The Effect of Unequal Demographic Representation in Medical Studies on Health Disparity

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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II. The Effect of Unequal Demographic Representation in Medical Studies on Health Disparity

(STS Research Paper)

Introduction:

      The United State of America, often self-labeled as the greatest country in the world, has the largest gross domestic product (GDP) globally with worse health outcomes relative to other economically developed nations. In particular, infant mortality rates, percent of adults aged 20-79 with diabetes, and other adverse health outcome rates are significantly higher comparatively to other nations (Geiss, 2014). There are many factors that this phenomenon is attributed towards, but one of the leadings causes is the capitalist nature of the healthcare system (Kennedy, 2015). In the United States (US) today, these negative health outcomes driven by profit, affect different people groups disproportionately (Don, 2015). A critical but often overlooked contributor to these disparities is the unequal demographic representation in medical studies. Historically, medical research and datasets have been focused disproportionately on certain populations, resulting in the marginalization of others (Benjamin, 2019).

      The significance of demographic diversity within medical research cannot be overstated. Doing so allows for medical devices, algorithms, models, and more to be universally applicable and just across all populations. The lack of diversity in specific data pools has contributed to the marginalization of racial, ethnic, and gender groups and the proliferation of health inequality. For example, medical algorithms used in health management have faced scrutiny regarding racial bias created by ill-represented datasets (Obermeyer, 2019). This bias extends to current medical devices such as the pulse oximeter, a device placed on patients' finger which uses infrared light to calculate blood oxygen content (Valbuena, 2022). The device has the light emitter on one side,

with a detector on the other; the amount of light that is absorbed by the oxygen carrying cells is used to calculate the oxygen content in the blood. The data used to calibrate the device's absorption readings that yield blood oxygen content was collected on predominantly white patients. This led to inaccurate readings for people of color. The darker pigmentation of their skin, due to a greater concentration of melanin, would absorb more infrared light and yield greater blood oxygen content readings than what was accurate (Sjoding et al., 2020).

This thesis explores the extent to which unequal demographic representation in medical studies contributes to negative health outcomes by exploring both the historical context of the foundations upon which the US medical industry was built, as well as the current state of demographic inclusion in medical research. With this context, the skewed representation in sleep studies becomes an important concern, as it is capable of perpetuating or worsening health disparities (Obermeyer et al., 2019). It is crucial, therefore, to examine the historical factors that shape how research studies have been conducted, as well as observing how they are conducted currently. Specifically, this thesis will be contextualized within the case of sleep studies at the University of Virginia (UVA) Sleep Disorders Center. A sleep study, or polysomnography, is a medical test that tracks sleep parameters using electroencephalogram (EEG) technology and other devices to measure brain activity, heart rate, and respiration rate during sleep. This is used to diagnose sleep disorders. Sleep studies can also refer to research studies that are conducted in the sleep disorder field. The examination of both concepts will be done using the Social Construction of Technology (SCOT) lens to consider the societal elements that might contribute to demographic disparity in patient population at the UVA Sleep Disorders Center. Through this lens, the relevant social groups in the technological system − that is the field of sleep research and treatment of sleep disorders – are broken down in order to consider some of the factors that

might lead to bias in this field. Further, these groups are contextualized by examining some of the social constructs that exist which uphold a system where racial and economic discrimination is proliferated. In particular, the patients, healthcare professionals, shareholders, and companies involved all have priorities that work together and clash to create the cycle that proliferates demographic disparity. Without addressing this phenomenon and understanding that the system is the culmination of implicit bias, it is not possible to break past that cycle. The social factors present in this technological artifact are broken down and concluded upon. This was discussed to better understand the next steps towards promoting inclusivity and accurate demographic representation, in the hopes that marginalized people groups would face less systemic bias.

Research Question and Methodology:

The STS research question used to focus the scope of all unequal demographic representation in medical studies is: "What are the factors that shape how sleep studies are conducted at the University of Virginia Sleep Clinic?" To answer this question, an in-depth literature review was conducted. This included both historical instances of bias within medical research as well as historical data regarding demographic breakdowns at the University of Virginia. Due to the lack of specific demographic information that can be disclosed by the UVA Sleep Disorder Center to protect patient data, literature that can act as a reasonable comparison will be used. For the literature review, Google Scholar was used to search for relevant journals with studies that supported the claims made in this paper. In addition, the UVA library was accessed to obtain books to further support the findings. Limitations to this methodology lie in the connections that have been made between the UVA Sleep Disorder Center (SDC) and the supporting papers used to illustrate the concepts. Without the demographic statistics for the specific SDC, only assumptions can be made based on the limited data accessible for the UVA

Health System as a whole. In addition, interviews with medical staff of the UVA SDC were originally intended but could not come to fruition.

Literature Review:

Pinch and Bijker's work from *The Social Construction of Facts and Artefacts* (1984) offers a lens to understand the relevant groups in the status quo of how sleep studies are conducted. These two introduced the concept of "relevant social groups" as being essential in understanding how technological artifacts − which they broadly define as any product, tool, process, or system developed through technological means – are constructed. Within the context of sleep studies, these technological artifacts could be seen as the research outcomes, methodologies, study protocols, and patient satisfaction. These stakeholders influence the design, interpretation, modifications, and product with different interests, values, and power inherent to their position in the system. For example, in the context of medical research, relevant social groups might include the patients, healthcare professionals, researchers, pharmaceutical companies, regulatory bodies, and investors. Each of these groups holds their own priorities and goals, which influences their decision-making and perception of medical technology.

A notable example of this is that patients might prioritize safety and efficacy in their experience as a trial participant, while researchers may focus on the scientific results of the treatment or therapies. Alternatively, the companies leading the study, both the hospital and the potential sponsor institution funding the study could prioritize marketability and profitability. In the US, the financial security and gain of research is important for its success, given that the entire industry stands on capitalism foundations. US hospitals also maintain the responsibility to continue to strive for profitability, as generating more profit leads to better resources; the more

resources a hospital has, the more capable it is at producing high level care. By operating in a capitalist manner, each relevant party is looking to maximize their individual gain. The US places the responsibility of governing this balance of profit and care on the private sector, the layman is left relying on health insurers (Kennedy, 2015). With health insurance companies being profit-driven, the market is in a constant cycle, where every party except the patients must prioritize fiscal gain to ensure their own security. Considering the occupational stratification that exists in the US healthcare system, there is the ideology that US Medical Doctors (USMDs) have better training when compared to others in healthcare, particularly non-USMDs. Occupational stratification is, in this case, defined as the implicit boundaries set in place that prevent upwards mobility for non-USMDs, while further enabling upwards mobility USMDs.

Therefore, USMDs consider themselves deserving of the most prestigious and high-paying jobs to justify the extreme cost and rigor of US medical school (Jenkins, 2020). With a culture where the healthcare providers view exorbitant income as a right, health insurance companies focus solely on profit, and hospitals and clinics are cognizant of the extreme costs required to operate, patients' quality of care and efforts towards their equitable treatment can become a secondary goal. This further emphasizes the cycle in which the US medical system operates: Profit-driven behavior from all service-providing parties. When considering the capitalist backbone of the US medical system, it is also important to note that the US also has a system where MDs receive a payment per prescription of a drug or treatment. Doctors are given different payment rates based on which drug brands they are prescribing. This introduces an additional fiscal bias when considering treatment plans. Because of the treatment requirements and costs, racial minorities or social economically disadvantaged groups might turn away from receiving proper treatment for sleep disorders.

As USMDs insert themselves into positions of prestige, there are positions in public and community hospitals that are left empty. Often this gap is left to be filled by nurse practitioners (NP) and non-USMDs, which occurs due to less competitive pay and lack of incentives. With these vital positions left for others to pick up, in conjunction with less funding, the patients without access to private medical institutions face systemic financial discrimination. This can lead to marginalization based on location, with lower income areas left with worse treatment options and resources. A high-ranking, private healthcare system such as the University of Virginia Health System also remains accessible only to those with the ability to travel there and the financial stability to afford the costs associated with visits.

Regulatory bodies in this system may enforce guidelines that inadvertently favor certain demographics or populations. The flexibility of what constitutes importance in research can lead to an industry that marginalizes the health concerns of underrepresented groups in the name of profit. By examining this through the SCOT lens, it becomes apparent that the underrepresentation of certain demographics in medical research is not an oversight from the organizers, but a socially constructed phenomenon shaped by the interactions between the relevant social groups.

Administrator bodies and stakeholders in the hospitals, clinics, and companies where these research studies are conducted also prioritize the performance of the study from a business standpoint. These groups aim to provide effective care to achieve high ratings from reviewing and ranking organizations and receive further business as a result. The investors behind the studies likely care less about the demographic reach of the research studies, as targeting a wholistic group of people would be more challenging and incur further costs. Oftentimes,

The area between profit maximization, optimal results, and demographic inclusion will be further explored as potential driving forces behind the way the UVA Sleep Disorder Center operates.

The application of the SCOT framework suggests that addressing health disparities requires a concerted effort to shift the consensus among relevant social groups towards more inclusive research practices. This could involve advocating for policy changes that mandate diverse representation in clinical trials, creating incentives for research that addresses the needs of underrepresented groups, and fostering collaborations between researchers and communities to ensure research agendas are responsive to the health needs of all demographic groups.

One foundational aspect in this thesis is the historical underrepresentation of minorities in clinical trials. Studies by Smart, A et al. (2020) and Jackson (2019) have highlighted the consistent underrepresentation of racial and ethnic minorities, women, and elderly populations in medical research. This lack of diversity present in research trials limits the ability for the findings to be generalized, which further contributes to inequalities in health outcomes. In his paper, Smart argues that a diverse participation pool in clinical trials is vital for developing treatments that are effective across different demographic groups. While it would be ideal for every research study to be conducted with a perfectly diverse dataset to maximize the applications of the findings, the reality is that certain demographics are harder to recruit for research involvement. In this case, it is unrealistic to search or advertise to individuals in a way that would achieve a perfect spread of individuals with different socio-economic, racial, and ethnic backgrounds. Thus, it is likely that the relevant groups funding the research studies see further investment to improve diversity in the participant pool to be unrewarding. Given that these studies that are being discussed are set within the US, it is important to note that even research is being

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conducted with profit as a goal. Whether this be through publications or payments from institutions, slowing the process of recruitment and making it a greater cost is likely a factor in considering trends of minorities being underrepresented.

Other literature also explores the direct impact of demographic disparities in medical research on health outcomes (Geller, 2018). In his paper, Geller highlights the lack of demographic diversity in clinical trials and how it has led to a limited understanding of disease manifestations across different populations, worsening health disparities. His work calls for systemic changes in research practices to address these disparities.

A notable example of addressing demographic representation in medical research can be found in the initiatives undertaken by the UVA Sleep Disorder Center. Specific study information from this center is not widely published in the context of demographic representation due to confidentiality reasons, institutions such as UVA play a critical role in advancing research practices that prioritize inclusivity. With the limited patient demographic information at the University of Virginia hospital, interesting conclusions can be made. According to US News, which is a widely renowned ranking site, the UVA Health system was found to have a significantly higher representation of low-income patients compared to other hospitals (University of Virginia Medical Center, nd.). Their work in sleep medicine incorporates diversity in patient populations for data and treatments to better understand sleep disorders across different groups. However, the representation of non-white patients and representation of black patients were both reported as being moderately lower than the community, with that range being 15 – 45% lower than the proportion of these groups in the community. The presentation data for Asian American and Pacific Islander, Hispanic, and Native American patients all had insufficient data to make a report on. This is indicative that while UVA Health might be making

efforts for economic inclusivity, their lack of outreach to underrepresented racial groups might be leading to inequitable health outcomes.

It is important to also consider the obstacles that exist when patients should be referred to sleep specialists (Hayes, 2012). The often-multidisciplinary team management of sleep disorder cases creates further barriers to treatment. Some key takeaways from this literature, particularly focusing on the sleep disorders of obstructive sleep apnea (OSA) and shift work disorder (SWD), are that OSA and SWD are generally underdiagnosed and undertreated by healthcare providers. Due to a lack of expertise and confidence among generalists when diagnosing or managing these medical conditions, many barriers to treatment arise. With a substantial gap in training between general practitioners and sleep specialists, generalists are hesitant to proactively screen for sleep disorders given its multifaceted treatment requirements. The paper also highlights the lack of collaboration between generalists and specialists, with the multidisciplinary team management of sleep disorders that is required creating barriers for both parties. Taking these findings into account, this barrier that exists in the diagnosis and treatment of sleep disorders can lead to further health disparities.

The underdiagnosis and lack of treatment of sleep disorders can widen health disparities of underrepresented populations due to the lack of access to specialists. With the previously discussed hesitance of generalists to screen for mental health, patients who only have access to generalists at community hospitals, might face further difficulty getting treatment for sleep disorders. It is important to note the implicit bias that exists in clinical settings towards people of color (POC). Notably, a study from 2010 found that between the years 2003 and 2008, POC over the age of 18 faced a 10% lower likelihood of being given an opioid regimen compared to their white patient counterparts (Mills, 2010). This serves as an illustration for the implicit bias that

doctors hold in the US, where multiple studies have shown that POC are viewed to have a higher pain tolerance (Kabir, 2022). The phenomenon of implicit racial and ethnic biases held by doctors regarding prescribing pain medications for POC patients can illustrate the challenge that racial minorities face when trying to be treated at the UVA Sleep Disorder Center. Understanding the bias in pain management in respect to racial factors, considering the inherent challenges that come with diagnosing and treating sleep disorders, and examining the crosstalk between these factors can indicate a concerning situation that racial, ethnic, and socioeconomic groups might find themselves facing while trying to receive proper treatment for sleep disorders.

The subsequent underdiagnosis and treatment due to these facts can exacerbate health disparities. In conjunction with this comes a lack of awareness and sleep disorders not only from the medical practitioners, but also from the patients themselves. Patients from less privileged backgrounds can face disproportionate barriers to healthcare and have lower health literacy. Untreated sleep disorders also have economic implications relating to loss of productivity and increased healthcare cost, which can further burden lower socioeconomic populations.

Another important aspect when considering treatment of patients of color, particularly when treated by white providers, is the concept of racial outsourcing. In this case, racial outsourcing is when the medical organizations or non-POC practitioners fail to change their work culture or normal operating procedures to be more inclusive, they reach out to POC healthcare professionals to do the labor themselves (Wingfield, 2019). This results in doctors of color needing to take that responsibility on themselves if they want to see change. It can also be described as weaponized ignorance or incompetence. This phenomenon helps illustrate the ideology that the responsibility to make meaningful change by investing time and resources

towards more equitable practices and research study inclusivity is pushed onto others. With this mindset, the cycle of underrepresentation of marginalized groups will only continue.

With these factors in mind, using SCOT as a lens sheds light on how the bias and discrimination found in medical research, sleep disorder research in particular, are a direct result of the relevant groups shaping the status quo. Factors creating a barrier for racial minorities and people of a lower social economic status have led to the technological artifacts of patient outreach and study outcomes being swayed in a way where these groups are underrepresented. With this underrepresentation, the methodologies of the medical research and study protocols are inevitably affected.

Conclusion:

The examination of the underdiagnosis and undertreatment of sleep disorders, namely OSA and SWD, highlights the idea that this technological system is shaped by the relevant social groups, rather than being solely rooted in medical reasons. The priorities held by medical general practitioners, sleep specialists, insurance companies, hospital boards, and patients all contribute to this. In addition, technological outcomes and clinical practices are significantly influenced by the socio-economic context and power dynamics between these groups. Lower prioritization of sleep disorders among certain groups can be understood to reflect healthcare priorities. With a lack of emphasis to amend these disparities, the gap will only continue to grow.

To address this gap, the problem needs to be redefined as socio-technical, such that efforts could be made by all relevant groups to create diagnostic tools and care plans that foster racial, ethnic, and socioeconomic diversity. Recognizing that technology is not separable from society, it is critical to engage these marginalized communities during the design of research

studies or technologies, as well as promoting advancements towards more equitable sleep disorder care. Other ways that research could better reflect the study group population would be to have greater transparency in writing. By clearly indicating the demographics of the racial, ethnic, and socioeconomic groups in the patient group within research projects and their titles, the results might be better understood in relation to who the results were obtained from. Most research projects contain important information such as the demographic breakdown of the study group, given the importance of recognizing variables, however oftentimes it is not clearly indicated aside from being highlighted in small sections.

Each of the relevant social groups behind research studies in the United States holds an important share of the solution towards equitable medical practice. It is through increased efforts from the social groups running the studies to increase inclusivity of demographic minorities that results applicable to all are achieved. This also places responsibilities on social groups to focus on increasing efforts in running research studies focused on demographic inclusion. Even with profit in mind, the greater benefit of universalized results yields greater rewards towards the individuals and society. It is through the adoption of a social construction of technology (SCOT) perspective that a holistic approach can be made towards equitable sleep healthcare.

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