Barriers to Organ Donation and Transplantation in Hispanics

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My background

I have been with UCSF for 30 years and it has all been with the Transplant Service. I started as a staff nurse and then went on to be a kidney transplant coordinator for about 18 years and then moved over to the Liver Transplant Service as a transplant coordinator. As of 2013, I graduated as a NP and work up the living liver and kidney donors and follow them postoperatively.

Research interests

- So, I will be speaking to you today about the barriers that have and continue to prevent Hispanics from the opportunity of a transplant.
- This became of interest to me when I started to work with many living organ donors.
- I saw an opportunity for me to learn about what I can do to help tear down the barriers and increase the transplant opportunities for Hispanics.

Who is Hispanic?

Merriam –Webster Dictionary Definition:

1. of or relating to the people, speech, or culture of Spain or of Spain and Portugal
2. of, relating to, or being of Latin American descent living in the United States; especially: one of Cuban, Mexican, or Puerto Rico origin
Liver and Kidney Waiting Lists

- 17,000 patients on the liver waiting list
- Annually >1500 patients die waiting for a transplant
- 6,000 patients are transplanted annually in the U.S.

- 110,000 patients on the kidney waiting list
- In 2014, 4,761 patients died waiting
- 3,668 became too sick for a transplant

What if you are Hispanic?

- There are 55 million Hispanics in U.S. as of July 1, 2014, making people of Hispanic origin the nation's largest ethnic or racial minority.
- Hispanics constitute 17% of the nation's total population as of 2015 per the U.S. Census Bureau
- 19.5% of those waiting for a kidney, and 17% of those waiting for a liver are Hispanic
- In California, there are 14 million Hispanics, making Hispanics the largest ethnic or racial group in the state, with the majority being of Mexican descent.
- There are 23,000 Hispanics listed nationally with 9,000 of those listed in California.

If you were in need of a kidney or liver transplant, would you be able to ask a loved one to be a donor?

In 2011, a study by J. Siegel, et.al, they identified:

- Those in need of a transplant are hesitant to ask their loved ones to become a living donor
- In a phone survey of 380 Hispanics identified by surnames on a list, the data showed that they would willingly donate a kidney to a loved one and accept the offer if they needed one
- Only half of the participants, felt comfortable asking a loved one to be a donor.
Clinical and socioeconomic issues

- There is a high incidence in Hispanics of risk factors for end-stage kidney disease and live donation that may prevent Hispanics from being living donors:
  1) diabetes
  2) hypertension
  3) obesity

Why the Reluctance?

- The recipient needs to believe that it is suitable, appropriate for them to ask a family member to be a donor.
- The recipient is not comfortable asking someone to be a donor.
- They think that their family will come forward and offer to be a donor without needing to be asked.
- There can be a great deal of fear and concern on their part about asking someone to be donor.
- What if the person they ask to be a donor for them turns them down?
- There can also be difficulty in accepting an offer from a potential donor.

What would help change their reluctance to acceptance?

Educating potential recipients about the benefits of living donation
- Treatment of choice for end-stage kidney disease
- Improved quality of life
- Lower mortality rate
- Increases the patient’s comfort level to initiate a conversation about living organ donation

Concerns or Misconceptions about Living Donation

- Not being able to offer a kidney to a child in the future
- It would prevent a woman to get pregnant or weaken a man's fertility
- Concerns about the donor’s long term well-being.
- Shorten their life expectancy

Concerns of Misconceptions about Living Donation

- Donating would affect the donor’s ability to return to a normal lifestyle.
- Donors would need to take medication for the rest of their lives.
- Concerned about the need to avoid or be careful when drinking alcohol, exercising, taking pain medications or nutritional supplements.


Family Discussions about Donating

- There are 2 types of authority figures in Hispanic families:
  1) the eldest family member or
  2) the family member who had lived the longest in the United States.

When both families had discussions about a donor’s decision to donate, the donor’s family members would try to discourage or prevent the donation. Sometimes, the donor would not avoid talking about donating to avoid the disapproval of family and friends.


Financial Burden of Donating

- Financially challenging for some Hispanics, as it has been reported that 29.8% of Hispanics are uninsured and 25.8% are living in poverty.
- Lack of publicly available information about the financial impact on donor’s lives.
- Being out of work and how bills were going to be paid.
- Cost of donor work up, postoperative care and complications.
- Support of family to help manage the cost of running the home.
- Patients on dialysis found it the most difficult as most were undocumented and unable to obtain government health assistance.

**Religion and Organ Donation**

- Most Hispanic are Roman Catholic and before organ donation was endorsed by the Vatican, they would not consider live donation as it was thought to be a form of mutilation.
- Even so, many Hispanics believe that the Catholic Church forbids donation.


**Other religious obstacles regarding deceased organ donation are:**

1. no open casket
2. mutilation of the body
3. body needs to remain whole for when it arrives in heaven
4. could delay moving forward with the funeral
5. a miracle could happen and delay death


**So why the religious obstacles?**

- Members of the church may not be aware of the churches’ stance on organ donation
- Lack of discussion of organ donation in church
- Concern that they would be placed on other government surveillance lists if they signed up to be an organ donor

If there is support from their religious community and their pastor or priest, people are more willing to move forward and donate.


**Solutions for Improvement**

- The Hispanic Transplant Program, established by Juan C. Caicedo, an associate professor in surgery and organ transplantation at Northwestern has increased living donor kidney transplants among Hispanic patients at Northwestern medicine by 70 percent.

Strategy for improvement

- Dr. Caicedo has done this by hiring bilingual staff, inviting patients and family, especially parents and grandparents and acknowledging and respecting cultural sensitivities.
- He and his team are now working with the Mayo Clinic in Phoenix and Baylor University Medical Center at Dallas to test these approaches there.


Education and Community Information Programs

- Culturally sensitive, mass media (television and radio)
- Websites addressing the difference between living donation and deceased donation tailored to Hispanics
- Providing access to Spanish-speaking clinicians
- Spanish-language educational materials
- Offering educational sessions in Spanish about live donation

Summary

- Language barriers
- Lack of information in Spanish
- Reducing financial barriers to live organ donation
  1) out of pocket costs
  2) lost wages
- Addressing misconceptions about organ donation

References

References


Thank you for your time & attention