Gasping for Change

December 17, 2013 By Tim Horn

On Tuesday, December 3rd, a 29-year-old HIV-positive man died on a New York City bus while on his way home from a doctor's appointment. As word of Lamont Valentin's death made its way through the community and HIV activism circles, heartbreak and anger quickly set in. The death of a young person is always difficult for anyone to wrap his or her head around. But when the death is likely the result of an injustice, the demand for answers -- and, indeed, solutions -- quickly turns grief into action.

Lamont Valentin

Born with HIV in 1984, more than a decade before potent combinations of antiretrovirals were an option for children living with the virus, Lamont struggled with numerous bouts of AIDS-related pulmonary infections. Though he persevered and was eventually able to access drug regimens to keep his viral load in check and his CD4 out of the red, there was no reversing the damage done to his lungs. Tethered to an oxygen tank and a litany of medications to manage the symptoms of his lung disease and its resulting pulmonary hypertension, Lamont's only option for long-term survival -- to watch his young son grow and flourish -- was a double lung transplant.

Denied.

Lamont was initially told that he could not receive a lung transplant in New York. Advocates with connections to NewYork-Presbyterian -- long a pioneer in the field of transplants among people living with HIV -- reached out to explore options for Lamont, but were told, in no uncertain terms, that HIV is an "absolute contraindication" to lung transplantation at NewYork-Presbyterian and many other centers in the country. In turn, Lamont wasn't evaluated as a possible lung transplant candidate and, as a result, died without even having the luxury of being placed onto the all-too-long waiting list for a possible match. The tragedy here stems from myriad issues:

1. There is no blanket policy by the United Network for Organ Sharing (UNOS) forbidding lung transplants in people living with HIV. The International Society for Heart and Lung Transplantation does, however, indicate that lung transplants are absolutely contraindicated in people with "non-curable chronic extrapulmonary infection including chronic active viral hepatitis B, hepatitis C, and human immunodeficiency virus."
2. In March 2009, the federal government's Organ Procurement and Transplant Network (OPTN) revised its policies on HIV status in recipients. It reiterates an earlier position that: "A potential candidate for organ transplantation whose test for HIV is positive but who is in an asymptomatic state should not necessarily be excluded from candidacy for organ transplantation, but should be advised that he or she may be at increased risk of morbidity and mortality because of immunosuppressive therapy."

3. There is no federal or New York State law forbidding lung transplants in people living with HIV.
4. This is an institution-specific determination, independent of ISHLT guidelines. Transplant teams at Massachusetts General Hospital and the University of California, San Francisco, agreed to evaluate Lamont and put him on the wait list if he qualified, but his New York public insurance carrier wouldn't permit this.
5. At least one other person living with HIV and advanced pulmonary disease has reported a different experience at NewYork-Presbyterian; he wasn't told that HIV is an absolute contraindication, but rather that he needed a CD4 cell count above 400 to qualify.
6. The research on solid organ transplants, conducted over the past 15 years, boded well for Lamont and should be the most important factor considered by the ISHLT (which hasn't updated its lung transplant candidate guidelines since 2006) and individual transplant programs going forward.

Making Sense of the Research

Prior to the widespread availability of modern-day antiretroviral therapy, transplant program refusals of people living with HIV was commonplace, based on the premise of limited survival expectancy and the risk of exacerbated CD4+ cell declines with the use of immune-suppressive agents to prevent organ rejection.

With the advent and evolution of HIV treatment, however, survival rates and transplant outcomes have improved remarkably. Data from several small studies reported over the past ten years have demonstrated acceptable patient survival rates (66 to 73% at three years; 50% at six years) and graft survival rates (45% at six years) for liver transplants and survival rates (82 to 100% at two years; 95% at five years) for kidney transplants that are comparable to those seen in HIV-negative populations.

One of the largest evaluations of organ transplantation was the HIV Solid Organ Transplant multicenter study, with Columbia University Medical Center -- now an institution of NewYork-Presbyterian -- participating as an HIV-positive adult and pediatric liver transplant center. Though acute rejection of transplanted kidneys were two- to three-fold higher than that seen in HIV-negative populations, average three-year survival of kidney recipients was comparable (90.6%) and kidney graft survival was comparable (75.5%) to that documented in older HIV-negative populations (>65 years of age). As for liver transplant recipients, patient and graft survival rates (66.4% and 61.5%, respectively) were lower than kidney recipients, but with a clear survival benefit for those with strong prognostic (MELD) scores -- similar to what is seen in HIV-negative liver transplant recipients.

One of the big concerns with using immune-suppressant drugs following transplant surgery is that people living with HIV will face an increased risk of opportunistic infections. However, relatively few opportunistic infections have been observed among participants in the HIV Transplant study. What's more, rates of serious non-opportunistic infections were comparable to those documented in HIV-negative kidney and liver transplant recipients. Data from this study also suggest that cancer rates following transplantation are similar to those documented in HIV-negative transplant recipients.

Encouraging outcomes have also been documented in case studies involving HIV-positive individuals receiving other transplants, including pancreas, stem cells, hearts -- again, NewYork-Presbyterian has been a leader in this regard -- and, yes, lungs.

The Challenge of Drug Interactions

It's important to acknowledge the challenges that come with managing interactions between immune-suppressive agents, antiretrovirals (notably protease inhibitors and non-nucleoside reverse transcriptase inhibitors), and drugs used to manage infectious complications that can arise in the setting of immune suppression. These are major issues and potentially contribute to sub-optimal concentrations of immune-suppressive agents and, consequently, higher rates of organ rejection in HIV-infected transplant recipients.

Careful monitoring and dose adjustments can potentially offset the heightened risk of organ rejection. Indeed, the substitution of any protease inhibitors or non-nucleoside reverse transcriptase inhibitors for the integrase inhibitor raltegravir (Isentress), or the recently approved dolutegravir (Tivicay), may offset significant drug-drug interaction concerns. It is also worth noting that the CCR5 receptor antagonist maraviroc (Selzentry) may have unique potential in the setting of solid organ transplantation, considering that CCR5 antagonism may actually decrease rates of graft rejection.

In effect it's very difficult to understand why HIV is an "absolute contraindication" to any organ transplantation procedure, including lung transplantation, particularly in the case of Lamont, whose HIV was well controlled, CD4 cell count was stable, was not a smoker, and whose pulmonary disease is the result of repeat pulmonary infections that occurred in the early years of his life in which effective antiretroviral therapy was not yet available.

Looking Forward

A worrying concern in the HIV community is that as many of us age, thanks to significant breakthroughs in antiretroviral drug research and development, we face an increased risk of end-organ disease due to higher prevalence rates of infectious and non-infectious comorbidities. In turn, the demand for safe and effective organ transplants for people living with HIV is expected to grow. To meet this need, one requirement will be a commitment to look beyond early ethical arguments surrounding transplantation and HIV-positive patients -- arguments that are simply no longer valid or justified -- and to continually advance the clinical science that is essential to the development of best medical practices for HIV-positive patients.

Indeed, last month, President Obama signed S.330, the HIV Organ Policy Equity (HOPE) Act, which for the first time will allow HIV-positive individuals to donate organs to their HIV-positive peers with end-stage organ disease, albeit within the confines of rigorous research protocols. Thus, there was neither a medical basis nor a legal one for denying Lamont a new organ -- even from another HIV-positive person -- there weren't any suitable IRB-approved studies open and enrolling when he needed them. I also feel compelled to add: Denying Lamont a lung transplant was potentially a violation of the Americans with Disabilities Act.

Activism to ensure that Lamont did not die in vain is very much under way. Tomorrow (Wednesday, December 18th) at 6:00, ACT UP/NY will be holding a rally for Lamont at Rockefeller Center, to share his story and demand that New York hospitals perform lung and other organ transplants in qualified people living with HIV.

Parallel efforts, which includes work being done by TAG in collaboration with members of ACT UP/NY, involve attempts to work directly with the directors of the lung transplant program at NewYork-Presbyterian, as well as the International Society for Heart & Lung Transplantation, to better understand (and refute) its scientific rationale for the unmistakable HIV obstacles in place, in the face of an

expanding evidence base to the contrary.

In Lamont’s own words:

> I’m not fighting for my life, I’m fighting for the lives of all these other people who have not been able to find help. We need to change medicine. We need to make history. For my son to be able to say ’that was my dad... he started this’. That would be amazing.

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