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Senior Seminar

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The Impact of Societal Perceptions of ADHD

As with anything else, there is a public opinion about ADHD. As with any mental health disorder, there is a stigma associated with ADHD. What are the implications and impacts of such opinions and stigma? How does the societal perception of ADHD impact medical treatment and treatment outcomes, and how does it impact the overall experience of those with ADHD?

My literature review revealed that there is, in fact, a generally negative stigma around ADHD, but my research also revealed that the treatment of ADHD by healthcare providers and the impact of treatment and the condition of ADHD itself on those with ADHD are under-researched areas. One study stated specifically that there is a scarcity of empirical studies on the "clinicians' stigmatizing attitudes regarding ADHD". This study also cited a national survey of U.S. pediatricians, in which 66% stated that they enjoy treating patients with ADHD, which suggests that age may be a factor. It concluded that the stigmatization toward children and adolescents differs from that towards adults, but there are negative perceptions toward people with ADHD at "all stages of development" (Lebowitz 203). There are barriers to recognizing ADHD in that teachers and healthcare providers lack "awareness, experience, understanding, and knowledge of ADHD" (French, Sayal and Daley 1047). Essentially, many clinicians (and teachers) are not well-educated on ADHD and having well-informed professionals would improve the quality of treatment those with ADHD receive. Particularly, there is a lack of awareness and recognition from general practitioners, and there are additional barriers in the form of long-waiting lists,

lack of age-appropriate resources, and many misconceptions about ADHD, such as the idea that it is caused by bad parenting, or the notion that ADHD is only found in children (French et al). There is varied adherence to treatment or willingness to start treatment for ADHD by ADHD patients, as a result of feeling concerned about side effects of medication, the stigma around medication, and conflicting opinions and goals of child/adolescent patients versus that of their caretakers (Bussing et al 95). This study suggests a need for better communication between caregivers, patients, and healthcare providers.

While there is "very little research within the past six years that examines community views toward ADHD", a study that sought to understand the "broader community" views of ADHD and how they may "facilitate public health interventions" and improve the outcomes for those with ADHD found in other existing research from multiple countries, including the United States, that there is varying knowledge and negative perceptions of ADHD, as well as a "desire for maintaining social distance from individuals with ADHD". It examined the views of the individual, teachers, primary care providers, and the public. The consensus is that there are generally negative views toward ADHD (Bisset 547). An incredibly important thing to note about the barriers to having ADHD be recognized by caregivers and/or healthcare providers (whether it be in getting a direct diagnosis, referral to specialist, or access to treatment), is that, not getting a diagnosis or treatment early on can have a largely negative impact on the life of a person with ADHD. Related to this, there is a misconception that ADHD is overdiagnosed, though research suggests it is underdiagnosed, which stands to create a cascade of difficulties:

Underdiagnosis is a problem because; the issues that people with ADHD experience in childhood can 'lead to cognitive and behavioral impairment impacting social behavior, schoolwork, and family life. In adulthood these are associated with higher rates of criminal behavior, loss of work, addiction, suicidality and failed relationships. Untreated ADHD can have strong economic and social burdens. There is therefore a strong need for early detection and diagnosis'. (French et al 4) Finally, there is a notable difference in the likelihood of males getting diagnosed, and getting diagnosed early on, whereas girls and women may have their ADHD go unnoticed and if they receive a diagnosis, it is typically later in life (French et al 7).

To reiterate, while there is existing research regarding the stigmatization of ADHD in the medical field and its consequences, as well as the related general societal stigma, there are several areas that are lacking in research. There is little discussion in the literature of counseling as treatment or co-treatment for ADHD, as well as little discussion of the involvement of healthcare professionals such as nurses and pharmacists. What I did find is that there is evidence that a great deal of negative perception and stigma toward ADHD exists, differently experienced than the stigma or perception of other mental illnesses, such as depression. There is also evidence that teachers and caregivers or parents play a large role in the recognition of ADHD and access to treatment, and a conclusion that the societal perception of ADHD does impact medical outcomes and life experience for ADHD patients may be drawn from these pieces of data.

Thirteen qualitative, semi-structured interviews were held. Of those interviews, four participants had ADHD, four did not have ADHD, two were parents of a child or multiple children with ADHD, one was an elementary teacher, one was a pediatric psychiatrist, and one was a general practitioner. All but one of the ADHD participants were female, and one was of South Asian descent, while the others were white. All interviewees, with the exception of parents and physicians, were in their early 20s. Two interviews had to be conducted over email, while all other interviews were held either in person or via Zoom.

All participants with ADHD stated that their doctors are sufficiently educated on ADHD, yet most also stated, when prompted, that they were never given any other resources or information regarding the spectrum of issues associated with ADHD and how to handle them. A majority said that the information they have was the result of their own research. None said that they felt like they had been directly discriminated against as a result of their ADHD, but rather discriminated against for their symptoms and not being like everybody else. All participants stated that their self-image and self-perception have been negatively affected by ADHD and all but one said they viewed their ADHD as an

overall negative. While multiple participants stated that they did not feel like they had been negatively treated by medical professionals, a few went on to describe negative experiences with medical professionals, such as being dismissed and belittled, or having their medication withheld. One participant specifically described two psychiatrists that had particularly antiquated views of ADHD, perhaps similar to what the psychiatrist interviewee was describing.

While my sample was skewed in that nearly all ADHD participants were female, I noticed that they all stated they received their diagnosis later in life whereas my male participant had a childhood diagnosis. Female participants expressed upset, frustration, and disappointment that their diagnosis came so late, as they felt it negatively impacted all areas of their life without them being able to understand it. One female participant wanted me to note specifically that getting a diagnosis is very difficult for women and particularly women of color, and that self-advocacy is a must in order to access it. There were varied responses in regard to fear of disclosing diagnosis and medication status across participants, but it came down to two general categories: disclosing in order to be open and honest, in hopes that others will be understanding, or not disclosing, for fear that they will "poison the well" and be perceived poorly or seen as lazy. All participants stated that they take medication for ADHD treatment and management, and generally described medication as a positive, but a few did express frustration with the difficulty of trying to obtain their medication as a controlled substance, and difficulty with some side effects. Female participants specifically talked about the difficulties they faced with emotional dysregulation and impulsivity as a result of ADHD and how it has negatively affected interpersonal relationships and finances.

Participants without ADHD generally had some understanding of ADHD and what it is, even if it was minimal. There was no negative feedback about people with ADHD. All participants stated they believe it is real, none stated that they would prefer to avoid people with ADHD. All interviewees knew at least one person with ADHD and had a generally positive perception of those with ADHD and did not have a negative perception of ADHD medication.

The teacher interviewed had neutral feelings about having ADHD children in her classroom and did not describe ADHD students as "difficult". The interviewee stated that she feels educated on ADHD as she has multiple coworkers with ADHD, and several students with ADHD. In her opinion, ADHD is underdiagnosed, as there are often students that she believes clearly have it, but parents are not interested in pursuing treatment or diagnosis. As a teacher, she notices when ADHD negatively affects students academically as well as socially in interactions with their peers. This interviewee also stated that she feels very confident in her own personal ability to accommodate students with ADHD, and to help offer the type of education and stimulation they need in the classroom, though the resources throughout the school may not always be available. Overall, the teacher had a generally positive perception of students with ADHD.

As stated, two individuals with a child with ADHD were interviewed. Neither parent felt as though they or their parenting had been blamed for their child's ADHD, aside from what one parent described as "persecution" and discrimination against her and her child in terms of his behavior resulting from undiagnosed ADHD. Both parent interviewees stated that social and academic difficulties, despite the child being academically advanced, prompted seeking a diagnosis. One parent had a very scientific understanding of ADHD, the other had a very psychological understanding of ADHD as a spectrum of various symptoms and difficulties ("scientific" and "psychological" being the words used by the interviewees). Both parents stated that they had little to no conflict in terms of desires and goals for treatment versus that of their child or their child's physician. One parent stated that ADHD is both under and over diagnosed in different circumstances, while the other felt it is often "misdiagnosed" in the presence of other mental health disorders. One of the parents stated that they had difficulty finding an adequate provider for their child.

The pediatric psychiatrist interviewed, as implied, typically works with children, but does have some experience working with adults. He stated that he enjoys treating patients with ADHD as he

believes he is able to make a large, positive change in people's lives. He feels very confident in his knowledge about ADHD and his ability to treat it and stated that he feels his coworkers in pediatrics are sufficiently educated, but adult psychiatrists, particularly older ones, have more outdated and less understanding views of ADHD. He stated that he would not describe ADHD patients as difficult, but perhaps more complex when they are adults and other comorbid disorders appear. Teachers were mentioned as a barrier, in that there are some teachers who "do not believe that any child should ever be treated for ADHD" and lie on student evaluation forms for ADHD, even though their answers contradict the child's behavior and report cards. In terms of under- and overdiagnosis, the participant stated that ADHD is overdiagnosed in more affluent areas where parents have access to resources for their children, as well as time to pay attention to their children, and are trying everything to get their children to succeed, whereas it is underdiagnosed in less-affluent areas, where parents cannot keep up with their kids as they are too busy. While he more often works with less privileged families, he still has times where he has to he situation and/or trying to obtain medication to sell. He also stated that ADHD may be mixed up with kids that are too anxious or otherwise disturbed to focus, but it is more important that treatment is beneficial and helpful for them than worrying about the exact label. He stated medication is generally positive and fairly straightforward for ADHD. Finally, he noted that he does see more male pediatric patients than females.

The PCP interviewed has had experience treating patients with ADHD but stated he frequently has difficulty making treatment plans, so he typically sends patients to a neuropsychologist to get a formal diagnosis. He does not feel that he himself, or his coworkers, are sufficiently educated on ADHD. He believes, similarly to the psychiatrist participant, that ADHD is both over- and underdiagnosed depending on the patient population. He is comfortable but not confident in treating ADHD patients. He recommends medication as treatment, and sometimes counseling. He hesitates in diagnosing and treating whenever there are concerns about substance abuse. In regard to the notion that children can "outgrow" ADHD, the participant stated that he believes it is possible to outgrow ADHD, but it is not absolute. He does not typically work with children and could not make a statement on the difference between pediatric

and adult care, besides the "obvious" difference of parental involvement. He believes it is possible to treat ADHD without medication but finds that most people prefer medication. He stated that medication can be positive and negative depending on the situation, as it generally leads to improvement in patients, but there are concerns for side effects as well as substance abuse. He says he mostly enjoys treating patients with ADHD.

There were many shared sentiments and thoughts between the PCP interviewee and the pediatric psychiatrist interviewee: while some kids can outgrow ADHD, some do not outgrow it all, some just find new coping and masking mechanisms. There is a hesitation to diagnose and treat when there are concerns of substance abuse (for the psychiatrist, it is the parents that are the concern for substance abuse and selling), both enjoy treating patients with ADHD and both believe that ADHD is under- and overdiagnosed depending on the area and the area's population.

Physicians, teachers, parents, and others without ADHD all seemed to have a positive perception of people with ADHD and did not perpetuate any stigma regarding ADHD. The PCP stated he and his coworkers are not sufficiently educated on ADHD or confident in treating it on their own, but the psychiatrist and teacher both felt very confident in their understanding of ADHD and their ability to either treat or accommodate it. The idea that ADHD is under- and overdiagnosed seemed to be shared not just by both doctors but also by others without ADHD. The same general reasoning behind each of those answers was that resources are not equally distributed and available to everyone, and some groups of people are more neglected than others.

Societal perception does have some impact on treatment outcomes for ADHD, and most certainly has an effect on the overall experience of those with ADHD. Medical professionals will treat patients with ADHD based on how much knowledge they have of ADHD and how they perceive ADHD. Societal pressures and judgements, among other factors, may discourage patients from seeking or continuing treatment. Because of the stigma around ADHD and the way its symptoms are perceived, patients may

have lowered self-esteem. The patients themselves seem to find ADHD to be a negative in their lives overall. ADHD patients (in my sample) do not seem to recognize until prompted that they have had negative experiences or that they have been given insufficient resources and information from those who are meant to provide it. Every participant that did not have ADHD knew or worked with at least one person with ADHD, which skewed the data in that they would have better access to knowledge about ADHD, and be more receptive to people with ADHD, or have a more positive perception of people with ADHD, than other people who do not know people with ADHD. The data I collected does not entirely match up with the data found in my literature review, but things such as the importance of teachers as barriers to care or the need for better education among primary care providers are highlighted in both. My sample is incredibly small, so it is not possible to make any generalizations based upon them, but it is an interesting look into the experiences of a few, and perhaps something that could be further researched on a larger scale. If further studied, it would be helpful to get feedback from adult psychiatrists and teachers that work with older students, such as at the high school or college level. As with any study, it would also make a positive difference to have a larger sample of those with and without ADHD.

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