

INVITED COMMENTARY

Children first in kidney allocation: the right thing to do

Sandra Amaral^{1,2} and Peter P. Reese^{2,3,4}

- 1 Division of Nephrology, The Children's Hospital of Philadelphia, Philadelphia, PA, USA
- 2 Department of Biostatistics and Epidemiology, University of Pennsylvania, Philadelphia, PA, USA
- 3 Leonard Davis Institute of Health Economics, University of Pennsylvania, Philadelphia, PA, USA
- 4 Renal-Electrolyte and Hypertension Division, Perelman School of Medicine at the University of Pennsylvania, Philadelphia, PA, USA

Correspondence

Peter P. Reese MD, MSCE, Center for Clinical Epidemiology and Biostatistics, University of Pennsylvania, 917 Blockley Hall, 423 Guardian Drive, Philadelphia, PA 19130, USA.

Tel.: 215 900 3782; fax: 215 615 0349;

e-mail: peter.reese@uphs.upenn.edu

Conflicts of interest

The authors have declared no conflicts of interest.

Received: 24 February 2014 Accepted: 26 February 2014

doi:10.1111/tri.12296

In this issue of Transplant International, Capitaine et al. [1] attempt to undermine the ethical foundation that supports pediatric priority for kidney transplantation. In their analysis of fairness, the authors dismiss a rich and deep tradition of allocating scarce resources to children in order to give them lifetime opportunities to flourish. In their analysis of utility, the authors take an extremely narrow view of the relevant health and social impact that pediatric prioritization in organ allocation aims to achieve in children's lives. The authors understate the harm that prolonged exposure to dialysis causes to children and overestimate the benefit that the elimination of pediatric priority would provide for adults. For all these reasons, this piece should be viewed primarily as a provocation. The transplant community should uphold its commitment to pediatric priority.

Giving children precedence in kidney allocation is fair. Adults have experienced childhood, while sick children may never have that opportunity. Scarce medical resources should be invested in a way that gives sick children the chance to survive childhood and achieve a

diverse array of mature goals, such as employment or intimate relationships. This concept of equity - in various forms - has been articulated by leading ethicists including Alan Williams, who argued for "intergenerational equity." [2,3] Policies that prioritize children are also supported by the perspective that the allocation of scarce resources may favor the "worst-off." [4] Suffering end-organ disease during the unique window of childhood growth and development is sufficient reason to consider a pediatric kidney transplant candidate among society's most disadvantaged [5]. Further, international policymakers have identified the need to ensure "a good start to life for every child" as an important goal toward achieving health equity and protecting future generations [6]. As early as 1924, the Geneva Declaration of the Rights of the Child affirmed: "men and women of all nations, recognizing that mankind owes to the child the best that it has to give, declare and accept it as their duty that,... the child must be given the means requisite for its normal development, ... the child must be first to receive relief in times of distress,..." [7].

Despite this rich perspective from the fields of ethics and human rights, Capitaine et al. claim that young age is not a valid basis on which to classify pediatric kidney transplant candidates as truly disadvantaged, because age is a poor "proxy for opportunities for medical well-being." They cite social determinants as important contributors to opportunities for health. In their example, a pediatric endstage renal disease (ESRD) patient might be from a wealthy family and, therefore, more advantaged than an impoverished 25 year old also waiting for a kidney. This argument fails on multiple counts. First, all adults, even those who are poor and have suffered, have nonetheless enjoyed more years of life than all children. Second, age is an objective and verifiable personal characteristic that can be applied in resource allocation, while psychosocial characteristics such as social capital are difficult to quantify in any unbiased manner and are therefore of questionable value in allocation [8]. By pointing out that the category of "sick child" is not the only reasonable way to identify disadvantaged transplant candidates, Capitaine et al. do not undermine the validity of this category for organ allocation.

Next, focusing on utility, the authors reveal a very constrained view of the relevant long-term health impact for children with ESRD. They acknowledge that pediatric dialysis patients are less likely to complete their education. We would also point to the growing literature documenting deficits in attention regulation and executive function in children with even mild-moderate chronic kidney disease [9,10]. The authors note that "there is relatively strong evidence in support of major disruptions in growth after long-term dialysis in a child." Capitaine et al. do allow that dialysis comes at a high social cost to children. Erikson's psychosocial development theory emphasizes that the years of childhood are formative ones for intra- and interpersonal development [11,12]. Yet, despite these acknowledgements, Capitaine et al. claim that children with advanced kidney disease have good quality of life and therefore are not harmed by lost opportunities to grow, gain an education and become socialized.

We take a far broader view of human health than one limited to survival and overall quality of life. Consistent with the views of Amartya Sen and others, we consider growth, education, and socialization as intrinsic dimensions of human flourishing [13,14]. Moreover, consider the likely outcomes in a world without pediatric priority allocation. In the United States, the average child would wait for an organ alongside adults for over 4 years. A child could potentially remain on dialysis from age 2 to 6, or from age 10 to 14. These crucial years for human growth, socialization, and general psychosocial development cannot be compared with what happens to adults during, say, ages 50–54 years.

Capitaine et al. also draw attention to the high rates of allograft loss observed among adolescent kidney transplant recipients (but not among younger children) and cite "widespread noncompliance" as a cause. However, while poor adherence may contribute to adolescent transplant outcomes, it is also quite possible that biologic differences related to a maturing immune system heighten rejection risks in this group [15,16]. In either case, Capitaine et al. should be as focused on remedies to improve adolescent outcomes – such as more effective immunosuppression or behavioral health interventions - as they are on removing pediatric priority. Further, it is unclear that nonadherence rates are higher among children than among adults [17,18]. The authors need be wary of suggesting that potential for noncompliance be considered as an allocation metric because this approach would also raise the bar of transplant eligibility for adults who have developed kidney disease due to behavioral choices such as poor diet or smoking.

As an additional utility argument against pediatric prioritization, the authors point out that children will "often need several re-transplants to come close to normalizing [their] life expectancy." While repeat transplantation poses valid problems of fairness, this practice is a separate issue from pediatric prioritization (as most repeat transplant candidates are adults) [19]. Further, normalization of life expectancy is not necessary to show the major survival benefits of transplant (versus dialysis) in virtually all age groups.

Finally, Capitaine et al. argue that the implementation of policies that enhanced pediatric priority allocation (e.g., Share 35 policy in the US) led to decreased living donation rates. In fact, the decline in living donation preceded Share 35 and was evident even among adults [20]. Although Share 35 was a hypothesized contributor, multiple other factors, such as higher rates of diabetes and hypertension among potential living donors and an economic recession, occurred simultaneously [21]. Notably, the increase in deceased donor kidney transplants after Share 35 resulted in an increase in approximately 100 deceased donor kidney transplants annually "diverted" to children from 2005 to 2008 [22]. Given 46 000-50 000 active adult waitlisted candidates annually during those years, it is highly unlikely that this "pediatric diversion" heavily penalizes adults as the authors presume.

In summary, Capitaine *et al.* postulate that pediatric priority allocation is harming adults and providing questionable benefit to children. Fortunately, there is a solid and durable ethical foundation that supports our commitment to elevating the needs of sick children. The analysis by Capitaine *et al.* does nothing to undermine that foundation. If their piece succeeds in provoking the transplant community, it should provoke useful efforts – like the development of interventions to augment living donation

and support medication adherence. Such efforts are far more likely to be successful in achieving positive long-term and equitable transplant outcomes than attempts to do away with pediatric priority allocation. In the meantime, promoting transplant access and optimizing long-term graft and patient survival for children should remain international priorities.

Funding

Dr. Amaral was supported by a grant from the National Institutes of Health (K23-DK083529). Dr. Reese was supported by a Greenwall Faculty Scholars grant. Drs. Amaral and Reese are members of Organ Procurement and Transplantation Network (OPTN) committees that develop and review transplant policy in the United States. This study is their own work and does not necessarily represent the views of the OPTN.

References

- 1. Capitaine L, Van Assche K, Pennings G, Sterckx S. Pediatric priority in kidney allocation: challenging its acceptability. *Transpl Int* 2014; **27**: 533.
- 2. Williams A. Intergenerational equity: an exploration of the 'fair innings' argument. *Health Econ* 1997; **6**: 117.
- 3. Daniels N. *Just Health: Meeting Health Needs Fairly.* New York: Cambridge University Press, 2008.
- 4. Rawls J. A Theory of Justice. Cambridge: Belknap Press,
- 5. Veatch RM. *Transplantation Ethics*. Washington, DC: Georgetown University Press, 2002.
- 6. Marmot M, Allen J, Bell R, Bloomer E, Goldblatt P. WHO European review of social determinants of health and the health divide. *Lancet* 2012; **380**: 1011.
- 7. League of Nations. *Geneva Declaration of the Rights of the Child.* 1924 [15 February, 2014]; Available from: http://www.un-documents.net/gdrc1924.htm.
- Kasiske BL, Ramos EL, Gaston RS, et al. The evaluation of renal transplant candidates: clinical practice guidelines.
 Patient Care and Education Committee of the American Society of Transplant Physicians. J Am Soc Nephrol 1995; 6: 1.
- 9. Hooper SR, Gerson AC, Butler RW, *et al.* Neurocognitive functioning of children and adolescents with mild-to-

- moderate chronic kidney disease. *Clin J Am Soc Nephrol* 2011; **6**: 1824.
- 10. Lande MB, Gerson AC, Hooper SR, *et al.* Casual blood pressure and neurocognitive function in children with chronic kidney disease: a report of the children with chronic kidney disease cohort study. *Clin J Am Soc Nephrol* 2011; **6**: 1831.
- Erikson EH. Childhood & Society. New York, NY: WW Norton & Co., 1950.
- 12. Darrow D, Stephens S. Interferences in psychosocial development of seriously health-impaired and physically disabled children. Educational implications. *Acta Paedopsychiatr* 1992; **55**: 41.
- Sen A. Development as Freedom. New York: Alfred A. Knopf, Inc., 1999.
- 14. Nussbaum M. Creating Capabilities: The Human Development Approach. Cambridge: Harvard University Press, 2011.
- Rudy BJ, Wilson CM, Durako S, Moscicki AB, Muenz L, Douglas SD. Peripheral blood lymphocyte subsets in adolescents: a longitudinal analysis from the REACH project. *Clin Diagn Lab Immunol* 2002; 9: 959.
- Shearer WT, Rosenblatt HM, Gelman RS, et al. Lymphocyte subsets in healthy children from birth through 18 years of age: the Pediatric AIDS Clinical Trials Group P1009 study. J Allergy Clin Immunol 2003; 112: 973.
- Dew MA, Dabbs AD, Myaskovsky L, et al. Meta-analysis of medical regimen adherence outcomes in pediatric solid organ transplantation. *Transplantation* 2009; 88: 736.
- Dew MA, DiMartini AF, De Vito Dabbs A, et al. Rates and risk factors for nonadherence to the medical regimen after adult solid organ transplantation. *Transplantation* 2007; 83: 858.
- 19. OPTN. *Transplant: Age Type by Previous Transplant. Based on Organ Procurement and Transplantation Network data* [February 15, 2014]; Available from: http://optn.transplant. hrsa.gov/latestData/rptData.asp.
- USRDS. Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, 2013.
- 21. Rodrigue JR, Schold JD, Mandelbrot DA. The decline in living kidney donation in the United States: random variation or cause for concern? *Transplantation* 2013; **96**: 767.
- Amaral S, Patzer RE, Kutner N, McClellan W. Racial disparities in access to pediatric kidney transplantation since share
 J Am Soc Nephrol 2012; 23: 1069.