HEALTHCARE EXPERIENCES FOR PEOPLE WITH CEREBRAL PALSY

by

CASSANDRA STEWART

A Thesis Submitted to The Honors College
In Partial Fulfillment of the Bachelors degree
With Honors in

Physiology

THE UNIVERSITY OF ARIZONA

MAY 2020

Approved by:
Dr. Sue Kroeger
Department of Education
ABSTRACT

This research will address how health outcomes can improve for adults with cerebral palsy by evaluating their experiences in the healthcare setting. The focus will be on patient-provider interaction, and specifically how provider attitudes and knowledge of disability affect care. Important factors to consider are conceptualizations of disability (i.e., social and medical models of disability) and how stigma shapes perception and treatment. Any intervention to improve healthcare experiences for people with cerebral palsy should address disability stigma and the complex physical and cognitive effects unique to cerebral palsy. The questions addressed in this research include:

● What is disability stigma?
● What is the difference between impairment and disability?
● How do we define and conceptualize disability, disabled people, and the disability experience?
● What is cerebral palsy physiologically?
● How do patients with cerebral palsy define their experience with healthcare providers?
● What prior programs have been implemented that are designed to improve relations between providers and disabled people?
● How can this information be applied to remove physical, cognitive, and attitudinal barriers in the healthcare setting?
DISABILITY STIGMA

The term “stigma” was coined by Erving Goffman in 1963. He defined the term as “the situation of the individual who is disqualified from full social acceptance” by an “attribute that is deeply discrediting” and reduces the person “from a whole and usual person to a tainted, discounted one,” (Goffman 3). Since then, definitions of the word have varied, however, there are four components of stigma that remain constant as described by Bruce G. Link, professor of Sociology and Public Policy at UC Riverside, and Jo C. Phelan, a research scientist in Sociomedical Sciences at Columbia University.

The first component of stigma is distinguishing and labeling differences. As stated by Link and Phelan, there is a “social selection of human differences when it comes to identifying differences that will matter socially,” (Link, Phelan). Labels are salient only for differences that social, economic, and cultural forces determine as worthy. For example, people tend not to intently care about the general shape of someone’s ears – there is no label or distinguishing factor that singles people out for these differences. However, we recognize that someone that cannot see or walk is, in fact, noticeably different enough by social standards to warrant being disabled.

The second component of stigma is associating these human differences with negative attributes. Link and Phelan describe this as “the label linking a person to a set of undesirable characteristics that form the stereotype,” (Link, Phelan). There are automatic perceptions of people based on socially defining characteristics. Some common characteristics associated with disability include reduced strength and endurance, dependence, and incompetence (Coleman, et. al). These stereotypes vary relative to various impairments, but all of them have some relevance to cerebral palsy.
The third component of stigma is separating “us” from “them.” “When labeled persons are believed to be distinctly different, stereotyping can be easily accomplished as there is little harm in attributing bad characteristics to ‘them,’” (Link, Phelan). As Link and Phelan further describe, a stigmatized person may become labeled as so different from “us” that they are seen as less human or not human at all. Making someone less human has unique consequences. This mentality not only justifies stigmatized people being mistreated, but it also justifies many kinds of negative feelings and behavior. In terms of disability, people with physical or mental impairment may also be associated with tragedy and pity (Coleman, et. al). As noted previously, this is because society often deems their lives as less meaningful than nondisabled people. Another common trope is feeling compassion or sympathy for people with impairment: “people may like individuals with a disability but they do not necessarily have respect for them,” (Coleman, et. al). Finally, because society deems the ‘normal’ body as superior, “people may feel a sense of fear or discomfort when interacting with an individual who is disabled,” (Coleman, et. al).

The final component of stigma is status loss, discrimination, and exclusion. “When people are labeled, set apart, and linked to undesirable characteristics, a rationale is constructed for devaluing, rejecting, and excluding them,” (Link, Phelan). A common example of this is separate classrooms in primary education. Regardless of type and functionality, students with disabilities are oftentimes relegated to one classroom where they receive a different education compared to their peers. As stated by Karin Sandstrom, professor of Health and Society at Linkoping University in Sweden, people with cerebral palsy report that “later in adulthood perceptions of difference were above all experienced through the attitudes of and treatment by strangers, sometimes leading to feelings of indignity,” (Sandstrom 435). Ultimately, the socially
constructed differences of people with impairments makes them a stigmatized group, and leads to their discrimination and mistreatment in a variety of settings.

**IMPAIRMENT VS. DISABILITY**

The distinction between impairment and disability is important for understanding conceptualizations and narratives relative to difference and stigma. The World Health Organization developed the International Classification of Functioning, Disability, and Health (ICF) that defines and measures physical conditions. According to the ICF, impairment is described as “a significant deviation, loss, or loss of use of any body structure or bodily function in an individual with a health condition, disorder, or disease.” Conversely, disability is defined as “activity limitations and/or participation restrictions in an individual with a health condition, disorder, or disease.” The American Medical Association claims a complex relationship between impairment and disability that is difficult to predict. Sometimes an impairment can be so significant that it severely impedes ability to participate in life functions. Other times, impairment may not hinder an individual’s ability to partake in life functions due to sufficient technologies and accommodations (Lowe).

Impairment and disability are key terms that can improve an individual’s perception and understanding of themselves, as well as society’s understanding. For example, blindness is an impairment, the inability to see is an impairment effect, and information in print format is the disability. While "disability and impairment" will continue to be used interchangeably, it is important to understand them conceptually so as to distinguish between personal and systemic barriers and constraints.
SOCIAL VS. MEDICAL MODEL OF DISABILITY

The medical model of disability defines and conceptualizes disability as something that is abnormal and deficient, attaches a negative value to these differences, and then responds by attempting to fix or cure the disabled individual. More specifically, it is described as “maintaining an outcome goal of attaining normality or some approximation of it, in intellectual, social and/or behavioral functioning” and a “medical problem that interferes with 'normal' functioning,” (Shyman). The medical model relies on the dichotomous assumption that you are either able or disabled, and subsequently normal or abnormal. In the healthcare setting, this creates a boundary via a hierarchical, inequitable relationship between a person needing curing versus the person doing the curing (Shyman). This provides the healthcare professional with the power to determine what is normal and abnormal. The medical model is widely accepted by society, and pressures people to seek treatment for their conditions. Generally speaking, this model of disability “continues to legitimate segregation and inequality and justify a dual system,” (Shyman). In the healthcare setting, the model retains dominance (Scullion). This results in a hostile environment for people with impairments.

The social model of disability focuses less on impairment and more on socially constructed environments whose poor designs exclude large numbers of people. Specifically, the social model explores “the ways in which disability is created – through the social, economic, political, cultural, relational and psychological exclusion of people with impairments,” (Goodley). This kind of ideology lays blame on extrinsic factors of society instead of intrinsic factors of the individual. For example, if a wheelchair user is unable to enter a building due to the existence of stairs only, the social model argues that the stairs are a socially constructed barrier that allows exclusion of people with mobility impairments. Another important distinction
with the social model is that “disabled people are an oppressed group and non-disabled people are the causes or contributors of that oppression,” (Shakespeare 195). Additionally, under the social model, impairment and disability are defined as two different terms. Impairment is a private personal matter, whereas disability is public and social. “While doctors and other healthcare professionals seek to remedy impairment, the real priority is to accept impairment and to remove disability,” (Shakespeare 197). Essentially, the key difference is that the medical model defines disability in terms of individual deficit, and the social model defines it in terms of exclusion and discrimination. In recent years, medical fields have introduced the social model of disability into curriculum, but the medical model remains dominant (Scullion).

OVERVIEW OF CEREBRAL PALSY: DEFINITION, INCIDENCE, & PHYSIOLOGY

Cerebral palsy is defined as “a group of nonprogressive neurological and physical problems that occur as a result of brain damage either before, during, or shortly after birth,” (Langwith 14). Cerebral palsy varies widely relative to severity and functional limitations, but it is generally understood as a condition that impairs motor function secondary to damage to the motor cortex. For example, people with CP that have less severe symptoms may “have only minor difficulty with fine motor skills, such as grasping and manipulating items with their hands,” (Langwith 15). On the other hand, people with severe CP “can involve significant muscle problems in all four limbs, mental retardation, seizures, and difficulties with vision, speech, and hearing,” (Langwith 15). Approximately 80% of individuals diagnosed with CP have spastic CP, which means muscles are stiff and movement is difficult (Langwith 16). This type of CP can be monoplegic, diplegic, hemiplegic, or quadriplegic. The other two types of CP affect the entire body. About 10% of people with CP have athetoid CP, where some muscles are spastic
and others are excessively loose. Another 10% have ataxic CP, meaning they have difficulty with balance and coordination (Langwith 17). In the United States, the rate of CP is about 2 of every 1000 births, meaning there are approximately 760,000 people living with CP in the country right now (Langwith 17).

To better understand the effects of CP, the physiology of the condition must be illustrated. Oftentimes CP is a result of premature birth, because premature infants are at an elevated risk for intraventricular hemorrhage due to fragility of blood vessels (Johnston and Hoon, 437). These hemorrhages cause damage to the deep white matter of the brain which is called periventricular leukomalacia (PVL), and is the most common cause of CP. The damage promotes white matter necrosis and ventricular enlargement, which impairs motor cortex function by interrupting important synaptic connections via injured myelination. PVL is strongly associated with spastic diplegia, and is associated with cognitive, behavioral, and sensory abnormalities as well (Johnston and Hoon, 437).

Another precursor to PVL are ischemia-reperfusion and infection, where fetuses are more vulnerable between 24- and 32-weeks gestation. This is because during this time frame, human late oligodendrocyte progenitors (pre-OLs) are not fully mature and lack basic myelination, making them extremely vulnerable to apoptosis by oxidative stress and hypoxia-ischemia (Johnston and Hoon, 438). Ultimately this leaves the white matter unprotected, so any lack of blood supply or infection can be detrimental.

PVL may also lead to neonatal stroke, which is associated with hemiparetic CP that causes weakness and reduced coordination on one side of the body. These cases may not be recognized initially at birth because the damage occurred prenatally, but others will present with seizures evident of venous occlusion. Another cause of neonatal stroke that induce CP and exist
without PVL are thrombophilic disorders. Regardless of cause, CP induced by stroke is linked to hemiparetic CP. (Johnston and Hoon, 445).

CP may also be caused by hypoxic-ischemic injury with term infants. Less than 15% of CP cases are caused this way in countries with modern medical care, but it is still prevalent in lesser developed countries. Term infants are less likely to suffer damage to the white matter of their brain because this area has become less vulnerable with maturation. Instead, structures such as the basal ganglia, hippocampus, cerebral cortex, and brainstem become more vulnerable to injury. CP infants with term birth will have an injury results from asphyxia, where cardiac output and contractility is reduced because of low oxygen. Injury can also occur by direct trauma, but is less common. Conditions of CP are dependent on the severity and longevity of the asphyxia. For example, infants exposed to a short but severe injury, like complete compression of the umbilical cord, are more likely to sustain a selective injury to a specific brain structure. The damage will likely result in rigidity and other movement disorders depending on the particular area of damage. On the other hand, infants that are exposed to a longer but less intense episode of asphyxia will likely sustain a multifocal or diffuse injury to the cerebral cortex. This will result in upper motor neuron abnormalities and spastic quadriplegia (Johnston and Hoon, 440).

The wide range of pathogenesis for CP is representative of the wide range of people with CP. No two people with CP are alike. Variation of cognitive and physical impairments is an important consideration for healthcare providers.
Patients with cerebral palsy have a unique set of characteristics, and as stated, no two people with cerebral palsy are alike. However, research has identified poor patterns in healthcare treatment that patients with CP attribute to disability stigma and a medical model conceptualization of disability and impairment. Studies acknowledged that because CP is considered a childhood chronic illness, many adult-centered physicians lack the training and experience to treat patients with CP and ultimately are uneducated or uninterested in caring for them (Binks, et. al). This can be extremely difficult for the individual with CP, as they likely had a dedicated care team specifically trained for CP as a child. Upon transition to adult-centered care, young adults with CP noted a distinct difference, in that their healthcare providers were “uncomfortable or ambivalent about some topics, had difficulty discussing bad news, and lacked specific training,” (Binks, et. al). Another common theme was focusing exclusively on the CP and failing to discuss the primary reason for the visit, perform routine health check-ups, and discuss health promotion services.

One narrative from an individual with CP is as follows: “In my experience, you come to some authority and are treated tactlessly; it’s awful, quite simply, because it happens often. I feel like I have to work so hard to convince people that I need help,” (Sandstrom 435). Additionally, a common thread of complaints of people with impairments regarding their healthcare professionals were “a lack of disability specific knowledge and providers' limited time and effort related to care,” (Kroll, Neri). In another research article, disabled individuals reported that “practitioners are not always knowledgeable about their disability, focus more on their disability than their general health, and do not provide as many preventive services,” (Branigan, et. al). One striking statistic from this research was that about 20% of the people with physical
impairments reported never having a thorough physical examination, compared with only 5% of the general population. Another issue was low discussion rates regarding reproductive and sexual health. Common issues evidently emerge across studies, concluding that there is a problem with healthcare providers’ ability to communicate with and effectively treat people with CP and other impairments.

While there could be other confounding factors, it is fair to speculate that, to some extent, these differences in health outcomes can be related to discrimination. Perhaps the reason providers are less likely to provide as many preventive services is because they do not see value in the life of an individual with cerebral palsy. Additionally, it could be possible that providers aren’t completing thorough examinations because they are uncomfortable. This is defined as “diagnostic overshadowing,” which can be understood as the “process whereby medical personnel are so overwhelmed by clients’ ‘disabled’ identity and the accompanying negative mindset becomes an additional barrier to health care when it is required by disabled people,” (Scullion). In comparing four barriers (physical, attitudinal, expertise, and systemic) that disabled people may face in healthcare, it was found that attitudinal barriers are the most significant (McColl, et. al). This suggests that there is an issue with medical professionals’ perception and subsequent treatment of individuals with impairments.

HEALTHCARE PROVIDER EXPERIENCE WITH PATIENTS WITH DISABILITIES

Healthcare providers' negative attitudes toward disabled people tend to mirror society, and can be portrayed in several different forms. The trend is that their conceptualization represents the medical model, or in other words, that disability/impairment is abnormal and/or
negative. Another perspective is that it is an illness, which disempowers the individual because they are viewed as sick. A qualitative survey of primary care physicians was performed to further illuminate the physicians’ perspective on treating individuals with impairments by Mary Ann McColl, PhD, et. al at Queens University with the following notable results:

- Physicians reported that seeing disabled people typically meant a much longer appointment.
- Physicians reported that seeing disabled people was often much more complex, and they did not feel like they had adequate training to treat them. They felt uncomfortable because they did not know how to properly position or examine people with certain physical impairments, and were also unsure about their greater need for medication.
- Some physicians view disabled people as a learning opportunity, both on specific medical issues they were unaccustomed to and the disabilities field in general.
- Physicians agreed that disabled people require the same monitoring and prevention services as nondisabled people.
- Physicians agreed that they were less likely to perform a full physical examination on disabled people for a variety of different reasons.
- Physicians admitted that they often were unable to perform preventive and monitoring services due to physical barriers, or because they were too overwhelmed by the volume of health concerns.
- Physicians report they are less likely to pay attention to sexual and reproductive issues for people with physical and intellectual impairments because they assumed they were not sexually active. Specifically with intellectual impairments, they report that they waive
screening such as Pap smears, prostate exams, and mammograms because they assume their patient will not understand it.

(McColl, et. al).

Another study evaluated medical students’ attitudes towards disabled people, which were generally deemed as negative. They found that male medical students were more likely to have these negative conceptions, and that students with any background of disability experience were more positive and comfortable. Similarly, the more positive they felt towards people with impairments, the more comfortable they were in treating them (Tervo, et. al). Ultimately these studies show that medical training is lacking in disabilities studies and is leading to adverse healthcare experiences for people with a variety of impairments.

PRIOR PROGRAMS TO IMPROVE DISABILITY STIGMA IN HEALTHCARE

A study at the University of East Anglia Medical School cross-compared different approaches to teaching about disability and their efficacy. These approaches included conventional lectures, lectures by disabled people/families, encounters with disabled people/families, visits or placements in the community, simulation exercises, and clinical experiences (Shakespeare and Kleine). It was determined that conventional lectures were ineffective in changing medical professionals’ attitudes towards disability; it is common to teach about disability but it lacks the resonating effect. Learning from disabled people appeared to be more impactful. Encounters with them were deemed even more impactful, as it increased the healthcare providers’ levels of comfort. Placements in the community seemed to have similar or greater effects, because these opportunities tend to be longer lasting than a single, scheduled
encounter. Simulation exercises work by spending time in a wheelchair or wearing glasses that simulate vision loss with the goal of increasing empathy and educating on practical issues like accessibility. (It should be noted that Simulation Exercise is highly criticized by disability scholars and activists). However, researchers found that this approach risks distorting perceptions about disabled people by only viewing them through their impairment. It fails to address other issues they might face like discrimination and prejudice. Clinical experience with disabled people was found to be valuable because the providers were able to learn in the setting that they would be working in. However, this modality did not necessarily change the negative attitudes. The cross-comparison ultimately determined that the best way to improve attitudes was for personal interaction with disabled people (Shakespeare and Kleine).

One specific example of a program designed to improve disability stigma in healthcare was a communication skills training session taught by people with intellectual, physical, or sensory impairments. The training was a 3-hour session where students completed an attitude scale at the beginning and end, and consisted of a lecture, direct contact with the tutors with disabilities, and ending with a communication exercise. The session resulted in the students having a significant attitude change. They felt more comfortable interacting with disabled people, and claimed to acknowledge them more as individuals (Tracey and Iacono). This study demonstrates that even quick interactions can change perceptions. It also illuminates how segregated we are, and how regular integration could improve attitudes in a multitude of fields.
BEST PRACTICE FOR IMPROVING DISABILITY STIGMA FOR PEOPLE WITH CEREBRAL PALSY IN HEALTHCARE

Cerebral palsy is an excellent case study for improving disability stigma due to the vast spectrum of impairment effects (i.e., physical, cognitive, emotional etc). This variability is important because it requires healthcare providers to assess people individually – a key component of best practice when assessing any person.

The first element of best practice is improving attitudes towards disabled people. Whether it be medical school, nursing school, medical assistant school, dental school, etc., students need to have interactions with people that have CP and other impairments. There should be at least one program like the communication skills training session as described previously. The first important interaction these professionals have with someone with CP should not be in their medical office. Due to the stigma surrounding disability in society, it is setting the medical professional and the person with CP up for failure if the professional is uncomfortable with cognitive and physical impairment.

The second element of best practice is training the healthcare providers about CP. They should be confident with their examination practices. Physicians, nurses, and medical assistants should all be trained on proper lifting techniques and possible spastic or sensory reactions. Being knowledgeable and prepared for these will instill confidence and comfort. People with CP need to be considered as a typical patient in training so providers aren’t confounded when they see them in practice.

The most important element is the healthcare professionals in practice. This is where providers have the opportunity to apply what they have learned and improve health outcomes for
people with CP. The first step to an effective appointment with someone with CP is allotting more time. This allows appropriate time for repositioning, lifting, or communication. This alone should relieve some stress for the provider. With more time, they are less likely to waive important monitoring and prevention services.

The next vital component is having someone available assistance. This is especially important for the physical examination. It should not be the responsibility of the disabled individual to accommodate the physician – the physician is there to service the individual and therefore they should have the training and resources to give proper care. A person with CP should not be required to have a caretaker present to help with lifting/positioning. Healthcare providers should be providing the same services to everyone, meaning the medical team must coordinate together to provide the best experience possible.

The final element is communication. While this may be difficult with a CP patient that has significant cognitive impairments, providers should not assume what issues they may encounter. Also, providers should not assume whether or not an individual is being seen for CP. Asking individuals what brought them in is a simple way to check assumptions. If they are there because of a concern regarding their CP, then it is appropriate to discuss it. If they are there for a common cold, it is probably not an appropriate time to discuss their CP. Too much focus on the impairment is what leads to disparities in other areas of health. The provider should care about removing barriers. Many people with CP view their condition as life and not as a problem to be fixed.
CONCLUSION

Disability-related stigma is significant in society and exists on all fronts including healthcare. While stigma is problematic in its own right, discrimination can be detrimental to one’s health, especially if it exists within healthcare. For this reason, medical professionals should lean toward a social model conceptualization of disability/impairment, rather than the dominant medical model conceptualization. Viewing disability as an individual deficit reduces the value of people with impairments. Understanding impairment as personal and disability as discrimination and exclusion may help change societal narratives.

Using cerebral palsy as a case study can help healthcare providers understand the complexities of both physical and cognitive impairments, and the continuum that exists. It can never be assumed that two patients are alike – especially patients with CP because they have multifaceted conditions. Assessing the problems faced by each individual is a key component in serving the disability community, as well as avoiding assumptions about their condition.

It has been demonstrated that many people with CP feel they are discounted in the healthcare setting and do not feel they are receiving adequate care, largely due to attitudinal bias. From physicians’ prospective, they agreed that they are not always capable of providing care, or feel overwhelmed and underprepared to serve individuals with varying impairments. Both sides supply evidence that there is an issue with healthcare practices relative to serving disabled people. There can be solutions.

Changing the negative attitudes of healthcare providers towards people with disabilities is a key step. This can be achieved through intentional encounters with disabled people to lessen the stigma. Next, they need to be trained on the conditions themselves. Providers should know
about CP and what physical and cognitive challenges there are so they are prepared for
interactions. This includes skills like lifting/positioning, as well as communication tactics. When
in office, providers should set aside appropriate time to address these additional challenges. Most
importantly, providers must locate the problem of the visit and remain focused on this.

A deeper understanding of impairments, impairment effects, and disability will lead to
better outcomes for disabled people. People with CP and other impairments need to be regarded
as typical patients so that education and training is sufficient to provide care for their unique
situations.
References


**Special note:**

This thesis included emphasis on disability-related word choice. It is important to distinguish between disability, impairment, and impairment effect with social model conceptualization. Throughout the writing notice the use of “disabled people” versus “people with disabilities.” This is more accepted by the disability community because it is an act of solidarity to reclaim their identity. Additionally, it is important to not label disabled people as “patients” as this encourages the medical model.