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With a Little Help from “Nuestros Amigos”: Hispanics and Kidney Transplants

June 8, 2000, was a day that would change everything in the life of Juan Caicedo. But he did not know that yet as he stood in the main lobby of Northwestern Memorial Hospital in Chicago, surrounded by doctors, patients, and visitors rushing to their destinations and a near-constant stream of announcements in a language he did not understand well enough to decipher. He only knew he felt overwhelmed and not a little intimidated.

Educated in general medicine and surgery at Universidad Nacional de Colombia, Caicedo had for several years been practicing transplant medicine in Bogotá, Colombia. He had a particular interest in organ transplantation in children as well as in adults, but knew he had much more to learn.

He determined that he would need to go to the United States to continue his training. His first step was to enroll in an intensive English language course at Indiana University in Bloomington. His second step, one that proved to be a crucial turning point in his career, was an opportunity that presented itself during an impromptu sightseeing trip to Chicago with his classmates in June 2000.

On that June day, Caicedo eventually found his way to the offices of Dr. Frank Stuart and Dr. Michael Abecassis, Northwestern's leading transplant surgeons. In halting English, Caicedo introduced himself, explained to the administrator that he was in town just for the day, and asked to meet with the doctors. It was an unusual request, but instead of saying no the administrator passed the request to the doctors, who were intrigued and agreed to meet with him if he returned in an hour. When he did, both surgeons spoke with Caicedo at length, and their meeting led to his receiving an extended fellowship at Northwestern Memorial in transplant surgery once he completed all the required examinations and obtained his Illinois medical license.

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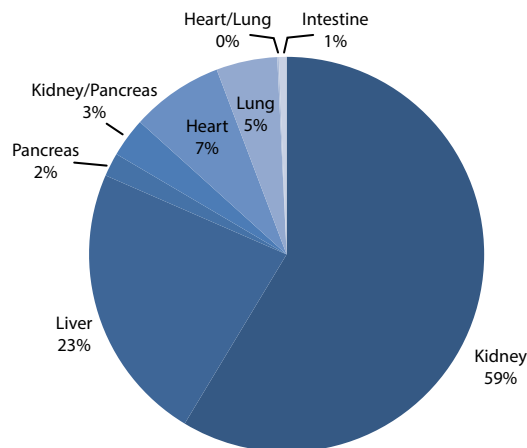
During his three years as a fellow, Caicedo was struck by the number of Hispanic patients on the kidney waiting list. Not only did Hispanic patients represent the highest growth group on the transplant waiting list, they also waited the longest for transplants and died while waiting at higher rates than non-Hispanic whites or African-Americans.¹ Caicedo also was alarmed by Hispanic patients' lower utilization of living donors for transplantation—they were underrepresented not only as live donor transplant patients, but also as donors.

As he neared the end of his fellowship in 2006, Caicedo wondered if the Hispanic population experienced unique barriers to transplantation and living donor usage, and began to think about how he could create a program to address these barriers.

Organ Transplants

In 2005 over 28,000 people received organ transplants in the United States. Nearly 60 percent of all organ transplants performed in the United States were kidney transplants (see **Figure 1**).

Figure 1: U.S. Transplants in 2005 by Organ Type



Source: United Network for Organ Sharing, Data, <https://www.unos.org/data> (accessed August 20, 2015).

Decades earlier when such procedures were rare, a transplant had been a newsworthy event. But by 2005 it had become a standard and successful treatment option for the end stage of many diseases and conditions.² Americans accepted the idea of transplants: in 2005 over 92 percent of Americans (and more than 94 percent of Hispanic Americans) supported or strongly supported

¹ Juan Carlos Caicedo, "Cultural Competency in Transplantation—A Call for Action," p. 28, Northwestern University Feinberg School of Medicine, presented as part of the General Surgery Resident Seminar Series at Northwestern Memorial Hospital, March 12, 2015.

² University of Michigan Transplant Center, FAQ, <http://www.transweb.org/faq/q30.shtml> (accessed August 7, 2015).

the donation of organs for transplants.³ Even Pope Francis described the act of organ donation as “a testimony of love for our neighbor.”⁴

Chronic Kidney Disease and Dialysis

The kidneys are two bean-shaped organs located on either side of the spine behind the abdominal organs. They perform several essential functions, the most important of which is filtering from the blood the waste products produced by metabolism, which then are excreted from the body in urine.

Chronic kidney disease (CKD) damages the kidneys and decreases their ability to filter blood. As a result, waste products accumulate, which leads to high blood pressure, anemia, weak bones, and nerve damage. Diabetes, the leading cause of CKD, occurred twice as often in Hispanic-Americans as in the non-Hispanic white population.⁵ Likewise, the occurrence of CKD was not evenly distributed across the U.S. population—Hispanic Americans had nearly twice the risk of non-Hispanic whites.

CKD often worsens until the kidneys fail, resulting in a condition known as end-stage renal disease (ESRD).⁶ When their kidneys fail, patients need either a new kidney via transplant or to undergo dialysis, a treatment in which their blood is cleaned using a mechanical or chemical process.⁷ Dialysis was time-consuming and inconvenient, and performed only about 10 percent of the cleaning and filtering done by healthy kidneys.⁸ Although dialysis kept patients alive, their health often deteriorated significantly. Patients typically needed three dialysis treatments per week, with the average treatment lasting four hours.⁹ Dialysis centers were located in small storefront locations in many neighborhoods.

Kidney Transplantation

Dialysis is not a cure for end-stage renal disease. Eventually, patients need to consider transplantation as an alternative to dialysis, and some doctors recommend transplantation before or instead of dialysis. A transplant offers the prospect of a more normal life, as the transplanted kidney performs all of the functions of the failed organs. Patients must take anti-rejection drugs

³ U.S. Department of Health and Human Services Health Resources and Services Administration, 2012 National Survey or Organ Donation Attitudes and Behaviors, <http://organdonor.gov/dtcp/nationalsurveyorgandonation.pdf> (accessed August 20, 2015).

⁴ “Pope Francis: ‘Organ Donation Is a Testimony of Love for Our Neighbour,’” *Independent Catholic News*, October 11, 2014, <http://www.indcatholicnews.com/news.php?viewStory=25737>.

⁵ University of California, San Francisco, “End-Stage Renal Disease,” <http://www.transplant.surgery.ucsf.edu/conditions-procedures/chronic-kidney-disease.aspx> (accessed August 7, 2015).

⁶ Ibid.

⁷ Ibid.

⁸ Beth Israel Deaconess Medical Center, “The Benefits of Transplant versus Dialysis,” <http://www.bidmc.org/Centers-and-Departments/Departments/Transplant-Institute/Kidney/The-Benefits-of-Transplant-versus-Dialysis.aspx> (accessed August 7, 2015).

⁹ National Kidney Foundation, “Dialysis,” <https://www.kidney.org/atoz/content/dialysisinfo> (accessed August 7, 2015).

and undergo monitoring to ensure the kidney is functioning correctly, but most find this to be far easier and more convenient than dialysis.¹⁰

The time-consuming dialysis regimen was more likely to interfere with patients' work schedules, making transplantation a better option for most patients' income-producing abilities. Total costs for dialysis treatment could be between \$70,000 and \$200,000 per year; a transplant cost an average of \$100,000 in the first year and \$35,000 annually thereafter.¹¹ Health insurance usually paid the majority of the costs for dialysis and transplantation.

Preparing for a kidney transplant was a lengthy and complex process. In addition to the transplant surgeon, the donor and recipient often needed to interact with other specialists, such as nephrologists, hepatologists, endocrinologists, and anesthesiologists, as well as social workers, nurses, transplant coordinators, financial coordinators, and medical assistants.

Although each patient's experience was unique, a typical "patient journey" could be developed to chart a patient's experience before, during, and after a transplant. This ethnographic technique gave doctors and others insight into and empathy for the experience of patients. **Exhibit 1** shows a typical journey for a transplant patient with CKD.¹²

Living vs. Deceased Donors

Unlike many other organs, kidneys could be transplanted from either deceased or living donors. However, donation from deceased donors did not meet the demand for kidneys—over 5,000 people died each year waiting for a transplant.¹³ Living kidney donation revolutionized kidney transplantation and was preferred over a deceased donor transplant for several reasons:

- It eliminated the need to place patients on the United Network for Organ Sharing's (UNOS) national waiting list for organ donation. Waiting time could be five or even ten years, which was often longer than the patient could live without a transplant.¹⁴
- It shortened the waiting time for other patients on the national waiting list.¹⁵
- Both short- and long-term survival rates were significantly better for transplants from living donors. On average, patients survived approximately eighteen years with a kidney from a living donor compared to thirteen years for a kidney from a deceased donor.
- It reduced or eliminated the need for dialysis. Since the health of patients deteriorated significantly while on dialysis, this represented a better outcome.

¹⁰ University of California, San Francisco, "End-Stage Renal Disease."

¹¹ Juan Carlos Caicedo, "Cultural Competency in Transplantation—A Call for Action," p. 21.

¹² For a more detailed perspective on the journey of a kidney patient before, during, and after treatment, see "In Focus: A Photojournalist Chronicles His Journey through Kidney Failure," John Martin's story of his transplant experience at Northwestern Memorial Hospital at <http://www.johnfmartin.net>.

¹³ Living Kidney Donors Network, "Benefits of Living Donation," http://www.lkdn.org/benefits_living_donation.html (accessed August 7, 2015).

¹⁴ Mayo Clinic, "Kidney Transplant Process at Mayo Clinic," <http://www.mayoclinic.org/departments-centers/transplant-center/kidney-transplant/preparing/process> (accessed August 7, 2015).

¹⁵ Living Kidney Donors Network, "Benefits of Living Donation."

In 2005 nearly 80 percent of living kidney donors were family members or spouses/partners of the transplant patient.¹⁶ Donors needed to be in excellent physical and mental health. Although there was a small risk of complications for the donor as the result of surgery, living donation was usually a positive experience for donors.

Generally, the donor's expenses for testing and surgery were paid by the patient's health insurance. However, the donor might be responsible for travel expenses and the cost of follow-up care, in addition to lost income from taking time off work for the surgery and recovery.

Hispanics in the United States

Hispanics were the largest and fastest-growing minority group in the United States. With a population of over 50 million, Hispanics made up 16 percent of U.S. residents. This group accounted for more than half of the nation's population growth from 2000 to 2010, and was projected to account for nearly one-fourth of the total population by 2030 based on 2010 U.S. Census data.¹⁷ Hispanics lived in all 50 U.S. states, but the population was concentrated in urban areas, particularly in western and southwestern states, Florida, eastern cities, and Chicago (see **Exhibit 2**). In 2006, Hispanics in the United States had lower median earnings than all other racial and ethnic groups.

Hispanics in the United States shared a link to a common language (Spanish), but they were not a homogeneous group. Roughly 65 percent were from Mexico, 14 percent from Central or South America, 9 percent from Puerto Rico, 4 percent from Cuba, and the remainder from other countries.

Beyond language, one of the most significant differences between Hispanic and non-Hispanic white households in the United States was family size. The average Hispanic household had 4.0 members compared to 2.9 members in the average non-Hispanic white American family.¹⁸ Roughly 23 percent of Hispanic households had five or more people, compared to 10 percent of the total U.S. population.¹⁹ In addition, Hispanic families were very connected outside the boundaries of their physical households. They were in contact with parents, brothers, sisters, and cousins much more frequently than non-Hispanic families, and extended family members were frequently consulted on major life decisions.

Hispanic families also were more likely to attend church regularly than other American families, and were more likely to affiliate with the Roman Catholic Church – 77 percent of American Hispanics claimed to have been raised as Catholics, and 60 percent claimed that religion was a very important influence in their lives.²⁰

In 2006, Hispanics were more than twice as likely as white non-Hispanics to lack private health care coverage – 35.6 percent of Hispanic people under 65 were without coverage, compared to 16.9

¹⁶ Organ Procurement and Transplantation Network, <http://optn.transplant.hrsa.gov/converge/latestData/rptData.asp> (accessed August 20, 2015).

¹⁷ Juan Carlos Caicedo, "Cultural Competency in Transplantation – A Call for Action," p. 12.

¹⁸ DataMonitor, "The Growing US Hispanic Population Presents a Wealth of Opportunities for the CPG Industry," September 23, 2010, http://www.datamonitor.com/store/News/the_growing_us_hispanic_population_presents_a_wealth_of_opportunities_for_the_cpg_industry?productid=D3AA920C-27D2-4597-B287-01A4A67E2F54.

¹⁹ Juan Carlos Caicedo, "Cultural Competency in Transplantation – A Call for Action," p. 19.

²⁰ Pew Research Center, "The Shifting Religious Identity of Latinos in the United States," May 7, 2014, <http://www.pewforum.org/2014/05/07/the-shifting-religious-identity-of-latinos-in-the-united-states>.

percent of the white non-Hispanic population.²¹ Treatment costs were a major concern for uninsured patients, and those that were insured had to understand the details of what their insurance would cover for transplantation. Some data suggested that Hispanics were slow to access health care even after they became insured.

Helping Hispanic Patients

By 2006 Caicedo had seen that Hispanic patients were less likely than other patients to have kidney transplants, and were even less likely to receive organs from living donors.

The hospital already had identified language as a barrier to transplantation and had attempted to bridge the language divide by making interpreters available for patients on request. However, Caicedo suspected that Hispanic transplant patients faced other, unique barriers, which needed to be addressed with a more comprehensive program.

²¹ J. R. Pleis and M. Lethbridge-Çejku, "Summary Health Statistics for U.S. Adults: National Health Interview Survey, 2006," National Center for Health Statistics, *Vital and Health Statistics* 10, no. 235 (December 2007).

Exhibit 1: Chronic Kidney Disease Patient Journey in the United States

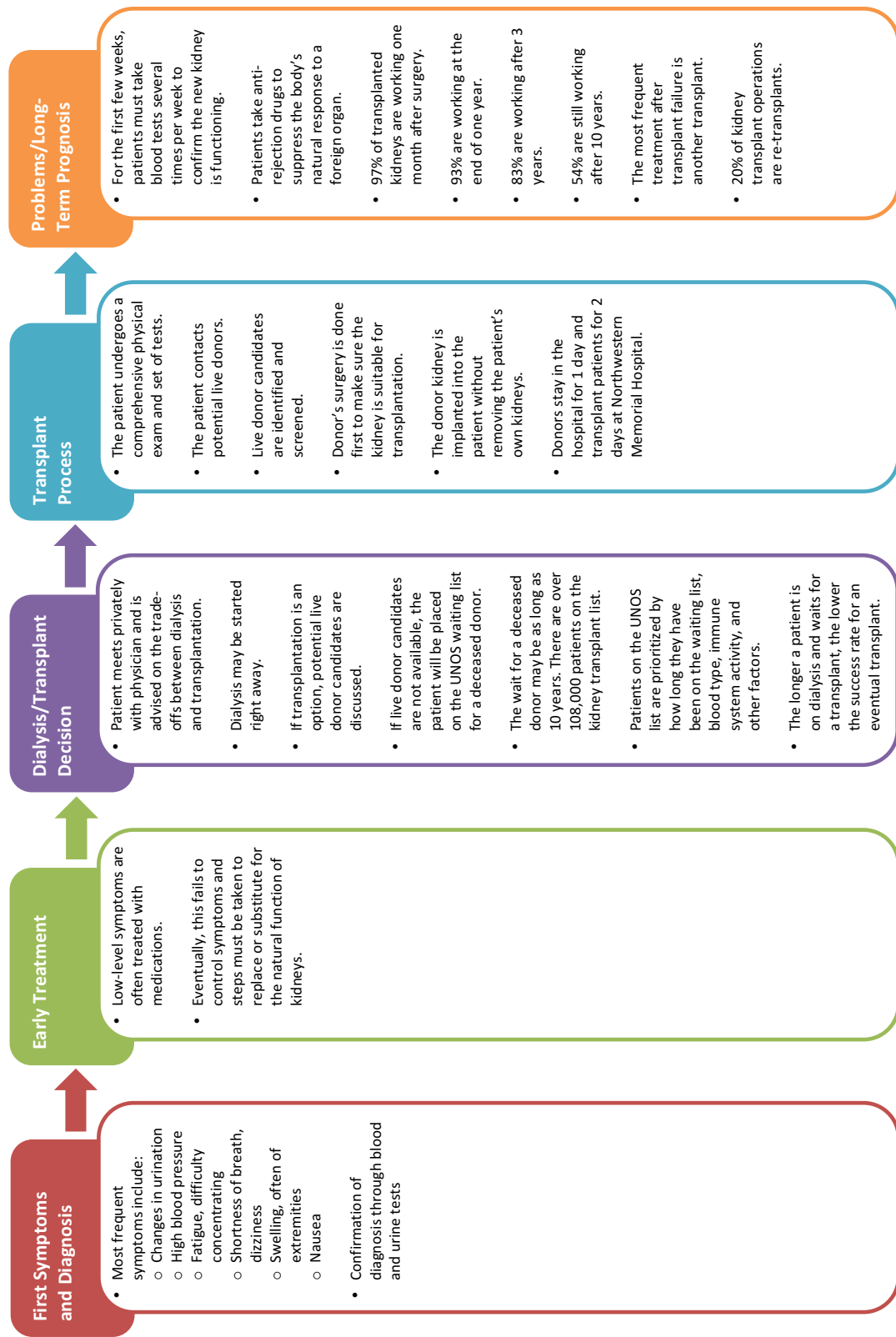


Exhibit 2: Hispanic or Latino Percentage of Population, 2006

