

Factors Contributing to Health Disparities in Liver Transplantation in a Hispanic Population

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Objective: Among the challenges that Puerto Rico transplant patients face are a lack of social support that would enable them to move away from Puerto Rico, the difficulty of obtaining insurance coverage, and limitations imposed by language barriers. These factors may lead to reduced access to liver transplantation, which is a form of healthcare disparity. The objective of the study is to describe a group of Puerto Rican liver transplant candidates for the first time and to determine whether the above-named factors limit the possibilities of these candidates to be listed for transplant.

Methods: Using non-public databases from the referral and the transplant center, we performed a retrospective analysis of the medical records of patients who had been evaluated for liver transplant candidacy. Candidates (137) from the Liver Transplant Clinic at the University of Puerto Rico School of Medicine pre-evaluated for transplant candidacy during the period of 2002 to 2008 were selected.

Results: Records from 86 men and 51 women were reviewed. The most predominant etiologies of liver disease were hepatitis C virus (36%), a combination of etiologies (26%), alcoholic liver disease (16%), and cryptogenic cirrhosis (10%). While social support and history of psychiatric disorders did not affect listing, private insurance increased the odds of being enlisted for liver transplant (OR = 2.97) (95%CI: 1.067-8.242) (p<0.05).

Conclusion: Access to private insurance increases the possibility of patient's being enlisted for liver transplantation. Recommendations for overcoming the gap in access to transplants by patients without private insurance are discussed. [*P R Health Sci J* 2012;4:199-204]

Key words: Disparities, Insurance, Hispanics, Barriers, MELD

The Puerto Rican population has a high prevalence of chronic liver diseases. Supporting this statement are several studies that examined the prevalence of hepatitis C (HCV) and of cirrhosis as well as that of the survival rate of hepatocellular carcinoma (HCC). According to recent studies in Puerto Rico, HCV has a prevalence of 6.3% per 100,000 in the adult population living in the San Juan area and 2.3% per 100,000 in the population of adults living outside of San Juan (1, 2). This is higher than the prevalence of 1.6% in the general population of the United States (US) (3). Risk factors associated with the high prevalence found in the PR population are tattooing practices, lifetime cocaine use, having had a blood transfusion prior to 1992, lifetime heroin use, and having a history of imprisonment (1). A review of 300 consecutive liver biopsies of Puerto Rican patients with hepatitis C determined that 30% of those patients had cirrhosis (4). In 2004, chronic liver disease and cirrhosis was the eleventh cause of death in Puerto Rico, with a mortality rate of 2.6 per 100,000 inhabitants (5). The survival rate of hepatocellular carcinoma in Puerto Ricans is inferior to the one observed in the US population (6). Incidence rates tripled in the US from 1975 through 2005, with a significant increase among middle-aged black, Hispanic, and white males (7). Liver transplantation is the only life-saving

treatment for end-stage liver disease, enzymatic liver disorders, hepatocellular carcinoma, and fulminant hepatic failure (8). In order for these patients to prolong survival and increase their chances of having a better quality of life, liver transplantation is recommended.

After being accepted for liver transplantation, patients are listed on the United Network for Organ Sharing (UNOS) recipient registry until an organ is allocated. Patients undergo a pre-transplant evaluation before being listed as a way to identify potential candidates and predict successful outcomes. Standardization of the selection process is urgently needed to diminish bias in the selection of candidates and to ensure equity and balance in the decision (9, 10).

Organ allocation is based on the Model for End-Stage Liver Disease (MELD) scoring system, which determines organ

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allocation using objective measures of disease severity (11). The MELD system does not take into account psychosocial factors that have been associated with transplantation. Information on psychosocial factors provides important input for the transplant team in determining post-transplant prognosis in terms of adherence to treatment and social support, factors that have been associated with outcomes in orthotopic liver transplantation (10). A given patient's history of substance abuse and treatment, history of active psychiatric illness, family and support network, history of medical non-compliance, coping mechanisms, cognitive functioning, diagnosis, liver disease severity, and insurance coverage are also assessed (10, 12). Nonetheless, even after using these criteria, transplants occur with lesser frequency in some groups. Among subgroups of Hispanic and Asian candidates, disparities based on race/ethnicity are prominent (12). Barriers other than race have also been studied and identified. Sex-based, regional, financial, cultural, and healthcare-system barriers that limit access to medical care in this population are still present (10, 13, 14). These barriers often cause gaps among vulnerable populations in the delivery of service, which tend to lead to health disparities.

Because of the high prevalence of chronic liver disease and cirrhosis in our population, it is imperative to make transplantation services available and feasible. The purpose of this study was to characterize the psychosocial composition of a group of Puerto Rican liver transplant candidates who were referred to a transplant center after they completed a pre-transplant evaluation; such characterization would—it is hoped—aid in the identification of barriers that might account for an individual's failing to be listed and lead to strategies that would increase the access of Puerto Rican candidates in general to liver transplants.

Materials and Methods

This study was approved by the Institutional Review Board (IRB) of the University of Puerto Rico, Medical Sciences Campus, in San Juan, Puerto Rico, and by the office of research at the liver transplant center in Tampa General Hospital, Florida (Protocol #1250410).

Since liver transplants were not performed in Puerto Rico until 2012, potential candidates were referred to transplant centers in the United States. Before 2012, most local, private gastroenterologists referred patients to the Liver Transplant Clinic at the University of Puerto Rico School of Medicine for pre-screening. Patients undergo a pre-transplant evaluation that consists of medical, psychological, and social work assessments and a determination of financial capability (that is, the ability to cover transplant expenses). Once potential candidacy has been confirmed, patients are referred to US transplant centers to undergo a second phase of screening that includes alcohol and drug screening, insurance coverage for immunosuppressants,

social support update, and lab work, among other elements. Then, a selection committee makes a final decision regarding transplant listing.

Two databases—one from the Gastroenterology Research Unit at University Hospital on the Medical Sciences Campus of the University of Puerto Rico and the other from the transplant center—were used to identify the records of liver transplant candidates. Records for 300 liver transplant candidates who began their pre-transplant evaluations at the UPR School of Medicine Liver Transplant Clinic from 2002 to 2008 were identified. A given patient's records were included in the study if the following conditions were met: 1) the patient was evaluated during the specified period, 2) the pre-transplant evaluation was completed and the patient referred to the transplant center, and 3) a decision regarding liver transplant listing was made by the selection committee at the transplant center. One hundred and sixty-three records showed no decision regarding liver transplant listing and so were excluded from the study. The remaining 137 patients were selected as our study population after qualifying with all inclusion criteria.

Records were reviewed retrospectively to collect data on the variables of interest to our study. The following were collected regarding the final decision as to whether to include or not include a given patient on the transplant list: demographics (age, gender, education, marital status), psychosocial data (travel support, history of suicide attempts, alcohol use, illegal drug use and/or psychiatric treatment, and type of insurance), psychological test data (Beck Depression Inventory-II/BDI-II, Beck Anxiety Inventory/BAI scores), and medical data (other medical conditions, etiology of chronic liver disease, MELD score). Both the BDI-II and BAI are instruments that measure the severity of symptoms, yielding scores that range from 0 (minimal) to 63 (severe) (15, 16). Other variables requiring definition for the purpose of data management were social support, education, marital status, and alcohol use. For the purposes of this study, travel-support availability and marital status variables were used as social-support markers. This was done based on the belief that having a companion to move off of the island to the transplant center and having a stable relationship imply assistance for the patient during the transplant journey. The variables listed above were further defined. Education: completed high school or less or completed college or more; marital status: in a stable relationship or living alone; travel support and insured: yes or no; type of travel support: immediate-family member (spouse, parent, child, sibling), extended-family member (aunt, uncle, grandparent, cousin, etc.), friend/s, or no such support; alcohol use: regular or on weekends or no use; illegal drug use: used illegal drugs for six months or more on a regular basis; history of suicide attempts: reported at least one episode of self-harm intended to end his/her life; insurance: private, government (Medicaid, called *Reforma*, locally), or uninsured. A standard interview

format was used to obtain this information from the patients at the time of evaluation. The researcher filled a data sheet that included all of the above mentioned variables, after which a database was created for eventual statistical analysis.

Data Analysis

Sociodemographic data was summarized by using mean, standard deviation, and the minimum/maximum values for continuous variables. Categorical data were presented as frequencies and percentage. Multivariate analyses of the factors associated with liver transplant listing were performed with logistic regression analysis. This model allowed the investigators to predict which factors increased the possibility of a given candidate’s being accepted for transplant listing. After doing a literature review, the selected variables were included in the model because of their involvement in the decision making-process associated with transplant listing. Before being accepted in the model, variables were checked for fit and adequacy ($X^2 = .51$). Variables included in the model were age, gender, education, marital status, psychiatric treatment history, illegal drug use history, alcohol use history, and type of insurance. These variables were identified as predictors, while the decision regarding liver transplant listing (accepted/not accepted) was identified as the outcome measure variable for the logistic regression analysis. A p-value of <.05 was established for the analysis. All statistical analyses were performed with SPSS version 17 statistical software (SPSS, IBM).

Results

Demographics and Characteristics of the Study Population

The study population consisted mostly of men (63%) whose mean age was 51 years (SD = 10) and who were in stable relationships (68%). The majority had a high-school level education or lower (61%). Table 1 shows the distribution for all the analyzed variables. The most predominant conditions were diabetes mellitus (23%), hypertension (21%), and asthma (7%). Ninety-eight percent of the patients indicated they had travel support, which was distributed between a first relative, a second relative, and a friend. The predominant etiologies for liver disease were HCV (36%), alcoholic liver disease (16%), cryptogenic cirrhosis (10%), and two or more etiologies (26%). In the last category, the most prominent were HCV plus alcoholic liver disease (ALD, 14 patients) and HCV plus hepatocellular carcinoma (HCC, 6 patients).

Factors associated with acceptance

One hundred and six of the original 137 patients were accepted for transplant listing. Variables included in the model were education, marital status, psychiatric history, history of alcohol use, history of illegal drug use, and type of insurance.

Analyses were adjusted by gender. A logistic regression analysis with the potential predictors was done. The only factor that was found to increase the odds of being accepted for transplant listing was having private insurance (OR = 2.97) (95%CI: 1.067-8.242) (p<0.05). None of the other suggested factors were found to increase the odds of being accepted for transplant listing (Table 2).

Table 1. Distribution of Study Characteristics

	Total N = 137	Accepted n = 106	Not Accepted n = 31
Gender			
F	51(37%)	42(40%)	9(29%)
M	86(63%)	64(60%)	22(71%)
Psych treatment history*			
Yes	29 (21%)	22 (21%)	7 (23%)
No	107 (79%)	83 (79%)	24 (77%)
Alcohol-Use history			
Yes	64 (47%)	47 (44%)	17 (55%)
No	73 (53%)	59 (56%)	14 (45%)
Illegal Drug-Use History			
Yes	27 (20%)	17 (16%)	10 (32%)
No	110 (80%)	89 (84%)	21 (68%)
Other medical conditions			
Yes	70 (51%)	55 (52%)	15 (48%)
No	67 (49%)	51 (48%)	16 (52%)
Type of Insurance			
Private	76 (58%)	66 (62%)	10 (38%)
Reforma	56 (42%)	40 (38%)	16 (62%)
	Min/Max	Mean/SD	Mean/SD
Age	19-68	50+9	51+11
MELD score	8-37	18+8	17+7
BDI-II	0-51	14+11	16+10
BAI	0-53	14+12	13+13

*variables considered without missing values.

Table 2. Factors Included in the Logistic Regression

Variables	Significance	Odds Ratio	Confidence Intervals	
Marital Status	.167	.435	.133	1.418
Psych. History	.919	.941	.294	3.017
Education	.072	.371	.126	1.093
Alcohol Use History	.321	1.808	.561	5.828
Illegal Drug History	.055	.317	.098	1.025
Gender	.342	.544	.155	1.910
Private insurance	.037	2.966	1.067	8.242

(P < .05)

Discussion

Our findings indicate that the main obstacle these patients face is related to insurance coverage, which obstacle has been

discussed in previous studies dealing with the disparities related to access to liver transplantation. Nguyen identified private insurance as an independent predictor of liver transplantation and noted that if a patient has private insurance, access to a subspecialist will be available and referral to a liver transplant center will occur (17). An insurance provider is among the variables that influence which patients get listed as well as patient's physician preferences, referral patterns, and regional and physician differences on appropriateness for listing and removal (11). Other researchers have also reported that insurance status is strongly associated with being referred and evaluated for liver transplantation with those having commercial insurance being much more likely to be referred and evaluated, much less likely to die, and more likely to be placed on the waiting list by a transplant center. Our findings are congruent with these studies (14). Having private insurance increased the chances of a candidate to be included in the list for transplantation in our population of Puerto Rican patients. Moreover, Puerto Rican patients also need to ensure that they have adequate financial coverage as a prerequisite to being referred to the United States transplant center after completing the pre-transplant evaluation in Puerto Rico. The financial coverage must be available for both the transplant procedure and, more importantly, for the post-transplant immunosuppressants if a given patient is to be considered for listing. We note that patients with government insurance may encounter more challenges in coverage when they move to the United States, as they need to obtain local insurance for post-transplant medications, which will no longer be provided by the Puerto Rican government insurance when out of state. This is a barrier because though financial aid to pay for the transplant may be present, it is possible that additional coverage for immunosuppressants may not be available.

Most of our patients had identified a person to support their travel needs. Although social support, defined as travel support for our purposes, was not found to increase the possibility of being accepted on the transplant list, it is interesting that the type of *travel support* most commonly reported (98%) was provided by a member of the patient's immediate family followed by that offered by relative member of that patient's extended family. Others have reported that immediate family and extended family members are the main support for transplant patients (18). The support person provides basic care, transportation, medication verification, emotional sustenance, and close involvement from the initial stages of assessment to the later stages of the transplantation process (19). Our results indicate that this support is provided mostly by a close family member and requires the supporter to also leave his/her social network to perform the duties of caretaker.

Results from the depression and anxiety inventories in the studied population suggest the existence of moderate symptoms of both conditions in a high percentage of patients. This finding is expected in the population of patients with advanced chronic

liver disease since depression is higher in medically ill patients and presents with more physical complaints. Depression has recently been associated with increased mortality after transplantation (20). Other factors contributing to depressed moods could include hopelessness and helplessness regarding the transplant process and feelings of guilt over the disruption and deprivation experienced by relatives (21). In heart transplant patients, anxiety is related to fears of annihilation, passivity and impotence, object loss, and guilt (22). Also implicated are the long wait times for transplantation, the knowledge of the gravity of the illness, and the possibility of complications. In the Puerto Rican patients included in our study, these feelings can also represent concerns about moving out of their social networks, language difficulties, financial barriers, and postoperative results. Absence of a previous psychiatric history, in contrast to results from the anxiety and depression inventories, suggests that there is a situational context for these symptoms and that prompt referral for mental health services should be made to help the patient understand his/her medical situation and develop the psychological resources necessary to cope.

We acknowledge several limitations of this study. Bias could have been caused using only those records that had a decision regarding listing; records in which no decision had been made were not included.

Therefore, further study of the factors that are present in the excluded records (those with no decision) is strongly recommended. To diminish bias regarding information, we worked to ensure that the quality and extent of the collected data from the records were similar. Those records in which data were lacking or were formatted differently were not included. The limitation of a small sample size is acknowledged, which we understand restricts the generalizability of the results. Nonetheless, our findings contribute to the existing literature and confirm the findings of previous research on disparities in access to healthcare services. We did not include the language and transportation (time to transplant center) variables because of the lack of data with regard to these characteristics, which exclusion we consider to be another limitation. However, we understand these are barriers for this population. Future studies including data on the language and transportation barriers, physician attitudes regarding referral, and patient's preferences will also allow us to develop strategies and advocate for services to this population.

In conclusion, the results of our study reveal that there are factors within the (PR) healthcare system that limit access to transplantation and that these factors are related to insurance coverage. Health insurance organizations are part of the healthcare system and are major factors in the financing of health services for patients. Our study confirmed the role of private insurance in this aspect. The results suggest that private insurance would increase the possibility of Puerto Ricans having access to transplantation by increasing their possibility of being placed on the transplant list.

We believe that changes to governmental and institutional policies regarding insurance coverage for this population are urgently needed. We also believe that the creation of a liaison between the transplant team and the insurance providers that will aid in the negotiation of adequate coverage for specific services for this population is needed.

Finally, health practitioners working with liver transplant patients need to increase their awareness of personal biases that might affect the delivery of transplant-related services and be empathic to the needs of the patients to ensure equity and justice in this process. In Puerto Rico, we have been committed to providing resources to the community of liver transplant patients for many years, despite the lack of a liver transplant program on the island. As part of that commitment, the University of Puerto Rico School of Medicine has been providing pre-evaluation services, identifying transplant centers in the US, and providing follow-up post-transplant care to transplant patients. Because of the significant challenges that this system represents for Puerto Rican patients, a substantial effort has been made to create the first liver transplant center in Puerto Rico, which performed the first liver transplant locally in February 2012; transportation, language, and waiting time for evaluation at a US-based transplant center will no longer be obstacles. Nonetheless, advocacy regarding the availability of insurance coverage for the procedure and immunosuppressants must continue, not only for Puerto Rican patients, but also for all of the members of the vulnerable and less-advantaged populations waiting to have this life-sustaining procedure.

Resumen

Objetivo: Entre los retos que enfrentan los pacientes puertorriqueños de trasplante hepático se encuentran la falta de apoyo social para mudarse fuera de PR, dificultad para obtener seguro médico y limitaciones de idioma. Estos factores pueden resultar en acceso limitado al trasplante hepático, una forma de disparidad de salud. El objetivo del estudio es describir por primera vez un grupo de candidatos de trasplante hepático puertorriqueños y conocer si los factores mencionados limitan el ser enlistados para trasplante. **Métodos:** Se realizó un análisis retrospectivo de los expedientes médicos de pacientes evaluados como candidatos utilizando bases de datos no públicas del centro de referido y de trasplante. Candidatos (137) de la Clínica de Trasplante de la Escuela de Medicina de la Universidad de Puerto Rico preevaluados para trasplante durante el periodo de 2002 a 2008 fueron seleccionados. **Resultados:** Los expedientes de 86 hombres y 51 mujeres fueron revisados. Las etiologías predominantes de la enfermedad hepática fueron el virus de hepatitis C (36%), una combinación de etiologías (26%), enfermedad hepática alcohólica (16%) y cirrosis criptogénica (10%). Mientras que el apoyo social y el historial de enfermedad psiquiátrica no afectó el ser incluido en la lista, el seguro

médico privado aumentó las posibilidades de ser enlistado para trasplante hepático (OR = 2.97) (95%CI: 1.067-8.242) ($p < 0.05$). **Conclusión:** El acceso a un seguro médico privado aumenta las posibilidades de los pacientes a ser enlistados para trasplante. Las recomendaciones para sobrepasar la barrera de acceso a trasplante que enfrentan los pacientes sin seguro privado se discuten.

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References

1. Pérez CM, Suárez E, Torres EA, Román K, Colón V. Seroprevalence of hepatitis C virus and associated risk behaviors: A population-based study in San Juan, PR. *Int J Epidemiol* 2005;34:593-599.
2. Pérez CM, Marrero E, Meléndez M, et al. Seroepidemiology of viral hepatitis, HIV and herpes simplex type 2 in the household population aged 21-64 years in Puerto Rico. *BMC Infect Dis* 2010;10:76.
3. Armstrong GL, Wasley A, Simard EP, McQuillan GM, Kuhnert WL, Alter MJ. The prevalence of hepatitis C virus infection in the United States, 1999 through 2002. *Ann Intern Med* 2006;144:705-714.
4. Carlo VL, Torres EA, Magno P, Vazquez M, Gonzalez-Keelan C, Sanabria D. Hispanics with chronic hepatitis C have more fibrosis and cirrhosis. *Gastroenterology* 2003;124:A384.
5. Department of Health, Auxiliary Secretary of Planning and Development, Division of Statistical Analysis, San Juan, PR, 2007.
6. Romero Marrero C, Ortiz AP, Pérez CM, Pérez J, Torres EA. Survival of hepatocellular carcinoma in Puerto Rico. *P R Health Sci J* 2009;28:105-113.
7. Altekruse SF, McGlynn KA, Reichman ME. Hepatocellular carcinoma incidence, mortality, and survival trends in the United States from 1975 to 2005. *J Clin Oncol* 2009; 27:1485-1491.
8. Alsina AE, Torres EA, Antúnez I, et al. Outcome of liver transplantation in a Hispanic population: 100 liver transplants in Puerto Ricans. *P R Health Sci J* 2009;28:301-306.
9. Dobbels F, Vanhaecke J, Dupont L, Nevens F, Verleden G. Pretransplant predictors of posttransplant adherence and clinical outcome: An evidence base for pretransplant psychosocial screening. *Transplantation* 2009;87:1497-1504.
10. Jowsey SG, Taylor ML, Schneekloth TD, Clark MM. Psychosocial challenges in transplantation. *J Psychiatr Pract* 2001;7:404-414.
11. Moylan CA, Brady CW, Johnson JL, Smith AD, Tuttle-Newhall JE, Muir AJ. Disparities in liver transplantation before and after introduction of the MELD score. *JAMA* 2008;300:2371-2378.
12. Mathur AK, Schaubel DE, Gong Q, Guidinger MK, Merion RM. Racial and ethnic disparities in access to liver transplantation. *Liver Transpl* 2010;16:1033-1040.
13. Stevenson L, Faucher Y, Hewlett S, Klemm K, Nelson D. Chronic hepatitis C virus and the Hispanic community: Cultural factors impacting care. *Gastroenterology Nurs* 2004;27:230-238.
14. Bryce CL, Angus DC, Arnold RM, et al. Sociodemographic Differences in early access to liver transplantation services. *Am J Transplant* 2009;9:2092-2101.
15. Beck A, Steer RA, Brown GK. The Beck Depression Inventory-II Manual, 2nd ed. San Antonio, TX: The Psychological Corporation, Harcourt Brace and Company; 1996.

16. Beck A, Steer R. *The Beck Anxiety Inventory Manual*. San Antonio, TX: The Psychological Corporation, Harcourt Brace and Company; 1993.
 17. Nguyen GC, Segev DL, Thuluvath PJ. Racial disparities in the management of hospitalized patients with cirrhosis and complications of portal hypertension. A National Study. *Hepatology* 2007;45:1282-1289.
 18. Cetingok, M, Winsett RP, Russell CL, Hathaway DK. Relationships between sex, race, and social class and social support network in kidney, liver, and pancreas transplant recipients. *Prog Transplant* 2008;18:80-88.
 19. Krahn LE, DiMartini A. Psychiatric and psychosocial aspects of liver transplantation. *Liver Transpl* 2005;11:1157-1168.
 20. DiMartini A, Dew MA, Chaiffetz D, Fitzgerald MG, de Vera ME, Fontes P. Early trajectories of depressive symptoms after liver transplantation for alcoholic liver transplantation for alcoholic liver disease predicts long-term survival. *Am J Transplant* 2011;11:1287-1295.
 21. Levenson JL, Olbrisch ME. Shortage of donor organs and long waits: New sources of stress for transplant patients. *Psychosomatics* 1987;28:399-403.
 22. Levenson JL, Olbrisch ME. Psychosocial evaluation of organ transplant candidates: a comparative survey of process, criteria, and outcomes in heart, liver, and kidney transplantation. *Psychosomatics* 1993;34:314-323.
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