Understanding and Overcoming Financial Risks for Living Organ Donors

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Living donor kidney transplantation is the optimal treatment for most patients with kidney failure, enabling improved length and quality of life in comparison to dialysis or deceased donor transplantation. The procedure is also unique among medical interventions in being not only cost-effective, but also cost-saving for the health care system. Although widely accepted that giving the gift of organ donation should be a financially neutral act for the donor, donation-related financial risks remain a reality within the structure of current practice and policies. Even in countries where donation-related medical expenses are covered by the recipient’s insurance or the health care system, donors may be responsible for many types of direct and indirect costs, such as travel, medications, lost wages, and dependent care. The economic impacts of donation may extend beyond direct costs to longer-term impacts on employment and socioeconomic status, but to date, there is limited information on these outcomes, despite the importance of financial impacts to the life satisfaction of living donors. In this context, a new study by Park et al offers a provocative examination of the economic outcomes of living kidney donors in South Korea over 5 years of follow-up.

In their important and well-done study, Park et al conducted a retrospective observational analysis of 1,285 living kidney donors who donated at 7 university-affiliated hospitals in South Korea in 2003-2016, selected from 1,865 living donors in the period after matching to an equal number of nondonor volunteers. The nondonor control group was drawn from 75,957 healthy individuals who received general health screenings at 2 of the tertiary centers, after matching for year of donation or health examination, age, sex, previous history of diabetes or hypertension, obesity (body mass index ≥25 kg/m²), baseline estimated glomerular filtration rate (≥10 mL/min/1.73 m²), place of residence (urban or rural), and baseline economic measures (insurance fee percentile and health insurance enrollment type). The economic status outcome measures were acquired through individual-level linkages to the National Health Insurance System database, wherein “economic status” was defined by the annual percentile of health insurance fee, determined from household income and assets. “Employment status” was defined by health insurance enrollment type, that is, being employed was defined based on receiving employer-supported health insurance and socioeconomic deprivation was defined by receiving “aided” health insurance provided to 3%-4% of Korean people. Annual economic status at the first to fifth follow-up anniversary was compared to the year before enrollment. Among the findings, living donors had higher likelihood of employment loss in year 1-2 after enrollment compared to healthy non-donor controls (21.7% vs 11.2%; adjusted odds ratio [AOR], 2.27), although differences were not statistically significant in subsequent years. Living donors also had lower likelihood of new employment in the first 2 years than nondonors (14.0% vs 19.0%; AOR of 0.67 in first observation year) but not subsequently. Economic status impacts were sustained, with donors having increased likelihood of worsened household economic quartiles (22.4% vs 15.9%; AOR, 1.54) and parallel decreases in the likelihood of economic improvement (31.2% vs 43.3%; AOR, 0.57) in year 1-2, with similar patterns in the 42%-53% with continued follow-up. Changing to severe economic deprivation was numerically more common among donors compared to controls, but this rare event occurred in 20 or fewer donors per year (compared to 2 or 3 controls). The authors conclude that socioeconomic impact should be considered along with long-term adverse health outcomes of donation.

While these findings are sobering, there are caveats to interpretation of the study findings for living donors in South Korea and internationally. Although the matching yielded good balance for observed factors, there is potential for uncontrolled confounding in the retrospective design. Notably, donors are most commonly women, which may impact economic vulnerability. The sex distribution of the donors and controls were well balanced, but it would be worthwhile to explore the magnitude of impacts among women versus men. There is also potential for selection bias, as the control sample of individuals who volunteered to participate in payment-requiring health screenings at the 2 centers may have distinct, unmeasured characteristics. The study sample of living donors represented 69% of living donors in the period (who were not formally compared to excluded donors), and follow-up attrition led to loss of 47%-80% of the samples over time. As recognized by the authors, most living donors in South Korea are in a close relationship with their recipient (37% parents, 27% siblings, and 27% spouses) and in addition to potential impacts of caregiver burden, the income and assets of the kidney patient appear to be part of the household economic status measure, which may inherently bias the measure towards lower status compared to families that do not include individuals with chronic illness. Some consistent trends were observed in secondary analysis among unrelated donors, although the sample was small (122 donors) and power was limited.
Dominance of close relationships also impacts generalizability; for example, in the United States, unrelated persons are the fastest-growing donor group. Perhaps most importantly, the economic measures drawn from records of a health insurance system provide an indirect reflection of income and assets of the individual’s household. Further research including granular information is necessary to understand causal pathways underlying the observations.

So what are the implications of the study by Park et al for living donors in South Korea and internationally? We believe that approaches to protecting the economic health of living donors should include the following: (1) education and informed consent; (2) research to better quantify short- and long-term financial impacts of donation; and (3) policies to support financial neutrality by mitigating these impacts (Fig 1).

The need for more transparent attention to financial risk in the counseling, education, and informed consent of living donor candidates is apparent. In the United States, a 2016 convenience sample of informed consent forms for living donor and transplant candidate evaluation from 9 programs found misconceptions about defraying donation-related costs, along with ambiguous wording or incomplete information in the informed consent materials presented to donors. Living donor candidates should receive regionally tailored counseling regarding financial costs and risks, should be informed about the existence of legitimate cost-replacement programs, and should be helped to access such programs. As an example of an educational resource, the American Society of Transplantation (AST) created an online toolkit to inform donor candidates about the financial implications of living organ donation. An AST Living Donor Community of Practice work group also prepared guidance to assist transplant centers in minimizing financial consequences to donors.

Although donation-related costs are the tip-of-the-iceberg in long-term economic impacts of donation, the findings of Park et al convey a strong reminder of the vital importance of ensuring cost neutrality during donation as a critical step in mitigating financial risks. In the United States, the National Organ Transplant Act has been clarified, to be explicit that “reasonable payments associated with … the expenses of travel, housing, and lost wages incurred by the donor” are legal, but nonetheless, financial loss is common. A recent systematic review estimated average donor-borne costs at US$900 to US$19,900 (2019 values) over the period from predonation evaluation to the end of the first year after surgery, and that 80% had financial loss. A single-center, retrospective survey of US living donors who were wage earners at the time of donation (2005-2015) found that greater delay in return to work was a significant predictor of financial burden, and that those in manual/skilled trade occupations had greatest financial burden for each week away from work. Older age at donation and nondirected (vs directed) donation were associated with significantly decreased financial burden. Initiatives to reduce the financial impacts of living donation, such as expansion of the US federally-funded National Living Donor Assistance Center (NLDAC) and the national Kidney Registry’s “Living Donor Shield” to include coverage of lost wages and dependent care for qualifying living donors, and employer-supplied leave programs, are gaining traction. Such policies are a welcome advance, but there are still limitations, such as NLDAC eligibility based on recipient means. Living donation may also impact ability to obtain life and disability insurance. In the United States, the Living Donor Protection Act, designed to protect employment during recovery after donation surgery and to prohibit discrimination in access to such insurance based
on status as an organ donor, was reintroduced into Congress in February 2021, but the fact that this no-cost protection has been debated in Congress since 2014 speaks to need for more rapid action.

Finally, the work of Park et al highlights the need for continued research on the understood topic of living donor economic outcomes. The 2017 KDIGO (Kidney Disease: Improving Global Outcomes) Living Donor Guideline recommends annual review and support of living donor psychosocial health and well-being, which should include economic health. New registries such as the US SRTR (Scientific Registry of Transplant Recipients) Living Donor Collective bring the opportunity to broaden the scope of long-term follow-up from solely medical outcomes to psychosocial and economic outcomes, and such registries should be considered across the world. Ongoing research is needed to determine the most meaningful follow-up measures and strategies to sustain long-term donor engagement with follow-up. While more work is needed to understand the mechanisms of the sobering findings reported by Park et al, there is a clear call for robust efforts to prioritize financial health along with medical health in protecting the short- and long-term safety of all individuals who benefit kidney patients and society through their generous gift of organ donation.

Article Information

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