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Let's Take Two Steps Forward

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On May 25, 2020, George Floyd was killed by police in Minneapolis, Minnesota triggering a modern-day civil rights movement within the Black community. Simultaneously, states were beginning to implement widespread shutdowns to contain the COVID-19 virus—a virus that contributed to a 3-year downturn in life expectancy for Black and Hispanic men. In this age of continuous news and social media, the fragility of the lives of marginalized racial and ethnic groups was on full display. While these health disparities were well known to investigators entrenched in health equity work, there had been a general apathy concerning these issues within the greater community, including in science. More recently there has been increased interest in racism globally and a public apology from the National Institutes of Health for underfunding the field, supported by a \$100 million commitment to disparities research.^{1,2} As investigators rush to take advantage of this new funding, some would even say that health disparities research is now “en vogue.”

The health disparities facing vulnerable populations seeking liver transplantation have similarly received increased attention in recent years. In fact, in this issue of *Liver Transplantation* there are two articles exploring this topic. Henson et al³ set out to provide a use case in how to identify local area-level social determinants that pose barriers to referral for liver transplant evaluation. Within North Carolina, they identify areas with a low density of GI providers, food insecurity, poor access to technology, and overall area-level deprivation. They demonstrate that these areas have the lowest rates of referral for liver transplant evaluation, yet the highest liver-related mortality. Ultimately, the authors propose liver transplant centers use similar methods to identify areas of need and to target interventions in their own catchment areas. In the second paper, Lim and colleagues⁴ use United Network of Organ Sharing (UNOS) data to explore racial disparities in waitlist outcomes, specifically in patients with non-alcoholic steatohepatitis (NASH) cirrhosis. They find that Black and Hispanic patients were listed with higher Model for End-Stage Liver Disease (MELD) scores and that Hispanic patients were less likely to undergo liver transplantation than their White counterparts. Conversely, they found that Black patients with NASH cirrhosis were more likely to undergo liver transplantation than White patients. These studies confirm ongoing racial, ethnic, and socioeconomic disparities across the full liver transplant care continuum from referral to transplantation.

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Health disparities research is a multidisciplinary field that includes influences from epidemiology, public health, sociology, and history. Without an understanding of these complex nuances, it can be challenging to produce scientifically rigorous and socially responsible work. In an effort to provide guidance, some journals have begun to publish best practices for how to design, report, contextualize, and mitigate unintended harm.⁵⁻⁸ This commentary is not meant to provide an exhaustive description of best practices but to highlight five best practices that are essential to ensuring forward momentum in liver transplantation disparities research (Figure 1).

1. *Address appropriate phase in health disparities research.* Kilbourne et al⁹ describes three phases of disparities research: 1) detecting, 2) understanding, and 3) reducing. After a disparity has been detected in a vulnerable population, the next step should be to understand the determinants of that disparity at the patient, provider, health system, and/or health policy level. Importantly, some areas in transplant hepatology still need detecting (i.e., liver transplant outcomes in Native American populations), but repeated detection of the same disparities prevents forward progress in the field. To avoid duplicating efforts, a thorough review of the literature that includes non-gastroenterology and hepatology journals as well as a review of subset analysis of larger studies that may have not focused primarily on disparities should be performed.
2. *Seek out necessary expertise.* Imagine a study about the epigenetics of fatty liver disease that did not include experts in chronic liver disease or epigenetics. How could the study design, analysis, or conclusions be trusted? Health disparities research is often complicated by biased datasets, complex conceptual frameworks, and nuanced data analysis considerations. Research that is not rigorous, well informed, and well executed can lead to spurious results that can hurt marginalized groups. Allies interested in doing this work should seek to build expert multidisciplinary teams that can help apply established conceptual frameworks as well as assist with study design, data analysis, and result interpretation.
3. *Explore social determinants of health.* While race, or racism, contributes to many health disparities, much of its impact is mediated through the social determinants of health (SDOH). All prospective studies that plan to explore racial and ethnic disparities in liver transplantation should also collect and analyze SDOH data. Similarly, observational studies should utilize available area and individual-level SDOH to inform results. When SDOH data are unavailable, the manuscript discussion should acknowledge this and reflect on potential hypotheses for how the SDOH may have impacted the study findings.
4. *Understand race as a social construct.* Race is different in time and space and shaped by geographic, cultural, and sociopolitical forces.¹⁰ The definition of African American or Black in the United States has changed multiple times throughout history.¹¹ Furthermore, Black race as we know it in the United States (US) has little meaning in many parts of the world. Any phenomenon that varies in both time and space cannot be biologic and should not be

treated as such. Lim and colleagues in their discussion of higher rates of liver transplantation in Black individuals provide an outdated hypothesis of larger muscle mass leading to inappropriately high creatinine levels driving inflated MELD scores and higher rates of liver transplantation. This is the very thinking that underlay the race-based eGFR equations health equity scholars have recently had success rectifying.¹² Race does impact health outcomes in the US, however, not because it reflects a person’s biology, but because it reflects social stratification, injustices, and systemic racism. It is imperative authors provide analysis that considers race in the appropriate context.

- 5. *Use appropriate nomenclature.* There has been an important move in hepatology to change nomenclature to precisely describe disease processes and to be non-stigmatizing to patients because nomenclature matters. There are references on how to use accurate, bias-free language when describing race and ethnicity in scientific writing that can be referenced for detail and should be referenced regularly as nomenclatures changes.⁵ Two frequent mistakes include using race as a noun (i.e., “Hispanics” or “minorities”) instead of as adjectives followed by an appropriate noun (i.e., Hispanic individuals, minority groups); and using African-American interchangeably with Black, when persons of Black race with ancestry outside of the US were included in the analysis.

I published my first paper on racial and ethnic disparities in 2009.¹³ Since that time, at some point I have made all five of these missteps. The key is to recognize the error and take the necessary steps to ensure the same mistakes are not made again. Investigators and journal editors should work together to ensure the integrity of health disparities research and the advancement of the field of liver transplantation toward health equity.

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Abbreviations:

MELD	Model for End-Stage Liver Disease
NASH	non-alcoholic steatohepatitis
SDOH	social determinants of health
UNOS	United Network of Organ Sharing
US	United States

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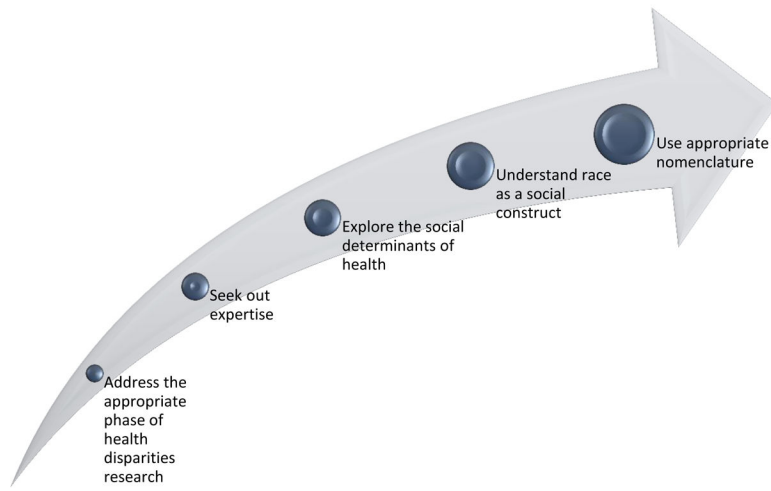


Figure 1.
Best Practices in Health Disparities Research

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