Barriers to kidney transplant in Jalisco, Mexico: the patient’s perspective.

Daniel Murillo-Brambila\textsuperscript{1,2,3}; Mónica Jimenez-Cornejo\textsuperscript{2,3}; Gabriela Abundis-Mora\textsuperscript{1,2,3}; Guillermo García García\textsuperscript{1,2}; Karina Renoirte-López\textsuperscript{1,2,3}.

1 Nephrology, Hospital Civil Guadalajara, Guadalajara, Jalisco, Mexico. 2 University of Guadalajara Health Sciences Center (CUCS), Guadalajara, Jalisco, Mexico. 3 SANEFRO, PiSA Hemodiálisis Clínica, Jalisco, Mexico.

Abstract

Background: In Mexico, up to 48% of the population does not have health insurance that includes coverage for chronic kidney disease. Renal transplantation is the best option for patients. In 2018, 15,072 patients were on the waiting list of deceased donors, but only 3,048 transplants were performed nationwide. The objective of this study was to investigate the barriers faced by insured and uninsured patients to perform renal transplant protocol.

Methods: Cross-sectional study of 200 prevalent hemodialysis patients in Mexico, insured and uninsured. A voluntary and anonymous survey per patient was applied. Data collected included the reasons for not performing a protocol.

Results: Only 72 patients (36%) had a protocol, 61.1% for deceased donor and only 30.6% for related living donor. 78% of patients with protocol were insured. Only 32 patients (44.4%) had completed protocol. 128 patients (64%) had no protocol, and 103 of them (80.4%) were insured. The reasons for not performing a protocol: not being a medically suitable candidate (36%), not having a compatible related living donor (16.4%), fear of transplant (15.6%), transplant was not offered (15.6%), lack of financial resources (14.1%). Diabetes was a significant condition for not running a protocol.

Conclusions: Barriers to kidney transplant are not being a medically appropriate candidate, lack of donor, fear of transplant, transplant modality is not offered, and lack of financial resources. Diabetic patients are less likely to run a protocol. These findings were similar between insured and uninsured patients.

Keywords: end stage renal disease; access; kidney transplant

Dr. Daniel Murillo Brambila,
Address: Av. España 1840, Colonia Moderna, CP 44190. Guadalajara, Jalisco, México.
Mail: murillo64@hotmail.com
Barreras para el trasplante renal en Jalisco, México: perspectiva del paciente.

Resumen

Introducción y objetivos:
En México, hasta un 48% de la población no cuenta con seguro médico con cobertura para la enfermedad renal crónica. El trasplante renal es la mejor opción para los pacientes. En el 2018, 15,072 pacientes estaban en la lista de espera de donante fallecido, pero solo se realizaron 3,048 trasplantes en todo el país. El objetivo de este estudio fue investigar las barreras de los pacientes asegurados y no asegurados para realizar protocolo de trasplante renal.

Métodos:
Estudio transversal de 200 pacientes prevalentes en hemodiálisis en México, asegurados y no asegurados. Se aplicó una encuesta voluntaria y anónima por paciente. Los datos recolectados incluyeron los motivos para no realizar protocolo de trasplante.

Resultados:
Solo 72 pacientes (36%) contaban con protocolo, la mayoría para donador fallecido (61.1%) y 30.6% para donador vivo. 78% eran asegurados. 32 (44.4%) tenían protocolo completo. 128 pacientes (64%) no tenían protocolo, el 80.4% de ellos eran asegurados. Razones para no realizar protocolo: no ser candidato médicamente (36%), no tener donador vivo (16.4%), miedo al trasplante (15.6%), hospital no ofreció trasplante (15.6%), falta de recursos (14.1%). La diabetes fue una condición significativa para no realizar protocolo.

Conclusiones:
Las barreras para el trasplante renal son no ser un candidato médicamente, falta de donante, miedo al trasplante, que la institución no lo ofrezca y la falta de recursos. Los pacientes con diabetes realizan menos protocolos. Estos hallazgos fueron similares entre los pacientes asegurados y no asegurados.
Background

Chronic Kidney Disease (CKD) represents a serious public health problem worldwide. Diabetes and hypertension remain as the main cause of End Stage Renal Disease (ESRD) in Mexico\cite{1}. CKD is the second cause of death in Mexico since 2007. Its incidence per million population (pmp) increased from 191 in 2000 to 411 in 2015, and its prevalence rose from 270 to 1557 pmp (215 and 576% increase in incidence and prevalence)\cite{2}.

It is important to point out the increase in the incidence and prevalence of CKD, and also the inequality in access to renal replacement therapies (RRT) among insured patients (51% of the population) and those uninsured (48%) (with no coverage for ESRD nor RRT expenses (see fig 1, with permission from G. García)\cite{2}.

Hemodialysis and peritoneal dialysis are high-cost therapies in developed countries, and prohibitive in developing countries like Mexico. More than 15 years ago, Mexican government implemented strategies to cover the expenses related to RRT thru the institution of a popular insurance for the poor. To date, they have failed. Uninsured patients still have no access to RRT, including kidney transplant.

Thus, limitations faced by patients to access RRT appear to be multifactorial. Contributing factors are: age, gender, educational level, out-of-the pocket expenses related to health, average salary, access to dialysis or transplant centers, the number of nephrologists and their geographical distribution, among others\cite{3,4}.

Among RRTs, kidney transplant remains the best treatment option and has the lowest morbidity and mortality rates\cite{5,6}. However, it seems that the economic disparity that persist in developing countries contributes to a lower rate of kidney transplant compared to that found in countries with a better economy\cite{7}. In Mexico, despite the institution of the Popular Insurance there has been no increase in the number of kidney transplants among its affiliates\cite{8}.

Kidney transplant rate in Mexico increased from 1.57 pmp in 1984 to 22.8 pmp in 2015. However, access among insured and uninsured patients remains uneven: the rate of kidney transplants is 130 pmp among insured patients’ vs 13 pmp among uninsured patients (fig. 1)\cite{2}.

In its 2018 annual report, the National Transplant Center (CENATRA) reported that there were 400 hospitals nationwide to procure different organs and perform transplants. By 2018, 15,072 patients were on the national waiting list for deceased kidney donor, but only 3048 kidney transplants were performed nationwide (figure 2), 2079 of them were from living donors and only 969 came from deceased donors\cite{9}. The state of Jalisco has a population of 8.2 million, and its capital, Guadalajara, is the second biggest city in the country\cite{10}. Jalisco has a kidney transplant rate of 63.2 pmp, most of them from related living donors (77%), 12% from unrelated living donors and only 11% from deceased donors\cite{11}.
In 2018, Jalisco ranked second in the number of kidney transplants performed (534), slightly outdone by Mexico City (898 kidney transplants). Fifty-five percent of transplants nationwide are performed at the National Social Security Institute (IMSS), followed by 25% in Public Health Institutions and 20% in the private sector (figure 3). Centro Médico Nacional de Occidente (West National Medical Center) belongs to Social Security and is in Jalisco. It is positioned as the most productive hospital carrying out kidney transplants in Mexico and Latin America. However, its rank falls to fifth national place for deceased donor transplants (only 45 were performed in 2018 vs. 207 from related living donor) [9, 11, 12].

**Objective**

The objective of this study was to investigate the barriers faced by insured and uninsured prevalent hemodialysis patients to undergo kidney transplant protocol.

**Methods**

Cross-sectional study of 200 prevalent hemodialysis patients from PISA-SANEFRO hemodialysis clinic, in Guadalajara, Jalisco. Patients were classified according to insurance status: insured patients and uninsured patients (with no coverage for RRT, including kidney transplant). A voluntary and anonymous survey was performed per patient. The sociodemographic characteristics (gender, age, employment status and type of housing) were included in the data collected. The preexistence of diabetes mellitus and/or hypertension, hemodialysis vintage expressed in months and affiliation medical insurance was included. Patients were categorized into those who carry out transplant protocol (group A) and those who are not carrying out the protocol (group B). Data is shown in percentages, mean and standard deviation and Pearson's Chi square for the comparison of groups with a value of p <0.05 as statistically significant.

The completion time of transplant protocol and the waiting time for the performance of transplant surgery were expressed in months (data shown in mean and standard deviation and Student's T with a value of p <0.05). Patients who were not carrying out transplant protocol were also divided into two groups: insured and uninsured. The main reasons from the patient’s perspective for not initiating transplant protocol were investigated: not being a transplant candidate, lack of financial resources, lack of living donors, refusal of the patient's family to donate, fear of transplant and, lastly, the hospital institution does not offer them this treatment modality.

The data are shown in percentages and comparison using Pearson's Chi square with a value of p <0.05 as statistically significant. For statistical calculations the statistical software IBM SPSS version 22 for Mac Os was used.

**Results**

The average age of the respondents was 43.5 years, 82% were insured, 67% were men, 33% were working and 77% had urban housing. Seventy-point five percent had hypertension and 36.5% had diabetes. The average time on hemodialysis was 36 months.

Only 72 (36%) patients were carrying out kidney transplant protocol; 78% of these patients were insured, 61.1% were carrying out a deceased donor protocol, 30.6% had a living donor and 8.3% an unrelated living donor (see table 1).

![Annual kidney transplant by medical institution, CENATRA 2018, Sistema Informático del Registro Nacional de Traspantes. Adapted by Karina Renoirte.](image)
Seventy-three patients had diabetes, and among them, only 13 (18%) were running a protocol (p< 0.01).

Among the 72 patients on protocol, only thirty-two patients (44.4%) had completed it (average time of 8.8 months to complete protocol). The average waiting time for surgery was 12.4 months after the protocol was concluded. They were divided into 2 groups: the insured patients required a mean of 9.1 months to complete the protocol vs. a mean of 6.6 months for the uninsured patients (p=0.006), and an average waiting time for surgery of 13.3 and 4 months respectively after protocol completion (p=0.25) (see table II).

The rest of the respondents (128 patients, 64%) were not undergoing transplant protocol, although 103 of them (80.4%) had medical insurance that covered the transplant.

The main reason why patients mentioned not being on transplant protocol were that they are medically inadequate candidates (36%). Other reasons were: they did not have a compatible related living donor (16.4%), they were afraid having the transplant surgery (15.6%), the institution does not offer them this treatment modality (15.6%), they lack financial resources (14.1%) and 3 patients do not have family members willing to donate a kidney (2.3%) (see table III).

**Discussion**

<table>
<thead>
<tr>
<th>Overall n=200</th>
<th>Transplant protocol (group A) n=72</th>
<th>No protocol (group B) n= 128</th>
<th>A vs B (p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (y)(SD)</td>
<td>43.5(19.02)</td>
<td>34.3(14.06)</td>
<td>48.7(19.4)</td>
</tr>
<tr>
<td>Male (%)</td>
<td>134(67)</td>
<td>21(29.2)</td>
<td>83(64.8)</td>
</tr>
<tr>
<td>Current worker (%)</td>
<td>66(33)</td>
<td>35(48.6)</td>
<td>31(24.2)</td>
</tr>
<tr>
<td>Currently studying (%)</td>
<td>13(6.5)</td>
<td>6(8.3)</td>
<td>7(5.5)</td>
</tr>
<tr>
<td>Urban housing (%)</td>
<td>154(77)</td>
<td>53(73.6)</td>
<td>90(70.3)</td>
</tr>
<tr>
<td>Rural housing (%)</td>
<td>46(23)</td>
<td>19(26.4)</td>
<td>38(29.7)</td>
</tr>
<tr>
<td>Hypertension (%)</td>
<td>141(70.5)</td>
<td>51(70.8)</td>
<td>90(70.3)</td>
</tr>
<tr>
<td>Diabetes (%)</td>
<td>73(36.5)</td>
<td>13(18.1)</td>
<td>60(46.9)</td>
</tr>
<tr>
<td>Average HD vintage (months) (SD)</td>
<td>36(32.6)</td>
<td>37.1(32.9)</td>
<td>35.7(32.6)</td>
</tr>
<tr>
<td>Insured (%)</td>
<td>164(82)</td>
<td>58(80.6)</td>
<td>103(80.5)</td>
</tr>
</tbody>
</table>

**Table I: Patients characteristics**

Chi –square, SD standart deviation; HD hemodialysis; NA does not-apply; p value <0.05.

<table>
<thead>
<tr>
<th>Type of donor</th>
<th>Overall n=200</th>
<th>Transplant protocol (group A) n=72</th>
<th>No protocol (group B) n= 128</th>
<th>A vs B (p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deceased donor(%)</td>
<td>NA</td>
<td>44(61.1)</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Related living donor(%)</td>
<td>NA</td>
<td>22(30.6)</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Unrelated living donor(%)</td>
<td>NA</td>
<td>6(8.3)</td>
<td>NA</td>
<td>NA</td>
</tr>
</tbody>
</table>

**Table II: time to protocol completion and time to surgery**

The rest of the respondents (128 patients, 64%) were not undergoing transplant protocol, although 103 of them (80.4%) had medical insurance that covered the transplant.

The main reason why patients mentioned not being on transplant protocol were that they are medically inadequate candidates (36%). Other reasons were: they did not have a compatible related living donor (16.4%), they were afraid having the transplant surgery (15.6%), the institution does not offer them this treatment modality (15.6%), they lack financial resources (14.1%) and 3 patients do not have family members willing to donate a kidney (2.3%) (see table III).
Lauren et al, mention that even though the treatment of choice in the patient with ESRD is kidney transplant and that access to it has improved, only 13% of patients with ESRD are on the waiting list or become transplanted in the first year of diagnosis[13]. It remains a very low percentage[14]. In this cross-sectional study of 200 prevalent patients on hemodialysis, we assessed the limitations to run a renal transplant protocol from the patient's perspective. Many of the barriers to transplant found in our study are similar to those already reported by other authors, but we found out that eventhough the population we surveyed had already an average of 36 months on hemodialysis, only 1 in 3 patients were running a protocol.

The USRDS report informed that black patients or those who do not have any kind of medical insurance have less access to transplant or its information [14]. In our analysis, we showed that regardless of the fact of having medical coverage for kidney transplant (82% of patients surveyed), only 1 in 3 patients was in a transplant protocol. In addition, no advantage was observed to initiate kidney transplant protocol among insured patients when compared to patients who did not had medical coverage for the transplant (p = 0.2 95% CI 0.75-3.7).

The main reason patients mentioned for not running a protocol was to be a medically unsuitable candidate, which differs from the findings of other authors mentioned previously[13,14,15]. This, in addition to the fact that diabetic patients were less likely to run a protocol (p <0.01) regardless of the medical coverage status, is an important preexistent condition to point out. One could think that there could be a bias among physians to determine if patients are medically suitable candidates for kidney transplant based merely on the fact of having or not diabetetes. Further studies might be needed to evaluate if medical criteria applied to determine if patients are medical suitable for transplant are accurate.

O'Hare et al. mentions that patients who live in urban areas have better access to transplant because most of the specialized hospital centers are there compared to rural areas[15]. In contrast, in our study, no statistical difference was observed among patients living in urban areas and those living in rural areas to initiate a transplant protocol. This may be because all patients are referred to concentration hospitals regardless of where they live (rural or urban areas), (p = 0.39 95%, CI 0.38-1.4).

Purnell et al, mention that patient referral to a transplant center is only the beginning of a long process. Our study makes clear that access disparities are not only due to the patient's referral process, but also to the complexity of the medical evaluation and the waiting list process for the surgical shift [16]. It is noteworthy that the time required to complete the transplant protocol was significantly longer for patients with medical coverage than those without medical coverage (9.1 vs. 6.6 months respectively) In addition, the waiting time for transplant surgery was much longer for patients with medical coverage (13.3 months) than for those without coverage (4 months). Although no statistical significance was evidenced in this last point, this may be due to the small sample. These findings agree with Purnell report, that mentions that despite an early referral of the patient to the transplant center, there is considerable time for the completion of the protocol and even more, to perform the surgery[16].

Álvardo et al, consider that the lack of information and fear of the transplant process are one of the main barriers that patient faces[17]. In our study, we found that fear of transplantation was only reported in 15.6% of patients as a reason for not having agreed to transplant protocol.
Boulware et al, mention that patients relatives can sometimes be a great limitation, feeling overwhelmed by the illness of their relative, patient’s denial about their disease, the stress of care giver when caring for the transplanted family member, the uncertainty about one’s own health or the health of family donors and the subsequent fear of getting the same disease as the patient. Factors such as social and financial support, personal knowledge and attitudes towards transplantation, and psychological burdens (for example, fear, anxiety and guilt) influence patient decision-making.

We did not address transplant communication campaigns. A survey conducted by Zepeda et al, shows that most of the Guadalajara’s population (Jalisco’s capital) knows and supports organ donation for transplant purposes, however, despite this, donation remains poor and Mexico is well below other countries with similar economies.

**Conclusions**

Patient’s perspective of barriers to kidney transplant are: not being medically appropriate candidate, the lack of a compatible living donor, the fear of having the transplant surgery, that the hospital institution does not offer them this treatment modality, that they lack financial resources and the lack of relatives who are willing to donate.

These findings were similar among insured and uninsured patients, indicating that other factors, in addition to the lack of medical coverage, significantly limit access to kidney transplantation.

Having diabetes seems to be a significant barrier to consider transplant. Further studies might be needed to evaluate if medical criteria applied to determine if patients are medical suitable for transplant are accurate.

The average time from protocol completion to surgery remains long, even in patients who have a living donor, which contributes to saturation of the hemodialysis services and represents higher patient care costs. It is important to take these observations into account to establish strategies that expedite the implementation of transplant protocols and improve time to perform kidney surgeries. Thus, the gap between the patients on waiting list and the transplanted patients can be minimized.

On the other hand, the lack of living donors could be addressed by increasing the number of kidney transplants from deceased donors.

**Conflict of interest**

Authors without conflict of interest
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