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Counseling Experiences in Physically Disabled Individuals

Leah Schulze

HONORS PROJECT

Submitted to the Honors College at Bowling Green State University in partial fulfillment of the requirements for graduation with

UNIVERSITY HONORS

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Disclaimer

I am aware it is a controversial topic when it comes to how you should refer to those in the disabled community. Some say that the best way is through person-first language. However, I and others believe that having a disability is a culture and that being afraid of the word disabled is part of the reason why it has become so controversial in the first place. I don't condone the use of the R-word or words like cripple or wheelchair-bound or someone saying I suffer from spina bifida. However, disabled, spina bifida, and wheelchair are not bad words. Those, such as myself and Lydia Brown the writer of "The Significance of Semantics: Person-First Language: Why It Matters" believe our disability, while not everything, is part of who we are and should not be shied away from (Brown 2022). If we shy away from it then it adds to the negative connotation. Neither way is necessarily wrong as long as the preference of the person in the community you are referring to is okay with the phrasing. For more information, the full article provided in the works cited can and should be read before reading this paper. It is because of my stance on this issue and my identity as a disabled person with spina bifida, that I use the phrase disabled person in this paper.

Introduction

It is estimated that around 1 in 10 people globally struggle with mental health in some way (Datani 2021). In the U.S the CDC estimates that around 32.9% of people with a disability experience frequent mental distress (CDC 2020). A common way of coping with this is by going to counseling. Often when I am frustrated about my disability I think “nobody understands what this is like” or sometimes I am frustrated with the opposite thinking “It’s just a wheelchair why does everyone think it’s the end of the world”. Based on this and my own experiences with mental health, I was interested in seeing if experiences and views of counseling and mental health would differ if someone has a physical disability or not. In addition, I wanted to know if anyone has ever had a counselor with a disability. What have their experiences with counseling been thus far? What qualities do they find important in a counselor? Lastly being aware of the poverty rate of disabled people, I wanted to know, how much people with physical disabilities struggle with finding available counseling.

Literature Review

A disability defined by the ADA is a physical or mental impairment that substantially limits one or more major life activities (ADA 2021). Based on data collected by CDC, it is suggested that the adult disabled population is one of the most at-risk populations for struggles with mental health. Based on their statistics, 1 in 4 adults, or at least 61 million in the United States, have a disability. In addition, 25 percent of disabled adults have 5 times the chance of experiencing frequent mental distress (CDC 2020). A study conducted in 2018, further estimated that 32.9 percent of adults with disabilities, or 17.4 million, experienced frequent mental distress in the last month (CDC 2020). Having more than a quarter of disabled adults with a mental health struggle shows that this is a persistent problem for this population. An important stressor in the lives of this population, and a theme in this paper is poverty. Of the people with a disability, it is estimated that in 2014 29% of those with a disability were also living below the poverty line (Center For Poverty 2022). In the U.S. a popular way for not only disabled people but the entire U.S. population is to go to a licensed therapist.

It is common knowledge that people will often use a therapist that matches the identities most important to them. I wanted to see what the literature said if anything, about disabled vs. non-disabled counselors. Specifically, their effect, in different ways, on both the disabled and non-disabled population in the U.S. Literature such as a study done by Mallinckrodt (1986) showed that when the licensed therapists disclosed their disability, they were seen as more approachable and more competently able to help the client with their issue. This occurred even when the client wasn't disabled. These results suggest that having more disabled counselors in the field could benefit the U.S. as a whole. Further evidence of this was found in a study done by

Hronis and Kneebone (2018) who found that counselors without any experience with intellectual disability had low confidence in counseling a client that had one. A licensed therapist who is not confident in their ability to help someone could potentially worsen their experience with these kinds of treatments.

A study done by Hodge (2012) showed that when a child was labeled with Autism, ableist comments by the therapist impeded the success of the therapy. Further, a study done by Strohmer (1983) showed that disabled clients specifically found disabled counselors to be more emphatic and competent in counseling them. This research allows me to question if other disabled people have also had any of these experiences, and if having more disabled counselors in the field might improve the situation in some way.

Methodology

To deeper explore the experiences people with disabilities have had with counseling, I conducted five, 30-minute interviews with physically disabled college students on campus. All 5 participants in my convenience sample were female, between 18-and 21 years of age. Of the 5 participants, only one had what would be considered to have a “visible” physical disability. Aside from this, the study did not ask for a specific diagnosis. To collect the data, a 4 question survey was used. The four questions asked in the interview were:

- a. What are your views on the effectiveness of counseling?
- b. What qualities do you believe are important for a counselor to have?
- c. What kind of experiences have you had with counselors?
- d. What experiences have you had with availability to therapy when it is needed?

All 5 interviews conducted used the video conferencing service Zoom. Zoom was specifically used to take advantage of the live transcription feature to record each participant's response. Then each transcription was randomly given an identification number. No names or identifying information were asked or recorded during the interview. Before all interviews were conducted, each participant read a document detailing the project and then provided their verbal consent. Once all interviews were completed, the transcriptions were uploaded to a password-protected computer in Dr. Brackenbury's locked office.

Results

The first question that was asked to the participants was, “What are your views on the effectiveness of counseling. All five participants stated that counseling seemed to be an “effective way of solving problems” because of the outside perspectives one can get by talking to an unbiased source about their struggles. While all five participants said that counseling could be an effective tool, participant 4 differed in their view of its effectiveness for them. Participant 4, who did have the more visible physical disability, said that “It is a good option for some people, but it doesn’t work for everyone, myself included.”

The second topic that was highlighted in all the interviews was what each participant felt were significant qualities for all counselors to have. The answers were all similar saying that to be a qualified counselor a person needed to be kind, open, honest, and have empathy. In addition, they needed to be culturally aware of the population of people that they choose to work with. Adding that they have to have a certain ability to respectfully be blunt and serious when a client is falling into an unhealthy habit. Essentially, a counselor needs to be a person who is firm but also a person who is safe and nonjudgmental that one can talk too easily.

The third question, possibly the most beneficial in terms of this study, was what experiences each participant had with counseling in the past. This question included all experiences, whether they were seen as positive or negative. Experiences across all participants were generally positive, but there were three notable negative experiences. Participant 3 commented on how her counselor crossed boundaries and cried to her about her diagnosis and

impending surgery. This resulted in participant 3 consoling her counselor during that session instead of getting the help that she needed.

Another notable negative experience was discussed by Participant 4. Recounting that while none of their 3 times in counseling have seemed to be entirely effective for them, their first time was the worst. While they were only in middle school, the expectations their counselor put on them were too high. The counselor expected them to be able to process and cope with an upcoming surgery and unexpected health challenges like they were an adult. The participant remarked that they believed this was because it was known that they had gone through surgeries previously. It was not the first time the participant had been operated on, so it was expected that they had the knowledge to cope. The last notable negative experience came from participant 5 who said that while her counselor in high school was a good one, her high school only had 1 counselor for her graduating class of 600 and 2 for the entire school.

As far as positive experiences go, the most notable positive experience came from Participant 2 who disclosed that they see a counselor that has the same disability that they have. Participant 2 noted that this counselor, who is the second one they have seen, is excellent at listening to them, and is also interested in learning more about her culture and how the participant's disability affects them. The counselor does not rely on the Participant to teach her everything about disability culture during their session when the focus is supposed to be on the Participant.

Another aspect that has made Participant 2's experience with their current counselor so great is that the counselor, being disabled themselves, already knows the effects it has on the Participant. Participant 2 noted that when they talk about a struggle they are dealing with

someone else “it’s hard to describe exactly what's going on with me like say I'm tired, but people don't get the tired”. They further explained that “there is a specific kind of tired that comes with the area, and she gets it.” Not only does ‘tired’ refer to fatigue caused by the condition, it also refers to the exhaustion of looking to be accommodated and just believed by doctors and other authority figures in general. Participant 2 also noted that when they describe how they are feeling, they aren’t just told to eat healthier or exercise more to solve the problem. By having the same disability as Participant 2, or even a disability at all, the counselor can have the cultural awareness that a lot of disabled people miss out on.

Finally, all participants were asked about the experiences they had with access to counseling when they needed it. All five participants said that they have been able to access counseling fairly easily when they require it since coming to college. Many noted that they use the services provided by the campus or a local facility that provides financial help to those who are enrolled at the college. The only answer that slightly differed was from participant 5 who as mentioned previously had difficulty getting access in high school because they were in a large district with access to only one psychologist. Participant 5 noted that since coming to college the problem resolved.

All participants said they were fortunate to have this access, acknowledging that for others without the resources they have it can be extremely hard to get these services. Specifically, participant 4 acknowledged that they were grateful that the insurance they got through their parents was able to cover mental health services in addition to their physical health. It was acknowledged by all that this was not the case for a lot of people with disabilities. Specifically, those who are from lower-income families and do not have the same services through their college.

Discussion/Further Research

Looking over the results of the first question, it seems to be known by disabled individuals that counseling can be a very effective tool for taking care of mental health. It's seen as effective due to the ability to get an outside, unbiased view of the problem you are having. However, it would be interesting to further study if the experiences of people with visible vs invisible disabilities are consistently different. While the difference in this pilot study could be based on numerous other non-disability-related factors, it w factors, it would be worth it to further investigate if a counselor's approach to a disabled client becomes different if they can visibly see the disability.

The results of question 2 showed that disabled individuals align with the non-disabled community on qualities they find important in a counselor. Where it deviated was when one of the participants appreciated not having to explain and educate their counselor on research they should do on their own. Too often, people with disabilities find that they have to explain themselves to others during a time that is supposed to be focused on them. This could then be a deterrent to getting help because they are afraid their disability will be the only thing that matters. These results are significant because it shows that people with disabilities want and are capable of wanting/ recognizing respect, and a person that cares about them as an individual in the same ways that anyone else would expect. Often with a disability, it can feel like people are more interested in what is “wrong” with you than in all the other significant parts that make you human. A common example of this and one I have heard from people outside of this study and experienced myself was going to a counselor for a problem related to the stressor of academics but the counselor assumed my trouble was caused by the “limitations” of my disability.

As mentioned, the results of question 3 were mostly positive, with a few negative experiences. The most notable negative experiences are two things. One is that Participant 4, the one with the visible disability, recounted her therapist expecting her to be able to process traumatic surgical experiences in the same way an adult would. It doesn't make sense to expect a young child to have these skills but because disabled people are seen as stronger this often happens. While it's common for people to say that children are resilient, it's even more common for people to have that view of disabled children. This way of thinking could be what was projected on the Participant, partly explaining why they believe counseling isn't an effective form of treatment for them. With more time and resources, it would be worth expanding on the difference between visible and invisible disabilities. It would be worth exploring if those with visible disabilities often are talked to like this by professionals. It would also be interesting to discover if those with invisible disabilities hear this more because they visually come off as fine.

The second negative, although non-disability related, was noted by Participant 5. They had trouble getting into a therapist when they were in high school. The difficulty they had with this was due lack of access to mental health services in the public school system. The participant's class of 600 only had one counselor assigned to them, and there were only two for the whole school. For lower-income families, a public school paid for by government taxes may be the only way they can get access to these services regularly. While this is not a disability exclusive issue, they along with other minorities are more likely to have a financial strain, giving them the need for these services. It is also more common for those with disabilities to live in cities (Guardian News 2018), where they can be closer to hospitals and other resources like public schools. However, these city schools tend to have less money because they have more children to spend that money on and fewer resources available to them. When paying out of

pocket isn't an option and neither is getting these resources through school, a lot of families are left putting mental health on the back burner.

As mentioned, the most notable positive came from Participant 2, who has a counselor with the same disability as they do. They mentioned the value of being able to talk to someone that understood what it truly meant when they said they were tired. They felt like the counselor was able to listen to them and hear their concerns in a way that previous therapists were unable to. This participant's view on the value of disabled therapists aligns with others, such as Ashley Mohesky (2021) who wrote an article in *The Mighty* advocating for more disabled therapists. When it comes to getting a therapist, people often look for someone that understands their way of life. This is found when people go to see Christian counselors, counselors of the same race, LGBTQ+ counselors, etc. These subcategories of counseling exist because people need to be able to talk to someone that has experience and knowledge on what are some of the most impactful qualities of their life.

While having a disability isn't a person's entire identity, it is a factor that impacts them. These people deserve to talk about the negative parts of this identity with someone who understands, just as any other person can get qualified advice when struggling with negative parts of what makes up their identity. It would be beneficial to do this study again, including a wider range of participants. With this wider range of participants, it would be beneficial to add in a question asking if they ever had a disabled therapist. This would be beneficial to see if there is a significantly relevant correlation between disabled individuals' views on counseling and if their therapist also has a disclosed disability.

The previous research and this study lean toward a correlation between satisfaction with counseling and the disability status of the counselor. However, most of the research has been on autism, or those a lot younger, or a lot older than the college-aged subjects in this study. All disabilities and categories of disability affect a person uniquely. It is important to include a range of disabilities to be able to better capture each individual's unique experiences in life. Including college students is also important as especially in young adults mental health is very stigmatized. Including information gathered on a larger sample of college students would help determine if having a disabled counselor would influence the disabled person's view on counseling positively.

The idea of having a counselor with a disability, specifically physical, seems to be such a rare feat though that the data might not be there. This evidence supports giving disabled people more encouragement to go into these fields. The impact that disabled mentors can have on disabled clients can't begin to be discovered if most feel the world is against them and that it doesn't focus on the positive contributions they can have to society. The results of this pilot study were promising and will hopefully drive others to research this important topic more thoroughly.

The fourth question was on access to therapy. All five of my participants said that they could access therapy when they needed to fairly easily. A factor in this is that counseling services are provided to most students that attend the college used in this study because the service is included in the regular student fees. Also, if services are not used on campus, there are mental health facilities close to campus that will wave costs if you can provide documentation that you are a student at the university. These two factors most likely help alleviate the difficulties other people with disabilities may face due to the poverty rate of this population mentioned previously.

Having counseling services paid for, and the fact that they are going to a state school puts these participants either in a different socioeconomic place than most or helps to alleviate the barriers that a lot of disabled people face. The demographic of these students were also 18-21 years old. Most, if not all, still receive some medical aid from their parents' insurance. Most participants of this study were not yet in a position where they are funding all of their medical care on their own. For those that are, the college requires that all students have health insurance, either independent or through the school. So these factors of being a student at this particular college, their age, affect this is in ways that are different from other disabled people. The number of disabled people who are also under the poverty line is a considerably high percentage. With this in mind, further research should be done with a sample of people with a wider range of ages and socioeconomic backgrounds. There are outliers, but a college education is often also associated with a higher socioeconomic status. The percentage of people with physical disabilities that go into higher education is also lower (American Psychological Association 2022), so this additional research would broaden the view more than this pilot study done on a Midwestern state college campus.

Other avenues for future research would include opening up interviews to include a wider mix of gender identification. This pilot study with its limited resources and time restrictions was only able to collect data from female students. Males in general are less likely to go to counseling or to openly talk about their mental health (BPS 2018) so it would be beneficial to see how their views would affect the data. Since males are less likely to be open, it would be interesting to see how that ties in with the stereotype that disabled and chronically ill people can stay strong consistently. This would be done easily by locating a larger sample of people that could be collected randomly. This study used a convenience sample, so the ability to have a

diverse sample was limited. The goal of this research is to make counseling as effective as possible for all with disabilities, so a diverse sample would be needed to truly meet that goal.

Conclusion

Going through life, it is easy at times to feel like nobody knows what it's like to be you, or that they can't possibly understand or relate to a situation. If left unaddressed, These feelings of loneliness and helplessness can seriously impact a person's mental health. Going to a licensed counselor or therapist is one of the most common ways that people seek treatment for these impacts. It can be extremely helpful to talk through a struggle with someone else who can offer a new way of looking at a situation or just be a listening ear. For those with physical disabilities, especially when the conditions are rare, it can be even easier to feel alone. This feeling of being misunderstood can even prevent most of them from even trying to talk about it. Opening up about a struggle could mean being pitied or getting comments about how strong they are and that they have made it through much worse. The second point titled inspiration porn by the disabled community makes it difficult to have these conversations. They don't want to be strong role models for others all the time they just want to live their lives to be validated like everyone else.

The above comments and feelings reflect experiences I faced often while growing up and still sometimes face to this day. It can be defeating when something is bringing me down to be met with invalidation or pity. While most of these comments are made by well-intended people, that doesn't make their impact on them any less harmful. This and other experiences by my disabled peers are the way I became passionate about this research and invested in becoming a mental health counselor myself. It is my belief along with many others that if we allow people with disabilities to fulfill these mentorship roles it will provide a positive impact on the generations after.

The reason that this is important connects to the academic theory of the disability model. In simple the theory states that the way a person perceives a disabled person and their abilities, or roles in society is there disability model (Ratief 2018). There are many different models including social, charity, religious, economic etc. While no view is exclusive to a disabled person or a non-disabled person, there are views that are more commonly associated with each group. This theory and the differing views of which model is “correct” is why disabled counselors are needed.

Often times those in positions of authority have what would be called either the medical model or the charity model. These people without disabilities believe that this “disadvantage” in someone is the most obvious thinking that should be helped or fixed. However, like stated previously most disabled people view being disabled as part of their identity. Having this identity model of disability disabled people don’t see it as something that needs it be fixed, it is just something that is. These differences of perceptions are what often cause disabled people to clash with those providing them healthcare. Educating on the disability models could help non disabled counselors become more effective by better understanding their client. However having someone that already understands the perception you have of yourself, is more productive as more focus can be placed on coping with “what is” and not on “what could be” and frankly does not need to be.

Having someone to sit with and talk to that understands one's experience is something disabled children and adults alike deserve to have. Every other minority including racial religion or gender can find a counselor that aligns with their culture if they choose to do so. Accessing care is hard enough for those with disabilities, but finding a counselor that has the same disability culture as them is for the most part unheard of, and it shouldn’t be. Through this

honors project and my future studies in BGSU's Clinical Mental Health Program, I hope to be able to expand on my knowledge, resources, and abilities. I hope to allow this to be a reality for even just a small amount of disabled people by working in a children's hospital. I can consider my life successful if I can just give a fraction of these people a resource I was never able to have.

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