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# Waiting for a Liver Transplant in New Mexico; Understanding the State's Multi-layered Adversity

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## Abstract

Contrary to the assumption of consistent medical care for patients with specific illnesses in the United States, research reveals vast inconsistencies and inequalities in healthcare delivery, affecting various aspects such as mental illness diagnosis and management, life expectancy differences, overall mortality rates, and healthcare accessibility due to racial, ethnic, and cultural disparities. Liver transplantation, particularly studied in the context of the state of New Mexico (NM), highlights the multilayered inherent disadvantages faced by its citizens. Despite these challenges, the new liver transplantation allocation system implemented by the Organ Procurement and Transplantation Network (OPTN) in 2020, which focuses on geographic concentric circles rather than donor service areas (DSA), cautiously raises hope for reducing these inequities. The future of decades' worth of adversity remains uncertain, but we are optimistic that New Mexicans' systemic difficulty in getting a new liver would eventually be eased.

**Keywords:** Healthcare adversity, Healthcare inequality, Liver transplantation, New Mexico

## 1. Introduction

According to the 2020 United States Census, approximately 62.1 million individuals in the country identify as Hispanic/LatinX, constituting about 18% of the total population. Despite this broad representation, there are distinct geographical concentrations of this demographic across the nation. NM stands out with the highest proportion, where 49.26% of the state's population identifies as Hispanic/LatinX. Texas follows closely at 39.7%, and California at 39.4%, ranking second and third, respectively.

The study of Social Determinants of Health (SDOH) explicitly highlights how ethnicity influences access to education, employment opportunities, community resources and healthcare access, which ultimately impacts health outcomes and disparities in marginalized communities.<sup>1-6</sup>

Liver transplantation offers a unique opportunity for precise examination of outcomes due to its nationally standardized systemic process, enabling clear

delineation of the influence of Social Determinants of Health (SDOH) and socio-economic conditions on liver disease prevalence and outcomes. Studying the impact of ethnicity on liver transplantation is most logical in the state with the highest percentage of Hispanic/LatinX population, such as NM.

Recognizing and understanding the major factors and challenges in medical services is the first step in addressing the gap in quality health care. Doing so may lead to interventions designed to bridge these gaps and better provide consistently equitable care to all populations.<sup>7,8</sup>

## 2. Historic background

Dr. Thomas Starzl performed the first liver transplant at the University of Colorado in 1962.<sup>9</sup> This was a unique advancement in the treatment of liver disease. For the subsequent 25 years, there was not a systemic way to triage for the acuity of need or for the severity of disease in patients in whom liver transplant was to be considered.<sup>10</sup>

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In 1984, the increasing demand for liver transplantation accompanied by a decreased availability of transplantable organs, resulted in the passage of the National Organ Transplant Act (NOTA). NOTA resulted in the creation of the Organ Procurement and Transplantation (OPTN) which was designed to insure equitable allocation of donor organs.<sup>11</sup>

This transition marked the initial move towards restructuring liver transplantation, shifting from a system primarily reliant on individual physicians and hospitals to one organized around the urgency of transplant needs. Under OPTN, patients were placed on a liver transplant waiting list according to severity of disease largely based on individual hospital evaluations. Four groups were considered: Group 1 included patients needing immediate life-saving transplantation; Group 2 were those patients hospitalized in the ICU; Group 3 included patients in non-ICU units; and Group 4 were non-hospitalized patients.<sup>12</sup> There was no rigid standardization of these groups and manipulation of hospitalization could easily move patients up or down the list.

In 1996, the Child-Turcotte-Pugh (CTP) score was added as a measure of disease severity. The implementation of CTP score added more objectivity to the process and eliminated some of inconsistencies inherent in the OPTN. The CTP score was based on laboratory data that can assesses liver function; including Prothrombin (PT), International Normalized Ratio (INR), bilirubin and albumin. These objective measures were used in conjunction with relatively subjective clinical evaluations such as ascites and encephalopathy.<sup>13</sup> Despite this advancement, there was significant concern about manipulation of reporting and result stratification concerns, so in 1998, the US Health and Human Services (HHS) outlined the principles governing organ allocation in a document termed the 'Final Rule'.<sup>14</sup>

The 'Final Rule' set a series of allocation performance goals which aimed to distribute "organs over as broad a geographic area as feasible and in order of decreasing medical urgency".<sup>15</sup>

Despite its title, the "final rule" faced numerous issues. These included some transplant center behavior, such as listing patients at multiple centers, which led to inefficiencies in organ allocation, as well as both geographic and waiting-time disparities. The geographic disparities mainly stemmed from relying on the proximity of the individual to donor hospitals. Regions with shorter wait times had a higher chance of receiving organs, disadvantaging those in areas with longer waits. By the early 2000s, the waiting list for liver transplantation had grown to more than 20,000 patients. This led to more deaths among patients who were on the list.<sup>16</sup>

Length of time on transplant waiting list then became a dominant factor for determining allocation of donated livers during that period. However, after two studies were published that documented that time spent on the waiting list as not associated with an increased death rate, waiting list time became a much less critical factor. This shifted the focus from waiting times back to medical necessity, which was vital to the creation of the MELD score.

By 2002, the MELD score was developed to estimate the risk of mortality of patients awaiting liver transplant and this successfully defined the criteria for medical urgency.<sup>17</sup> The MELD score is used in response to a government mandate to distribute organs based on medical necessity.

In 2013, the Regional Share 35 policy was established which was to be an impetus to eliminating geographic and racial disparity. It was created to provide improved access to organs for patients with MELD scores  $\geq 35$ , this policy was enacted because of the high waitlist mortality in patients with the highest MELD scores.<sup>18</sup> Despite this effort, when put in practice, Regional Share 35 policy still favored regions with higher donor rates and patients with higher MELD scores, perpetuating unequal access to organs and exacerbating waitlist disparities among transplant candidates. As a result, in 2020, the OPTN implemented a new allocation system for liver transplantation base on concentric circles of geographic proximity rather than arbitrarily delineated donor service areas (DSA).<sup>19</sup> This policy replaced the decades old DSA with 11 transplant regions. This system was based on the urgency of patient need and the distance between donor hospital and recipient hospital. Per policy, livers were first offered to patients with urgent need at hospitals within 500 miles of the donor hospital. Further study by Goldberg et al. found that increasing the distance between transplant centers from 150 mile to 500 miles led to significantly higher mortality rates.<sup>20</sup>

Even though attempts were being made to address geographic needs, albeit incompletely, racial disparity remained a more difficult issue to address. Black patients had disproportionately low transplant rates relative to the number of deaths caused by end stage liver disease. This, despite better post-operative outcomes for black patients.<sup>21,22</sup>

New Mexico is the only state without a liver transplant institution. While it may appear that this constitutes a significant portion of the issue, the actual problem is more fundamental and multifaceted in nature. The challenge stems from the absence of a focal point, the capacity for referral, and the prospects of receiving care following a referral. We will outline the difficulties encountered

in the chronological order of the process required to undergo a liver transplant when necessary.

### 3. Getting through the transplant door in New Mexico

Primary care providers are a vital link in the chain which will connect liver transplant candidates to the needed liver as they are often the initiators of the process. NM is consistently ranked very low on numbers of primary care physicians per population.<sup>23</sup> It is expected that these primary care physician shortages will continue in NM into the foreseeable future. In a study that developed demand and supply models to forecast predicted physician shortages in each of the 50 states utilizing population size and age, NM was anticipated to have the second largest statewide physician shortage.<sup>24</sup>

Primary care physicians serve as the gateway for patients to access specialty care in the US. In New Mexico, the scarcity of primary care physicians poses a significant challenge, as patients requiring liver specialist care must first obtain a referral from their primary physician, further complicating access to specialized treatment. Gastroenterologists and Hepatologists play a key role in arranging liver transplants as well. A retrospective study from 2002 to 2010 showed that for patients referred for liver transplant, the number of gastroenterologists in their home DSA independently increased the chance of receiving a liver transplant by 12% with each additional gastroenterologist per 100000 population.<sup>25</sup> Our literature review revealed a lack of national or statewide statistics for comparing the prevalence of gastroenterologists in NM with other demographics. Nonetheless, it is not unreasonable to infer that a state consistently ranking poorly in the prevalence of primary care physicians would likely exhibit a similar shortage in gastroenterologists or hepatologists.

### 4. Pervasive racial disparity

Another hurdle for New Mexicans relates to the odds of referral for liver transplant. Numerous studies show that minority population members are less likely to be referred for liver transplant. To some degree, this disparity stems from these populations being publicly insured and geographically distant from transplant centers. These factors lead to discouragement from placement on transplant lists and they do not diminish after the patients are listed for the process.<sup>26–29</sup>

In New Mexico, the racial makeup of the population not only decreases both referral rates and the

rate of acceptance to the waitlist, but it also increases the likelihood of removal from the list and lower rates of acceptance for transplant once on the list.<sup>29</sup> Several studies have tried to investigate the factors which contribute to these disparities and several issues have been noted including selection bias at the level of referral,<sup>30</sup> funding sources, the type of insurer<sup>31,32</sup> and socioeconomic status.<sup>29</sup>

### 5. Unfortunately, special

New Mexicans needing liver transplant face difficulty at every step of the process. New Mexico has no transplant centers and, as such, more than 95% of the population live more than 150 miles from a surgical center. This, as previously mentioned, was shown by Goldberg et al. that those patients living more than 150 miles from transplant centers have increased mortality.<sup>20</sup> In addition, those living further away from transplant centers have less access to complex care and are usually sicker at the time of listing for transplant. There is also reluctance to be moved to another state for care as many New Mexicans are transferred to Arizona or Colorado resulting in delay of care. This is supported by higher MELD scores for non-Hispanic blacks and Hispanic/LatinX at the time of referral.<sup>33</sup> This geographical peculiarity may be one of the reasons why New Mexicans have the highest age-adjusted deaths from chronic liver disease. According to CDC data, age-adjusted death rates from liver disease from 2005 to 2014 are the lowest in New York, (where the entire population lives within 150 miles of a liver transplant center). By contrast, NM had the highest age-adjusted death rates, and >95% of those states' populations live >150 miles from an Liver Transplant center.<sup>33</sup>

Finally, in the event of successful listing on a liver transplantation list, data suggests that the critical step of transitioning from transplant candidate to transplant recipient demonstrates racial and ethnic variation as well.<sup>29</sup> A retrospective study that evaluated the correlation between candidate ethnicity and race and liver transplant rates for candidates with end stage liver disease that were waitlisted between 2002 and 2007 suggested that Hispanic/LatinX candidates had a significantly lower transplant rate compared to the white population.<sup>33</sup>

### 6. Distance helping or hindering treatment

If a candidate from NM is eligible for transplant, he/she, along with family members, are forced to relocate out of state to pursue treatment, as NM is the only state without a liver transplantation center. However, based on a 2019 study, only (2.8%) of



waitlist registrations pursued listing at a distant center. This particularly important for New Mexicans as placement on a liver transplant waitlist outside the home transplantation region has shown to be associated with disproportionate level of engagement in patients who are minorities, have lower levels of education, or have public insurance.<sup>34</sup> Distant placement has been New Mexican's only option since the closure of the only liver transplantation center in 1999.<sup>34</sup>

The financial burden of travel, recovering away from home, along with the financial responsibilities of living donor expenses that are usually covered by the recipient (these refer to any expenses a living donor may incur such as medical evaluation costs and transport costs) further compounds the financial strains faced by liver transplant recipients who must travel out of state.<sup>35</sup>

Considering that travel is the only recourse for New Mexicans requiring a liver transplant, it's essential to weigh the financial ramifications of the procedure against the financial circumstances of New Mexicans; NM tops the five poorest U.S. states with a median household income of \$51,945, with a poverty rate of 18.2%, the third highest in the country. The estimated mean cost of U.S. liver transplantation was US\$163,438 (US\$145,277–181,598) compared to US\$103,548 (US\$85,514–121,582) for other Organization for Economic Cooperation and Development (OECD) countries. The total cost of liver transplantation is forecast to increase by 33% in 10 years and 81% in 20 years.<sup>36</sup> That does not include non-medical costs including food, lodging, travel, childcare, lost wages, etc. One can estimate that while patients may not bear the entire financial burden, there are significant personal and ancillary costs that accompany a procedure of this magnitude. This is something that we as providers often marginalize and overlook.

## 7. Conclusion

In the realm of liver transplants, New Mexicans encounter a complex array of barriers, encompassing ethnic, racial, economic, geographic, and structural dimensions. The recent adoption of the liver transplantation allocation system by OPTN, with its focus on geographic concentric circles rather than DSA, presents a promising avenue for mitigating these disparities. By placing a greater emphasis on patient health status over zip codes, this strategy holds potential for rectifying the inequities faced by New Mexicans. However, given the well-known historical shortcomings of well-intended systems in clinical practice, the responsibility falls heavily on physicians,

healthcare providers, and epidemiologists to actively engage in ongoing assessment and advocacy. Physicians and healthcare workers bear the responsibility of advocating for marginalized groups, and grasping the injustices they endure is the initial stride toward proactive involvement and change. Their critical role in scrutinizing the transplantation landscape and vocalizing concerns to policymakers is indispensable in ensuring that adjustments to the system effectively deconstruct inequities.

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