Healthcare Disparities Amongst the Disabled

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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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Introduction

According to RTI Health Advance (2023), individuals with disabilities are recognized as the largest subpopulation in the United States. There are 61 million adults and 3 million children, 28% of Americans, living with a disability (RTI Health Advance, 2023). Medical treatments and devices are used to diagnose and treat illnesses, as well as assist individuals with a wide spectrum of disabilities, such as long-term physical disabilities (LTPD) and intellectual disabilities. However, a national study assessing the perceptions of practicing physicians found that “roughly one-fifth strongly agreed that the health care system often treats disabled patients unfairly” (Iezzoni et al., 2021, p. 301).

Despite the greater need for health care services among individuals with disabilities, research has shown that able-bodied people "were more likely to have better physical access to healthcare on several measures than persons with a disability" (Mutwali & Ross, 2019, p. 40). These physical barriers, such as inaccessible buildings and equipment, limit their ability to receive help they may desperately need. Research has shown that “timely access to health care services and durable medical equipment may have serious impact on the health status and maintenance of individuals with LTPD” (Wong et al., 2019, p. 373).

These disparities within the healthcare system significantly reduce the quality and accessibility of care. In interviews with fourteen healthcare practitioners, all of which being experienced in caring for physically disabled patients, "very few reported that they had accessible scales that could accommodate patients who used wheelchairs" (Mitra et al., 2017, p. 448). These inequalities result from various factors, such as insufficient medical education and biases held by physicians toward individuals with disabilities. A recent study focusing on medical education found that “only 20% of American medical/dental schools included disability awareness content" (Lee et al., 2021, p. 2).

Downstream effects of poor health care can include the worsening of their current condition or the addition of another. Not only do these disparities result in the reduction of their physical health, it can also significantly affect their quality of life and perception of themselves. Further research is essential to reduce the disparities experienced by disabled individuals within healthcare. The sociotechnical aspect of my thesis examines the inequalities that individuals with disabilities experience in the healthcare system, in regard to the medical equipment and the medical provider.

Case Context

Individuals with physical and mental limitations require unique methods of care that demand further medical education to understand. Insufficient knowledge of how to care for people with disabilities (PWDs) results in inadequate treatment of these conditions. A study conducted by Gonzalez and Hsiao (2020) examined the differences in education curriculums across various healthcare programs and discerned that “diversity in health care will improve the quality of care and access to care for underrepresented groups” (Gonzalez & Hsiao, 2020, p. 54). Prior research has also indicated that physician biases, such as ableism, can reduce the accessibility and quality of healthcare for those with disabilities (Mulcahy et al., 2022). Hence, it is essential to advance disability awareness and education of their specific healthcare needs.

A study conducted by Shon et al. (2020) interviewed various healthcare professionals from medical, academic, and government sectors to gather their opinions regarding the information PWDs require and their awareness of such information. The majority of interviewees “felt that most health-care facilities and medical professionals do not have a sufficient understanding of the conditions experienced by PWDs” (Shon et al., 2020, p. 4). This deficit in knowledge results in inadequate care concerning the medicine and assistive devices given to them for treatment. They also discussed financial aspects that can reduce the quality of care given to PWDs, “as these cases generally involve a relatively low medical fee”, so physicians are less inclined to provide them with care (Shon et al., 2020, p. 4).

Another crucial aspect is health insurance coverage. Individuals with disabilities are more likely to have health insurance due to their greater need for medical assistance. However, research has shown that “disparities in access to health care based on disability status remain even for persons who have insurance” (Henning-Smith et al., 2013, p. 1015). Although they still experience inequality, it is significantly reduced when the patient is insured (Miller et al., 2014).

These disparities arise from not only physically inaccessible areas, but also due to social stigmas and assumptions surrounding those with disabilities. Physicians tend to “assume that everyone must be able to independently fill out forms, undress unaided, transfer to high examination tables, and communicate in spoken English to receive standard health care services” (Yee, 2011). Stigmas associated with the disabled include helplessness and the inability to take care of oneself, as well as reduced quality of life and aspirations. For example, “many physicians assume that patients with disabilities are not sexually active, and therefore do not provide them with information about contraception, sexually transmitted infections or testing for cancers associated with sexual activity” (Kent, 2021). Due to these stereotypes, “there are sizable and persistent gaps in health data with respect to people with disabilities”, which leads to these disparities in care (Osman & Sun, 2023).

People with physical disabilities tend to have impaired functions and require additional support and resources to achieve the same as those without any limitations. The decreased ability to accomplish physical labor can reduce their available employment options. Therefore, “the individual is likely to have lower income-earning potential than if able-bodied”, which can affect their ability to pay for treatments, as well as for transportation to access these treatments (Anderson et al., 2018, p. 47). Studies have shown that, when faced with these barriers, “individuals with a disability have been shown to be more likely to delay/forego care”, which can have adverse effects on their overall health (Pellegrini & Geissler, 2020, p. 244).

My research involves various stakeholders, including the doctors and physical therapists providing care, as well as the patients receiving this care. Healthcare administrators and insurance companies also play a significant role in healthcare regulations. Strengthening the relationship between stakeholders is essential to understand their needs and ensure accountability within the healthcare system. For example, the Hippocratic oath is used to uphold ethical standards regarding patient safety and providing proper care. However, the knowledge gap as well as social stigmas regarding disabled communities leads to inadequate healthcare and potential harm to patients.

STS Theory

The Social Construction of Technology (SCOT) serves as a theoretical framework for analyzing complex systems and emphasizing the influence of social interaction on the development of technology. I will utilize SCOT to examine the various factors surrounding my research, including technical and social factors, and how they impact the care received by individuals with disabilities. This allows for better understanding of the socio-technical relationships, which could improve the interaction between the patients, providers, and the medical equipment used. The SCOT framework is composed of four main key concepts - interpretative flexibility, relevant social groups, closure, and stabilization.

The design and implementation of such equipment depends on the social group it is being applied to. For example, individuals with disabilities require more assistance when moving around. Therefore, an improvement to the original design, made for those without disabilities, must be altered in order to accommodate and deliver adequate care to those in need. This phenomenon is known as interpretative flexibility, which allows various social groups to design and utilize technology in ways that work best for them (Pinch & Bijker, 1984). For example, an individual that is handicapped requires a different design, compared to someone who is not, in order for them to be able to use it. The efficacy of medical treatment is significantly influenced by the machines employed by doctors, shaping the treatment process and its outcomes.

Additionally, the social aspect affecting the patient’s health is the extent of the doctor’s knowledge and their ability to care for the physically disabled. Enhancing the overall understanding of disabilities and their unique healthcare needs will allow for advanced care and improved well-being for these patients. For example, “only 40.7 percent of physicians were very confident about their ability to provide the same quality of care to patients with disability” (Iezzoni et al., 2021, p. 297). This lack of knowledge, from those providing the care, has major consequences involving the individual’s health and well-being. The second main concept of SCOT depends on the interactions between relevant social groups, the doctor and patient in this scenario. The disparities experienced by the disabled arise when the doctor cannot provide adequate care based on the individual’s unique requirements. Whether this is caused by a deficit in knowledge or a negative perception associated with the disabled, the provider's actions directly impact the well-being of the individual.

The third and fourth main concepts, closure and stabilization, are closely related within the framework. This occurs when the technological artifact requires no further design modifications. Once all relevant social groups have adequate use and meaning of the artifact, and do not conflict with other groups, the overall design will stabilize, and the associated problem will be considered solved. In this case, several medical devices and other types of equipment do not properly address the needs of the disabled. For example, many hospitals and private medical practices require patients to climb onto high examination tables (Krahn et al., 2015). However, for those that are wheelchair-bound, this is nearly impossible and results in less adequate healthcare. Therefore, they have not reached closure and design stabilization. Further research needs to be conducted in order to accommodate the technologies and treatments for people with limitations, physical or intellectual, and their unique needs.

Through the lens of SCOT, I can better analyze the following research methods and the various stakeholders involved in the healthcare system to determine their roles in addressing this inequality.

Research Question and Methods

People with disabilities tend to require additional medical care and supervision compared to those who are able-bodied. However, they encounter numerous obstacles when seeking this healthcare, which results in disparities that affect the quality of care they do receive. This prompts the question: How can we improve the quality and accessibility of healthcare for individuals with disabilities?

To examine these disparities, I will research previous surveys and interviews performed by studies regarding people's opinions on healthcare. These studies provide in depth knowledge of how practicing physicians view those with disabilities as well as their ability and willingness to provide them with care. Additionally, I will be conducting personal interviews with practicing medical providers, shown in Table 1. The reason for choosing these two doctors was due to our personal relationship, my friend's parents. Therefore, I was able to ask detailed questions, as shown in Table 2, and receive unbiased and unrestricted answers. First-hand information is essential for analyzing a system as complex as healthcare. The primary stakeholders surrounding my research are doctors and patients receiving this care. Directly observing the interactions between these stakeholders is crucial to gaining insight into their relationship. Through interviews, I aim to gather information regarding the doctor's extent of knowledge of various disabilities and their unique healthcare needs. I will also examine the employment and educational requirements associated with these medical professions.

In addition, I plan on researching prior literature and legislative regulations related to individuals with disabilities, such as the ADA. Reviewing various healthcare regulations will allow for comparison of the current healthcare practices affecting the disabled community and how to better align them with these federal standards. Given the many obstacles that individuals with disabilities experience in receiving proper health care, government assistance plays a vital role in reducing these barriers. I will use the Social Construction of Technology framework to better analyze and understand the results, specifically the relationship between primary stakeholders, provided by the methods previously mentioned.

Table 1. Personal Interviewees	
Name and Title	**Job Position**
Michael Pitttaro, M.D.	Cardiologist
Denise Pittaro, M.D.	Radiologist

Table 2. Personal Interview Questions
Are there any pieces of equipment you use that accommodate disabilities? If so, how does it differ from the other design? For example, a height-adjustable examination table for someone in a wheelchair.
Do you know if there is a cost or supply difference in regards to this equipment, compared to the original design?
Do you think your place of work has the necessary equipment to accommodate people with different limitations, physical or mental? Why?
During medical school, did you have any additional subjects or training regarding those with long-term disabilities and their unique healthcare needs?
Do you think you had the proper educational training to treat people with different healthcare needs?
During the employment process, what training, if any, did you have in regards to patients with special needs and the equipment they use?

Results

The primary factors affecting the quality and accessibility of healthcare being provided to individuals with disabilities are as follows: medical training, personal knowledge and biases, and federal regulations. Through research and interview analysis, I was able to identify and examine these three factors affecting the care given to the disabled patient. In relation to the SCOT framework, there are four main components – interpretative flexibility, relevant social groups, closure, and stabilization – that I used to analyze my results. One factor affecting the quality of care is the extent of training and education that the medical provider has in regard to people with disabilities. For example, inadequate training of their specific healthcare needs can result in insufficient care and worsened patient health outcomes. Another primary factor affecting these disparities is personal knowledge and biases towards the other relevant social groups and of the healthcare system as a whole. For instance, physicians with negative perceptions of the disabled community tend to provide substandard care compared to physicians who view a disabled individual's health in the same light as able-bodied patients. And lastly, the existence and enforcement of federal regulations impacts the inequalities in care given to those with disabilities, as well as other minority groups. The ADA was originally passed into legislature in order to prohibit discrimination towards disabled individuals. However, this is not the case due to the prevalence of healthcare barriers. Therefore, a crucial step in this process is to actively enforce the legislation, which is not currently being accomplished.

Medical Training

My personal interviews revealed a significant gap in disability training required within medical education programs. While the interviewees remained confident in their ability to care for those with disabilities, they did state the lack of explicit mandatory training within their educational and employment processes. Dr. Michael Pittaro mentioned that despite the absence of formal training, "just being an understanding and compassionate human seems to more than meet my patient's needs" (M. Pittaro, personal communication, February, 2024). Despite this mindset, which many doctors share, the disparities continue to exist. Due to this perspective, some doctors are more reluctant in admitting the need for further education. However, this is not all encompassing. For example, a medical provider's lack of frequent patients with disabilities can lead to unintentional blindness of their specific healthcare needs.

A recent study conducted by Agaronnik et al. (2019) interviewed twenty-five physicians, with a mean number of 27.4 years in practice, to examine their knowledge and understanding of their obligations in providing care, specifically in regard to patients with disabilities. Almost all the participants reported having no formal training, and only one participant reported having received this training in medical school. Due to this lack of education regarding the unique needs of the disabled community, medical providers tend to "be unaware of approaches to accommodating patients with different disability types" (Agaronnik et al., 2019, p. 552). Therefore, a potential solution would be to enact mandatory training for all medical practitioners, regardless of how they personally feel about their knowledge regarding individuals with disabilities.

In regard to SCOT, interpretive flexibility allows various social groups to design and utilize technology in ways that work best for them and their lifestyle. Particularly in healthcare, interpretive flexibility is required to ensure all patients receive adequate care, associated with their unique needs. Each patient has their own individual interpretations and usages of the medical equipment and knowledge available. For example, a height-adjustable examination table would allow an individual with mobility issues to achieve the same result as an able-bodied individual. Therefore, medical design innovation is a crucial step in providing sufficient care for diverse groups. In addition, training medical providers to use the modified technology is required for proper implementation.

Personal Knowledge and Biases

As mentioned previously in this paper, it is important to identify and examine the relevant social groups. In this case, the medical provider and patient are the main stakeholders. However, insurance companies and those with legislative power also have a large impact on the level of care given to people with disabilities, which I will discuss later in regard to federal regulations. All relevant social groups have significant influence on the meaning and utilization of various technological artifacts (Pinch & Bijker, 1984). Therefore, it is imperative to identify these groups and account for their respective interpretations. For example, how the physician chooses to use the medical device will depict the quality of care given to the disabled patient.

The key research study I chose to examine consisted of a focus group interview conducted by Shon et al. (2020) highlighting the importance of health information accessibility for individuals with disabilities. The presence of health information corresponds to knowledge regarding the maintenance and management of one's own disability, which significantly improves patient outcome (Shon et al., 2020). This review also emphasized the lack of knowledge that most doctors have in regard to the specialized healthcare needs of disabled patients, as well as their lack of initiative to change this insufficiency. Through interview analysis, they concluded that the most common cause of health information inaccessibility is the lack of understanding among medical providers (Shon et al., 2020, p. 4). In addition, I reviewed a published study concerning the unmet healthcare needs of people with disabilities, as well as transgender individuals, conducted by Mulcahy et al. (2022). Ableism and other types of discrimination towards individuals with disabilities cause an increase in disparities and distrust in the healthcare system (Mulcahy et al., 2022).

Physicians’ negative perceptions such as the ones mentioned above have a detrimental effect on the healthcare provided. For example, previous research has reported that “more than four-fifths of physicians think that people with significant disability have worse quality of life than others” (Iezzoni et al., 2022, p. 101). This assumption further exacerbates the disparities that disabled patients experience, causing them more hesitancy when seeking care. Therefore, improved perceptions from both the physician and the patient would enhance the quality and accessibility of this care.

Federal Regulations

Several federal guidelines currently exist to help manage and reduce these negative experiences, such as the Americans with Disabilities Act of 1990 (ADA) and Section 504 of the Rehabilitation Act of 1973. Under Section 504, all programs receiving federal financial assistance are prohibited from discriminating on the basis of disability. Both Title II and Title III of the ADA share similar requirements with Section 504. However, they expand the scope to include programs receiving assistance from local and state governments as well as private businesses that are generally open to the public, such as restaurants and hotels. In reference to my research, these civil rights laws require healthcare systems, such as hospitals and other medical practices, to provide accessible care to those with disabilities, whether or not they are privately owned (Iezzoni et al., 2022). This includes having accommodated equipment and examination rooms readily available, as well as accessible entryways. For example, medical providers are required to use height-adjustable examination tables, or otherwise accessible tables, to assist patients with mobility issues and other physical limitations.

However, these inequalities persist, despite the existing guidelines. One reason for this is the utter lack of enforcement within the healthcare system. According to a recent study, physicians were asked about their knowledge of the ADA, and the results were nearly unanimous, with respondents having “little or no training on ADA laws and its implications for their practices” (Rodriguez, 2022). In addition to this lack of knowledge, some medical providers chose to disregard their need for accommodations. For example, “even with accessible exam tables, some physicians do not transfer patients who use wheelchairs, leaving patients dissatisfied with their care” (Iezzoni et al., 2022, p. 101). While this is not necessarily done with malice, it still has a negative impact on the level of healthcare the individual receives and the potential medical outcome. Staff training as well as constant regulatory enforcement is an essential component of how we can best improve the quality and accessibility of healthcare to those with disabilities.

The third and fourth components of SCOT, closure and stabilization, occur when the technological artifact requires no further design modifications and each relevant social group has adequate use of it (Pinch & Bijker, 1984). In this case, neither closure nor stabilization has been established due to the insufficient medical equipment and training regarding the disabled. Federal regulations and policies are designed to create closure and resolve conflicts between relevant social groups associated with technological designs. For example, Title II of the ADA addresses issues associated with public transportation, which is one of the main accessibility barriers. This legislation requires all public services to accommodate individuals with disabilities, such as installing a wheelchair lift. The additional modifications to the original design allow for all relevant social groups to have adequate use of the technology, such as a city bus, resulting in design closure and stabilization. However, enacting these regulations is not enough, so continuous reinforcement is required for proper implementation and stabilization of all medical devices used in the treatment of disabled patients.

Discussion

Through analysis of my results within the lens of the SCOT framework, I was able to determine the primary factors affecting disability healthcare. Individuals with disabilities represent a large minority group, which tends to introduce inequities across all aspects of life. For example, those with physical limitations require accommodations when receiving healthcare that able-bodied individuals may not. Therefore, regulations must be put in place to prevent any barriers they may face in everyday life. Regulations need to be enacted and enforced regarding the social and education aspects of healthcare to ensure all relevant social groups receive adequate care. Overall, this research demonstrates the importance of technological design and human interactions in regard to the quality and accessibility of healthcare given to people with disabilities.

The main limitation associated with my research and corresponding results is the restriction on available information. For example, in interview analysis, I am given a small portion of the results and conclusions from their study. When publishing a paper, you pick and choose what you write in the final submission, so I don’t receive the full story unless I conduct the interview myself. In addition, most of my research is based on the personal perceptions of individuals, particularly the medical providers, so some of my results could be skewed depending on the interviewee and their experiences.

In future studies, I would include more personal interviews to better understand the opinions of practicing medical providers and ask more detailed questions regarding their individual experience. I would also include more information about the patient's experience and their personal perceptions of the healthcare they received. I mainly researched information regarding the medical providers and their educational requirements. However, an additional step would be to study the real-life obstacles that individuals with disabilities experience and how they affect them directly.

I will use this research to advance my engineering techniques by examining all relevant social groups and how the technological design would affect them, and vice versa. In this case, understanding the unique needs of all potential patients is essential in maintaining proper health care that is inclusive for all populations.

Conclusion

The identification of possible risk factors and the various causes of inequalities allows for a better understanding of the issue at hand and how to best solve it. These disparities exist within multiple areas of life and can affect each person differently. For example, individuals with disabilities experience obstacles when utilizing public transportation. Many of these people, depending on their specific disability, have difficulty traveling from one place to another due to the lack of accessible and inexpensive transportation (Wong et al., 2019). Another factor discussed within this paper that affects the quality and accessibility of care is the doctor's extent of knowledge regarding individuals with disabilities. There is an inverse relationship between the level of a doctor's knowledge and the number of healthcare barriers experienced by disabled patients. Therefore, proper medical education is an essential step in reducing these disparities. However, this must be combined with several other advancements to ensure equity within healthcare. The scope of this research can be expanded to incorporate various minority populations and the inequalities they experience. In the case of healthcare, previous studies have shown that different ethnic groups as well as transgender individuals face discrimination, resulting in worsened health outcomes and unmet needs (Mitra et al., 2022). An example of a potential next step for other people is to examine how additional underrepresented groups, such as the indigenous population, experience healthcare or another type of public service. The takeaway message from my research is that regulations, both social and educational, need to be enacted and enforced to prevent disparities from existing in all aspects of life, particularly in healthcare.

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