The increasing number of young patients is graduating from pediatric to adult care programs due to improved outcomes of chronic childhood diseases. However, the transfer of these patients from small, well-resourced pediatric programs to much larger adult programs is often poorly coordinated with a lack of integration between pediatric and adult services. In addition, a similar number of young adult patients (aged 16-30) present to adult care for the first time with end-stage kidney disease (ESKD). Young adult transplant recipients have an increased risk of non-adherence with immunosuppression, leading to late acute rejection and reduced 5-year graft survival.

Adolescence is a time of increasing independence, experimentation, and rebellious behavior, which may manifest as non-adherence and lack of engagement with medical services. An early graft loss is associated with educational, employment, and social failure. It is imperative to develop strategies targeted at improving transition and young adult services in an attempt to improve outcomes including graft survival.

Transition of teenage and young adults to adult care

ESKD is a significant but rare problem in young adults aged 16 to 30, with a prevalence rate of <50 per million population and representing approximately 5% of the adult ESKD population. Multiple national and international guidelines for the transition of young patients into adult care aim to ensure that these patients are assessed and adequately prepared for transfer to adult care in a coordinated care pathway. An important component of the transition process is that it should be personalized for each patient. Multiple factors including physical and psychological development and measures of self-care can be assessed using transition readiness scales. Ultimate transfer to adult care should occur at a time, which results in minimal social and educational disruption. Transition should be introduced early (aged 12-14), allowing time for the development of a personalized integrated care pathway. A nominated key worker, typically a social worker or a nurse, plays a valuable role in coordination of transition, providing ongoing practical assistance and advice throughout the process. An important component is an integrated transition service with joint pediatric–adult clinics involving participation from both pediatric and adult health care workers (Figure 1). This integrated approach allows the familiarization of the
transitioning young adult and his/her family with the future adult team. This results in reducing the anxiety that may be associated with changing to a new health care team and allows the development of vital trust with the adult team.

Transfer to adult care should be a collective decision made by the patient, family, and both pediatric and adult health care teams once the patient feels fully prepared to self-manage their kidney transplant. Optimally, the young adult patient should be seen in the adult service by a specialist team that has been involved throughout the transition process. This will ensure the continuity of care and allows the development of clinical trust between the patient and key health care workers required to ensure a smooth transition.

Young adults presenting directly to adult care
There has been greater focus in recent years in ensuring that patients transferring from pediatric to adult care are provided with appropriate support at a particularly difficult and vulnerable time. However, much less emphasis has been placed on the need for the support of young adult patients who present directly to adult services. Indeed, 52% of patients in a young adult renal disease population (aged 16-30) presented directly to adult care with progressive chronic kidney disease or ESKD, whereas 48% transitioned from pediatric care. Young adults presenting directly to adult care often have major issues with coming to terms with the shock of discovering their renal failure. This frequently results in periods of denial, which may manifest as disengagement from medical treatment. Frequently, these patients struggle to integrate dialysis or transplantation into their daily lives, resulting in high rates of non-adherence with therapy and immunosuppression. This is compounded by isolation from interaction with peers of a similar age with ESKD, and a frequent struggle to attain their education and employment goals.

Strategies to overcome poorer outcomes in young adult transplant recipients
Specialized young adult clinics are a useful way to catalyze interaction between patients of a similar age, enabling peer support and encouraging the rebuilding of self-esteem and confidence. We have developed a comprehensive young adult transplant service for 16- to 30-year-old patients, comprising a community-based young adult clinic with targeted peer group interaction facilitated by a youth worker both pre- and post-transplantation (Figure 2a). In addition, the youth worker provides 1:1 support for many of the young adult patients directly in their community. This can be a very effective way of helping with immunosuppression adherence through the simplification of the drug regimen to once daily dosing, use of dosette boxes, and daily mobile phone alarms to remind the patient to take his/her medication (Figure 2b).
INTEGRATED MULTIDISCIPLINARY CARE

special communication

Figure 2. A) Multiple team sports, including football, squash and badminton are initiated by youth worker at young adult clinics within the community. This facilitates peer interaction, confidence building and rebuilding self-esteem. B) One-on-one peer support with a youth worker can provide advice on immunosuppression adherence, dosette box use as well as identifying problems a patient has that have yet to be identified by the clinical team.

Conclusion
Adolescence and young adulthood is a time of increasing independence, experimentation, and rebellious behavior, which may manifest as non-adherence. Transition from pediatric to adult care is associated with an increased risk of late acute rejection due to non-adherence with immunosuppression, leading to a 30% risk of transplant failure within 36 months of transfer to adult care.7

Early graft loss is associated with educational, employment, and social failure. Young adult patients presenting directly to adult care have major problems with denial and resultant non-adherence with medical therapy and attendance for outpatient care. The development of a dedicated young adult service that incorporates both transitioning patients from pediatric care and young adult patients presenting initially to adult care can lead to structured peer support and the maintenance of continuity of care. A vital component of the health care team is a youth worker who can act as a bridge between the young adult patient and the traditional medical team. This model has led to a 67% reduction in transplant failure associated with transition in our experience.6

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