### INVITED COMMENTARY

# We have to do more for former paediatric renal transplant recipients!

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Renal transplantation is the therapy of choice for endstage kidney disease (ESKD) in children and adolescents [1]. Patients, caregivers and physicians deem a successful transplantation as a highly rewarding and definitive treatment. With current cost-effective immunosuppression regimes [2] rejection rates are low, and the recipient can look forward to long-term graft survival. The main medical concerns are (i) prolonging allograft survival, (ii) preventing cardiorenal syndrome type IV [3] and (iii) preparing adolescents and young adults to successfully self-manage their condition as they transition to adult-focused services. Once the adherence challenges during puberty are overcome, these patients enjoy quite favourable outcomes including a normal height owing to the use of recombinant human growth hormone, both before and after renal transplantation [4]. The importance of final height was stressed in studies performed in Europe [5–7], China [8] and the USA [9].

However, social rehabilitation leaves a lot to be desired. Data on social rehabilitation suggest that a relatively large proportion (18.7%) receive disability pension and the rate of marriage is low, especially in males (27%), while 46% still live with their parents 15 years postrenal transplantation [4]. This information is quite old (patients were transplanted between 1973 and 1985), and there is hope that by now, these findings have improved.

Data on the health-related quality of life (HRQOL) are scant. In this context, we are delighted to see the study by Kira Endén et al. in this edition of Transplant International, entitled 'Lower quality of life in young men after pediatric kidney transplantation when compared to healthy controls and survivors of childhood leukemia - a cross-sectional study' [10]. Their study former paediatric renal transplant included 29 recipients, 52 survivors of childhood-onset acute

lymphoblastic leukaemia (ALL) and 56 age and gendermatched controls, during the period of 1983–2011. The renal patients received a transplant at the median age of 8.6 years, with a median post-transplant follow-up of 18.7 years and a median age at dialysis onset of 7.5 years. The strengths of their protocol include the study design with a 2:1 control to case ratio, the use of established surveys and a nationwide approach with a moderate response rate.

Endén *et al.* found a significantly lower HRQOL among kidney transplant recipients, compared to both control groups, particularly if they were older or had longer duration on dialysis, lower graft function and/or a greater number of retransplants [10]. The authors also found that compared to the control groups, the paediatric-onset kidney transplant recipients had more unemployment (24%); less biological children (10%) and were less likely to be in a permanent relationship (41%). Similar social outcomes were reported in the European, Chinese and USA cohorts previously mentioned. [5–9]

The study by Endén *et al.* reported that depression scores were significantly worse for former paediatric transplant recipients compared to the two control groups; especially if the patients had no life partner, biological children or were less educated or unemployed. Further, longer duration of dialysis was significantly and independently associated with lower HRQOL scores. Treating nephrologists can influence these scores, by pushing for earlier pre-emptive transplantation [11] and advocating for organ allocation systems that achieve higher priority for children and adolescents, particularly as about half of the children in the US are transplanted in less than 1 year [11].

Endén et al. also confirmed the importance of final height, similar to the findings by Broyer [4]. Despite the proven effectiveness of growth hormone supplementation, poor adherence to this treatment post-transplant has been reported from patient/caregiver and providers [12]. Moreover, even with significant advances in immunosuppression regimes [13], the long-term rehabilitation of these patients still leaves a lot to be desired. Ongoing efforts are needed to improve the social rehabilitation and HRQOL of our paediatric renal transplant

recipients. Potential interventions to improve HRQOL include pre-emptive transplantation, early listing for renal transplantation, consistent use of recombinant human growth hormone and stressing the importance of education or training to gain future employment. An interdisciplinary approach is mandatory to optimize outcomes beyond the paediatric years [14], however, transition to adult-focused care continues to be a major challenge [15]. There is a need for yearly assessments of self-management and/or transition readiness in both, the paediatric- and adult-focused settings [16] and for the allocation of similar ancillary resources in the young adult – focused clinics as those available in the paediatric settings.

We congratulate Kira Endén and colleagues on this important study. The use of survivors of paediatriconset ALL as a control group was an interesting strategy, as most of these survivors cancer have less medication and treatment burden compared to kidney transplant patients. Yet, the ALL survivors did not achieve the employment and life milestones rates of the healthy controls. In the public perception, cancer is a most challenging and life-threatening diagnosis that yields an enormous amount of public support. Cure rates for ALL are now consistently over 90% in developed countries [17]. By contrast, philanthropy support for ESKD is much lower, as there is a perception that successful transplantation constitutes a cure for ESKD. It does not; it just provides a better modality of renal replacement therapy. A public awareness campaign is needed to help raise more funds for research and services aimed at improving the long-term HRQOL and rehabilitation of children and adolescents with ESKD and ALL. This in turn will optimize the outcomes of these important patients and their families.

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### **Conflicts of Interest**

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