Educational Needs of Young Adult Renal Transplant Recipients

Subjects: Transplantation | Urology & Nephrology

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Renal transplantation is the gold-standard treatment for adolescents and young adults with end-stage renal disease. Despite enjoying excellent short-term outcomes, they suffer the worst rates of premature transplant function loss. Health behaviors: such as lack of adherence to immunosuppressive medications, are felt to be the major contributory factor. Understanding the educational needs of young renal transplant recipients allows healthcare practitioners to better support patients in managing their chronic disease.

kidney transplant adolescent young adult

1. Introduction

Children on hemodialysis have a reported 55-fold increased mortality risk compared to the healthy population of a similar age [1]. Cardiovascular disease mortality accounts for 40% of deaths of young adult end-stage renal disease (ESRD) patients (500 times increased risk compared to the general population) [2]. Renal transplantation is the ‘gold-standard’ renal replacement therapy available to patients who reach ESRD providing significantly longer quantity and quality of life to patients [3]. Transplantation has been consistently shown to dramatically reduce mortality in patients with ESRD, with some studies reporting a reduction in up to 84% [4].

For young people, the benefits of transplantation are multiple and diverse and go beyond the excellent survival benefits. The overall accrual of disease burden is significantly less than when on dialysis, and a functioning transplant graft facilitates normal growth and development [5]. Young adult transplant recipients report increased exercise tolerability [6], better energy, and an enhanced sense of wellness compared to when receiving dialysis therapies [7]. Transplantation offers young people a less disrupted education and allows them to engage more fully in the workplace [8].

Despite the overwhelming benefits of transplantation, it is also associated with challenges. Many young transplant recipients (up to 30%) show symptoms in keeping with post-traumatic stress disorder (PTSD) after transplantation [9]. Patients can have body-confidence issues due to scars related to the operation [10]. Recipients also must become accustomed to attending regular appointments and adhering to a strict medication regimen whilst dealing with the complications associated with long-term immunosuppressive therapies (some with obvious early manifestations such as weight gain and acne seen with steroids) [11].

Adolescents and young adults enjoy better short-term outcomes following renal transplantation than any other age group [12]. Despite better initial outcomes, later rates of graft loss in adolescents and young adults are the highest of all age groups [13]. The mean survival of transplant grafts has been reported to be 7 years in younger recipients [14] compared to 10.4 years in all recipients from deceased donors [15]. This means that 50% of patients who have been transplanted in childhood will require a second transplant before reaching 25 years of age [16].

Albeit complex and multifactorial, the reason for the high rates of transplant graft loss in this group is often attributed to health behaviors and lack of adherence to prescribed therapies [17]. Adolescents and young adults have a higher rate of non-attendance to transplant appointments where monitoring and interventions to prolong graft function can be planned [18]. They also have higher rates of admission for transplant-related problems via emergency departments suggesting late presentation with complications—making recovery of transplant function more difficult [19]. Premature loss of a renal transplant is associated with increased mortality, increased morbidity, increased mental health problems, and decreased quality of life [10]. Finding a second suitable kidney for transplantation can often be difficult in this population due to the development of antibodies, and if compliance is suspected to be an issue, clinical teams can be wary of putting patients forward for subsequent transplantation [20]. Hence, young people with failed transplants often wait for long periods of time for a second transplant and are typically disproportionally represented in the suspended transplant waiting list [21].

2. The Needs of the Disrupted Youth

Some young transplant recipients appear to face substantial delays in their education, and their levels of qualifications are lower than their peers [22]. The disruption to educational attainment is particularly marked by already vulnerable groups, such as those from ethnic minorities or those belonging to lower socioeconomic groups [8]. Those who do achieve high educational and professional attainment are more adherent to immunosuppression medications and are at a reduced risk of developing depression or anxiety [8].

Studies also investigated how disruption to their youth impacts young transplant recipients meeting major psychosocial milestones [22]. Young adult transplant recipients remain living with their parents at much higher rates than their peers and appear to be delayed in developing romantic relationships [23]. The delay in reaching psychosocial milestones in young transplant recipients reduced their sense of autonomy, their satisfaction with life, and their own attitudes to health [24].

Researchers suggest that young people who are supported to reach their full potential (either professionally or personally) seem to enjoy additional protection from anxiety and depression and even have better clinical outcomes, such as improved transplant function [25].

3. The Needs of the Disorganised Youth

The selected studies focusing on the importance of young transplant recipients developing organizational skills, engaging with their health, and having self-motivation as they hypothesized that this would lead to better transplant

and overall health outcomes.

The largest reported barrier to developing self-reliance skills in recipients was a lack of knowledge and understanding of their condition and medications. Studies described how recipients feel disengaged with their own health and often are disempowered due to a lack of health knowledge [26]. Those who were transplanted at a young age were at the most risk of having insufficient health knowledge as education efforts at the time of transplantation were directed at their parents [27]. When recipients begin to take increasing responsibility for managing their own health, they often feel overwhelmed and underprepared and are subsequently more likely to partake in health-risky behaviors [28].

Many young adult transplant recipients lack coping mechanisms or strategies to help them deal with the extra organizational burden of being a transplant patient [23]. Researchers investigated barriers to the normal development of these important traits and skills in young transplant recipients. A lack of, or disruption to, the routine was suggested to be detrimental to recipients' organizational skills acquirement. Periods such as weekends, leaving the family home, or transitioning from pediatric to adult health services were associated with reduced compliance to medication and were highlighted as times when support was most required [29]. Good family support and help in developing organizational skills, particularly with taking medications, were protective against poor health outcomes [30][31].

This transition from dependent child to independent adult often leaves recipients feeling unprepared, uninformed, and unable to become fully responsible for their health—increasing their risk of complications, especially around clinic attendance, blood sampling, and medication compliance [32].

4. The Needs of the Distressed Youth

Studies showed that young transplant recipients craved "normality" and wished to be viewed as similar to their peers [27]. Some young recipients had a level of disappointment following transplantation as they still did not feel "normal" and were unprepared for those emotions following transplantation [30]. Body image issues were commonly investigated by researchers [14], as were the side effects of medications related to transplants [33]. Young transplant recipients often reported high levels of depression and anxiety related to physical signs/symptoms related to transplantation and poor coping mechanisms to deal with this psychological burden [26].

Studies consistently demonstrated recipients reporting symptoms or diagnostic signs of anxiety, depression, irrational anger, and even post-traumatic stress disorder [31]. Psychological distress or a mental health diagnosis was the most important independent factor in predicting not only the quality of life of young recipients but also transplant-related health outcomes, such as graft survival [34]. Researchers found that young transplant recipients often have inadequate resilience or coping skills related to mental health [35]. The most deployed strategies observed in these young recipients were denial and avoidance (not wishing to talk about transplant/voice concerns). It was perceived that many young recipients had been inadequately prepared for the mental stresses associated with transplantation, were ill-equipped to be resilient to psychological stressors, and lacked sufficient

support when dealing with mental health problems [36]. Two studies reported young transplant recipients who have developed symptoms consistent with PTSD. Interestingly PTSD symptoms did not seem to be related to clinical factors (such as the severity of illness, time on dialysis, and risk of mortality) but related to a complex adjustment to the variety of subjective stressors (body image, lacking normality, childhood illness, family dynamics) faced by young recipients [37].

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