence by encouraging the patient to be more actively engaged in their care and assume some degree of independence [15]. Renal transplant recipients should achieve certain milestones prior to transfer of care, as proposed by Bell et al, which include: understanding of their cause of renal failure, awareness of both short- and long-term implications of their transplant condition including impact on reproductive health, demonstration of a sense

of responsibility for their care, ability to provide most care independently, and expression of readiness for transition [16]. Patients as well as new providers should be provided written medical summaries [17].

Transition clinics for transplant recipients have been proposed as a bridge between the pediatric and adult health systems, during which time they can acquire readiness skills for transfer. Proposed models vary, but share the common theme of collaboration between child-centric and adult-centric providers, such that providers learn from each other and factors unique to the adolescent patients' health are addressed. General themes that seem important in transition clinics are discussed below [12,15,16,18].

Having a specific transitional nurse who is knowledgeable with adolescent psychology and familiar with the adolescent challenges is important. The transitional nurse serves as the primary educator and provides support to the patient and families as patients acquire autonomy, and as parents and pediatric nephrologists gradually let go. Education includes matters relevant to immunosuppressive medications and transplant-related complications. There is an emphasis on compliance, recognizing signs and symptoms of rejection, infection, and dehydration. Other important health aspects are addressed including education on matters related to sexuality, fertility, contraception, and teratogenicity related to certain medications. Additionally, risks associated with recreational drugs, alcohol and tobacco would be explored. Patients additionally receive education related to general health and wellbeing, including weight control and exercise, use of sun protection, cancer screening and immunization.

To support autonomy, patients are encouraged to take responsibility for making appointments, getting refills on their medications and allowed decision making while being supervised in a protected environment.

To support compliance, various methods may be considered and individualized including the use of medication diary or flow sheet, pill boxes, and cell phone alarms. Additionally, accessibility to the health care team should be ensured via methods of emailing, text messaging, or telephoning the team, as appropriate.

Health insurance in adults is another very important issue that must be addressed during the transition as children lose their insurance coverage that they have either through their parents or through the state. A social worker knowledgeable of available resources is an integral part of the transitional process.

Additional information

In closing, a carefully planned approach to the transition of renal transplant recipients from pediatric to adult care is important to ensure the best possible long-term outcomes. More information can be found through the National Alliance to Advance Adolescent Health, which is a non-profit organization that provides education, research, policy analysis, and technical assistance to improve health care for adolescents, and received a 5-year award to operate the Center for Health Care Transition Improvement in order to expand the availability of effective health care transition support. The following website: www.

gottransition.org is an excellent resource for transition tips and tools representing the Center for Health Care Transition Improvement, and is geared towards health care professionals, patients, families, and health policy makers. A link to other useful websites can be found on the website for the American Society of Transplant.

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