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Clinician Perspectives of Adult High-Functioning Autism Support Groups' Use of Neurodiversity Concept

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Abstract

Ample research has examind the impact of autism for children and families, but less has addressed the effects of this condition for adults. The literature indicates that adults on the autism spectrum suffer from depression and have a heightened risk of suicidal ideation because of their social skills deficits [1]. Research also shows that individuals with high-functioning autism (HFA) can benefit from participating in support groups. In addition, research indicates that use of the term *"neurodiversity"* rather than other diagnostic labels encourages increased self-esteem to persons on the autism spectrum. This grounded theory study sought to understand the belief of clinicians with regard to the incorporation of the concept of neurodiversity in support groups for adults with HFA [2].

The population for this study comprised clinicians who led support groups for adults with HFA. The specific foundational theories used were Tuckman's stage model of group development and Salzer's peer support model. Data consisted of 3 pilot study interviews and 12 additional interviews. Participant recruitment occurred through LinkedIn, and interviews took place online through the chat modality GoToMeeting. Interview data were entered into NVivo and a Van Kaam coding procedure was used to decipher recurring themes. Key results indicated that clinicians believe that the incorporation of the concept of neurodiversity can help adults with autism to build self-esteem and change the way individuals with HFA consider the condition, which in turn can assist them to build social skills, and relationships with their peers. Positive social change that may result from this study includes encouragement for increased use of the concept of neurodiversity as a tool in support groups for people with HFA, and stimulation of further study of this concept for decreasing bias against those with HFA.

Keywords: Neurodiversity; Adult High-Functioning Autism

Background

Persons with high-functioning autism (HFA) often have a difficult time interacting with others. These social difficulties can thwart their ability to coexist easily with neurotypical people [3]. These difficulties can also inhibit individuals with HFA from holding down a job, communicating their needs effectively, and obtaining needed social support [3]. The autism spectrum disorder prevalence rate amongst individuals in the United States is 1 in 68 [4]. Of those, 41% meet the criteria as high functioning [4,5].

Many people with HFA have above average IQs and have a number of talents to share with the whole of society. For the purpose of this study, persons defined as having HFA have level 1functionality as defined by APA Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition [6].

According to the DSM-5 (2013) [6], the diagnostic criteria for ASD are specific. Diagnosis based on a number of issues includes an individual's ability to communicate efficiently and the use of repetitive behaviors. The DSM-5 defined three levels of severity. Persons at level 3 require substantial support. Persons on level 2 require significant support, and individuals on level 1 require support [6].

In 1998, Singer started the neurodiversity movement (NDM), and first used the term in online chat rooms and blogs during the same year [7]. The use of the neurodiversity concept can change the way persons on the autism spectrum feel about their diagnosis [8,9]. Neurodiversity is another view of differences in mental functionality. Although some individuals with autism do have significant intellectual disabilities, others are highly intelligent [10]. However, these highly intelligent people often do not fit the mold that society deems appropriate [3]. Society often views individuals with autism as disabled, and thus, subpar [8]. The concept of neurodiversity challenges that notion, and its proponents contend that people who are neurologically different need acknowledgment and support for their achievements just as persons who are neurotypical do.

One therapeutic measure for assisting persons with HFA is to help them develop social skills, which often includes the use of support groups [11]. For this study, clinicians who work with individuals with HFA discussed their thoughts, experiences, and ideas regarding incorporating the concept of neurodiversity into support groups with the goal of improving the lives of persons with HFA. An opportunity exists for social change because persons participating in support groups can begin to build camaraderie. Social change may also occur because group facilitators may have the opportunity to introduce a new concept, and group participants may be introduced to a new frame for self-conceptualization. The whole of society could benefit from the neurodiversity framework as it may lessen popular misconceptions about people with autism and bring about acceptance.

Problem Statement

Autism is a condition that ranges along a spectrum of severity [12]. According to the APA Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition [6], persons with autism exhibit qualitative impairment in social interactions and communication as well as different stereotypical behaviors such as hand flapping, echolalia, and poor eye contact [13]. Many individuals with autism have limited functionality and struggle to live independently because of comorbid conditions such as cognitive impairments and sensory overstimulation [14].

However, a substantial subpopulation of persons with autism lead relatively independent adult lives with minimal support [8]. Individuals with HFA are persons with Autism Spectrum Disorder (ASD) who have minimal cognitive deficits and are self-reliant and independent. However, their deficits in social skills often isolate them from much of society [3].

Considerable effort by professionals has gone into helping persons with HFA function better in mainstream culture [15]. Since its inception in 1998, the NDM has gained increasing acceptance amongst people with HFA and those interested in their wellbeing [7]. The proponents of the NDM aim to promote social acceptance and understanding of people with HFA by people who are not autistic and who fall in the standard part of the neural spectrum [8]. Proponents of the NDM reject the disability and medical models that overemphasize disability and neglect the gifts and strengths of people with HFA [16]. Supporters of the NDM do not deny that conditions such as HFA need treatment, but take a holistic approach that also involves observing strengths, building assets, and increasing self-esteem. The neurodiversity concept promoted by the NDM encompasses various areas of neurological atypicality including dyslexia, autism, attention deficit/hyperactivity disorders, and other similar atypical characteristics [17].

An essential part of the NDM provides persons with HFA an opportunity to congregate to develop a sense of positive identity, acquire skills, and identify resources [18]. The peer-support model in support groups led by licensed clinicians focuses on specific clinical deficits, especially social interactions and communication. Resolutions of specific clinical deficits are essential for people with HFA, and clinicians can use support groups to help persons with HFA learn how to make and keep friends [19,20]. The incorporation of these support groups by clinicians can even help these individuals meet romantic partners [21].

Although the incorporation of support groups has been shown to be effective in improving clinical and social outcomes for other mental disorders; it remains unclear how well the support group model will work for an adult population that consists of persons with inherent difficulties with communication and social interaction [11,22]. Limited research exists on this subject, and on how clinicians perceive the incorporation of the neurodiversity concept into support groups for adults with HFA [8,18,23,24]. With my study, I sought to understand the experiences of clinicians who work with persons with HFA.

Purpose of the Study

The goal of this study was to help professionals in the field of autism determine how clinicians perceived the concept of neurodiversity in support groups for adults with HFA. I approached this research as the first step in making direct, positive change in the lives of adults with HFA [25]. I sought to use these questions to determine the efficacy of implementing another support methodology for adults with HFA. One-step required to incorporate the neurodiversity concept into support groups for adults with HFA is to pinpoint how the neurodiversity concept relates to persons with HFA. Another step is to see how clinicians who work with persons on the autism spectrum perceive its implementation in peer support groups. These two factors served as necessary aims of this study.

Nature of the Study

For this study, data collected consist of guided interviews with clinicians who worked, at the time of data collection, with adults who had HFA. Data collected from these interviews would lose meaning and context if I were to have used a quantitative method because it is difficult to quantify experiences, beliefs, and opinions. Thus, I determined that a qualitative research methodology was appropriate [26]. Qualitative methodology offered me the flexibility inherent to semi-structured interviews [27,28]. Further, I used grounded theory research design to guide the study and used a pilot study to assist with the construction of the interview process.

Conceptual Framework

Tuckman's stage model of group development

Tuckman first hypothesized his stage model for group development. Tuckman's model organizes group development into the

following stages: (a) forming, (b) storming, (c) norming, (d) performing, and (e) adjourning and transforming. Tuckman's central premise was that group development requires various phases for a group to flourish and be productive. Tuckman's theory was relevant to my study because it helped me theorize how a group comprised of adults with HFA may develop with the incorporation of the neurodiversity concept [29].

Salzer's peer support model

Salzer introduced a theoretical model that relates specifically to the development of peer-support groups. His peer-support model emphasizes the elements of social learning theory and works from the premise that peer-support groups help increase the self-improvement of participants by developing their skills and offering a sense of hope while helping to diminish fears. While neither of these theories incorporates the concept of neurodiversity, they both serve group facilitators as valuable tools and are well-suited for use in support groups for people with HFA [30].

Main Research Questions

This study's main research questions are as follows: How do clinicians perceive the neurodiversity concept? What are clinicians' impressions of a potential for social change in the lives of persons with HFA resulting from the implementation of the neurodiversity concept into support groups? What are clinicians' thoughts regarding the implementation of the neurodiversity concept in support groups?

Methodology

Participant Selection

Population: The participant pool consisted of clinicians who worked with persons with HFA in the United States at the time of data collection. Criteria for participation included professionals who (a) had experience working with persons with HFA, (b) had at least two years of clinical experience, (c) held a minimum of a master's degree, and (d) held licensure from their state. For the purpose of this study, HFA refers to participants diagnosed by a clinician with ASD with Level 1 functionality as defined by DSM-5 (2013) [6].

The participant pool consisted of a convenience sample. Participants were recruited in according to ease of contact after I determined that they met the study criteria. Convenience sampling was the best choice for this research study due to time constraints. Potential participant selection correlated with the availability to sit for an interview after participants met the study criteria.

Participants in the pilot study consisted of two males and one female. Their ages ranged from 29 to 65, and they were licensed in the states of Colorado, California, and Hawaii respectively. Two participants self-identified as White, and one self-identified as Polynesian. Of these three participants, two held doctoral level degrees, and one held a master's level degree.

Using a convenience sampling method, I recruited and interviewed 12 participants for the full study from LinkedIn. These participants lived throughout the geographic regions of the United States, and were from eight different states. All the participants had either a master's degree or a doctoral degree. I recruited both male and female participants. Participants ranged in age from 29 to 56 years old ($M = 39.75$). Participants also had ethnic diversity, and self-identified as White, Hispanic, Black, and Asian.

Saturation and Sample Size: Guest et al. noted that 12 interviews from one homogenous group are common to reach saturation of knowledge. In the case of this study, the homogenous groups were the 12 participants who met the qualification as participants for the study [31]. By maintaining the recommended number of interviews, the results from the data elicited quality. The participant size for this study was 12. Sbaraini *et al*. stated that by conducting multiple interviews, a point occurs when there is an established pattern, known as the saturation of knowledge [32]. To conduct interviews after the saturation of knowledge is established was a moot point as no new knowledge was attainable. I assessed for saturation by notating any obvious recurring themes throughout the interview process.

Procedures for Recruitment: I posted an advertisement on my page in LinkedIn about the study, which outlined the participant criteria. Once interested, a potential participant contacted me via the LinkedIn inner mail. I contacted a number of clinicians through her second and third-degree connections along with contacting specialized groups. Second and third-degree connections were connections of my first-degree connections, but had no direct connection with me. LinkedIn also provided a platform for specialized professional groups to form so that professionals can collaborate and network, which I used. More specifically, I posted a call for participants on my LinkedIn page on August 28, 2015. I also posted calls for study participation in LinkedIn groups such as Autism Meta Network, American Psychological Association Division #33--Intellectual Disabilities/Autism Spectrum Disorders, and Autism Speaks. As a result, I sent out 42 LinkedIn emails to potential participants.

This initial effort yielded 41 potential participants, and I emailed consent forms to all who responded. Two respondents stated that they did not qualify. Nine of the initial respondents heard about the study through Autism Meta Network, ten respondents came from the call for participants advertisement that I placed in Autism Speaks. One respondent came from American Psychological

Association Division #33. Fourteen respondents came from second and third degree LinkedIn connections. Five respondents came from first-level connections who shared my call for participants with their contacts. Of the 41 possible participants who qualified, nine consented to participate in the study. A week after sending out the consent form, I sent follow-up emails to each of the potential participants asking if they were still interested in taking part in the study. Six potential participants responded to the follow-up email.

Pilot study: A pilot test of questions commenced [33]. Three non-biased, test subjects served as participants at my convenience. Test subjects held the same participant qualifications and did not receive compensation in any way. The pilot interviews allowed me to test and ensure the methodology of data collection would run smoothly.

Procedures for participation: Interested study participants contacted me via LinkedIn mail. Delivery of an informed consent form for review and signature to the potential participant ensued once I received the potential participant's inquiry. Upon signing the consent form, research participants verified they met the eligibility requirements for this study. Once the signed informed consent form reached me, I sent a potential participant an email to arrange a meeting time. I then set up a chat room through GoToMeeting and delivered the login information to the potential participants. Participant confidentiality was of utmost importance.

Setting

I conducted interviews using the Internet chat modality GoToMeeting, and served as the sole interviewer for this study. GoToMeeting was the primary data accrual instrument used throughout the entire interview process. Interviews were conducted at places of convenience for both parties involved. To maintain participant confidentiality, I conducted these interviews from my personal computer, in a private setting, with no distractions. I also had no association with the participants prior to the interviews, either personally or professionally.

Data Collection

For each interview, I set up a time that was mutually agreeable to both me and the participant subsequent to the participant's consent to the items contained in the consent form. I sent participants an email reminder that they needed to research the term *neurodiversity* using a web browser of their choice prior to the interview. The interview then commenced.

Data Analysis

I used a Van Kaam coding procedure within the NVivo software for data analysis [34]. With the Van Kaam coding procedure, I was able to create nodes for each of the eight interview questions and queries within those nodes based on the participants' responses. I created a query for each of these themes within the interview question node. I used this procedure for each of the eight interview questions during the coding process. By using this method, I was able to find commonalities in the responses, and these responses served as the results of the study [35]. For example, the first interview question was: What thoughts do you have with regard to stereotypical behaviors and stigma that may surround an ASD diagnosis, even for individuals who are high functioning? I created a node in NVivo for this question. From this interview question, the following themes emerged from the participant responses: negative stereotypes, a wide range of functionality, society is quick to judge, lack of social skills, quick to label, strong push to teach normalcy. I created a query for each of these themes within the interview question node. I used this procedure for each of the eight interview questions during the coding process.

Results

Research Question Findings

Each interview question (IQ) developed by me posed a specific question to help clarify each research question (RQ). The formatting of this section is by individual research questions. A discussion regarding the results of each interview questions as they relate to the research question follows.

RQ1: How do clinicians perceive the neurodiversity concept? The following three interview questions posed to participants aided me in answering the first research question posed above. These questions were important tools I had to answer the research question. Clinicians all stated that neurodiversity could be a positive influence when introduced to persons with ASD.

IQ1- What thoughts does the clinician have with regard to stereotypical behaviors and stigma that may surround an ASD diagnosis, even for individuals who are high functioning? 12 out of 12 of the participants feel that there are stigma and stereotypes associated with persons with ASD. This question was relevant to the first research question because it is part of what neurodiversity proponents aim to thwart. It was important to establish if clinicians believe that there are stigma and stereotypes associated with ASD.

IQ2- As an experienced clinician who has worked with persons with autism spectrum disorder, how does the clinician perceive an autism diagnosis affects the individual in terms of self-esteem? Participants varied in their responses, with responses that led to an "it depends on some factors" response. One issue that emerged was that self-esteem is dependent upon the individual's

environment and their level of functionality and self-perception. A participant stated that levels of functionality also affect people's perception of themselves in the world. These perceptions can be causality for self-esteem issues, perceived or actualized. One participant said, "… diagnosed individuals become depressed, and their self-esteem drops." This interview question is also important in answering the first research question because it is the antithesis of what neurodiversity proponents want to build.

IQ3 - How does the clinician perceive the concept of neurodiversity? From the data, 12 out of 12 participants viewed the concept of neurodiversity as a positive one. Clinicians were eager and excited about the new terminology. Participants widely received the concept of neurodiversity. This question helped me ascertain if the participant understood the concept of neurodiversity in general terms, which is necessary to answer the first research question accurately. The clinicians interviewed were able to give accurate descriptions of the concept.

RQ2: What are clinicians' impressions towards a potential for social change in the lives of persons with HFA by implementing the neurodiversity concept into support groups? The following three interview questions served as tools for me to answer the second research question posed above. Participants stated that there was potential for social change as the notion can build up self-esteem and autonomy in individuals with high-functioning autism. An important theme was that some participants believed that the cognitive level of the individual could affect the impact of neurodiversity, meaning that individuals who had higher cognitions could personally relate to the term more efficiently than those who were lower cognitively inclined.

IQ4- Does the clinician believe the concept of neurodiversity can influence persons on the autism spectrum perceive their diagnosis? Participants agreed that the concept of neurodiversity could change the way people with HFA feel about their diagnosis in 11 out of 12 participants. A participant stated that persons on the autism spectrum could not comprehend the concept, and, therefore, believed the concept would not change the way a person with HFA felt about their diagnosis. It is important to note that this participant was relating their answer to those whom were severely cognitively impaired, not those who were high-functioning. Another important concept was that neurodiversity is still a label. This interview question was important for me to ask because it asks if the notion of neurodiversity may help individuals with HFA feel different about their diagnosis.

IQ5- Does the clinician believe the concept of neurodiversity will hurt or hinder autonomy of individuals with ASD? Participants ascertained that the notion of neurodiversity would help autonomy of individuals with ASD. Participants interviewed agree that autonomous individuality can benefit from the notion of neurodiversity in 12 out of 12 participants.

IQ6- Does the clinician believe the concept of neurodiversity will hurt or hinder self-esteem of individuals with ASD? From the participants, I interviewed, the conclusion was that clinicians believe that the notion of neurodiversity will help self-esteem in individuals with ASD in 12 out of 12 instances. One person alluded to the notion that personality and level of functionality are a factor. Another important comment was that self-esteem as it relates to neurodiversity could also come from the extrinsic view of individuals on the autism spectrum as people can become more accepting of those with HFA. This notion helps answer the second research question because the growth of self-esteem is an avenue towards social change.

RQ3: What are clinicians' thoughts regarding the implementation of the neurodiversity concept in support groups? I used the last two interview questions below, to answer this research question. Clinicians' thoughts regarding the implementation of the neurodiversity concept into support groups are positive. I reached data saturation, as the consensus was clear.

IQ7- How does the clinician consider persons with HFA will feel about the notion of neurodiversity? 11 out of 12 participants agreed that persons with HFA will embrace and accept the concept. Two people interviewed thought that some individuals might not understand the concept and that cognitive impairment would get in the way. Another participant stated that he or she was indifferent and that it depends on the person's personality. This interview question helped me to answer this research question because how a clinician believes individuals with HFA will react to the notion is important to know if they believe if it will benefit the same population when implemented in support groups.

IQ8- Does the clinician believe the concept of neurodiversity will influence adults with HFA's well-being when implemented in the domain of support groups? Participants again stated that the idea of neurodiversity would influence adults with HFA when implemented in the domain of support groups in 12 out of 12 participants. One person stated that when grouped together, participants of these support groups will have an opportunity to share ideas and will help them to "think outside the box." The responses from this interview question helped me to answer the third research question because it answers it directly.

Limitations of the Study

A limitation of this study was its sampling strategy. I used a convenience sampling technique, recruiting participants on LinkedIn. Another limitation was that the data collection consisted of only online chat interviews. Some potential participants may not have been comfortable using this format and may have preferred a verbal exchange or an emailed survey. Furthermore, the sample was limited to only clinicians at the masters and doctoral levels.

Recommendations

One suggestion for future research would be to separate the participants demographically. By dividing participants by demographics, researchers could determine whether other factors, such as socioeconomic or geographic factors, influence the responses of participants. Because this study focused on just clinicians in the field, additional detailed studies relating to the way teachers, therapists, others in the mental health or educational field feel about neurodiversity would be beneficial. A study of persons with HFA in support groups that use the neurodiversity concept would contribute to the knowledge in the field. This study could gather data from participants before and after participation to test the effectiveness of using neurodiversity in support groups for adults with HFA. The researcher would collect baseline data relating to social skills and well-being before the implementation of the neurodiversity based modality. After the implementation of the concept, the researcher would again gather data and would analyze the information to see how perceptions have changed. Because the primary finding was that clinicians had a positive outlook on the neurodiversity concept, my study clearly points to the need for further exploration of the neurodiversity concept.

Implications

The potential implications of this study are that the notion of neurodiversity could potentially open the door for more research regarding the usefulness of neurodiversity as a therapeutic implement. Persons on the autism spectrum have some difficulties coping in a neurotypical world. Current research suggests that by applying the concept of neurodiversity in support groups, persons on the autism spectrum may grow in self-esteem and confidence.

Implementing the neurodiversity concept in support groups for adults with HFA has the potential to make positive social change. By examining the thoughts of clinicians who work with persons with HFA, I took the first step in broadening the knowledge of the field regarding the potential implementation of this new therapeutic modality [8]. Persons on the autism spectrum are at- risk for societal stigma and being ostracized from their communities [36]. Neurodiversity can help clinicians turn maladaptive notions around and help retrain both individuals on the autism spectrum and persons within the community.

Positive social changes begin with the individual. The concept of neurodiversity can change the way an individual feels about him or herself and can also help thwart maladaptive perceptions leading to depression and anxiety in individuals [36]. The neurodiversity concept can help individuals understand their innate talents and the goals they can achieve.

Families can also benefit from the incorporation of the concept of neurodiversity into support groups for adults with HFA [37]. One main benefit is that families can have another way to redirect maladaptive notions in their loved one's mindset to help mitigate self-esteem and depressive episodes. Neurodiversity can also help family members view their loved one as merely neurologically different, rather than disabled or defective [38].

At the organizational level, incorporation of the neurodiversity concept into support groups for adults with HFA can lead to higher levels of acceptance [39]. This acceptance can also help those who would not otherwise seek out treatment because of the stigmatization of treatment, thus bringing about more business to the organization providing services [40]. This practice can also lead to more research opportunities, and thus more publications and presentations as research on the topic increases.

This concept can also lead to improved levels of accepting attitudes toward autism, which, in turn, can help individuals on the autism spectrum attain higher rates of acceptance in the community. This higher rate of acceptance can lead to more opportunities such as employment, personal relationships, and other forms of community inclusion [3]. This integrative mindset can help individuals feel as though they are a part of the community in which they live, which can lead to higher rates of self-esteem and mitigate depression [41,42].

Conclusion

Individuals with HFA face a number of difficulties. One of these difficulties is stigmatization and ostracization from the community. Rejection from one's community can cause lasting harm to the individual, and can hinder an individual's ability to flourish and progress. One aspect of this harm is that the poor treatment of a person by others can have an effect on how that individual views his or her self.

The concept of neurodiversity is a new modality for potential treatment of persons on the autism spectrum. Proponents of this concept hold the position that persons with neuroatypicality should have the opportunity for full social inclusion [43]. Society can change its understanding of and behavior toward those with autism spectrum disorder. In turn, those with HFA will learn to love and appreciate themselves. Individuals, regardless of their innate ability or disability, should be uplifted and praised for their unique abilities. If society focuses on an individual's abilities rather than on their disabilities, as does the neurodiversity concept, there is a significant opportunity for social change that will benefit all.

Definitions

Clinician

Educated persons in the field of psychotherapy and who actively provide clinical services [44]. These individuals are highly trained to diagnose and treat their patients. Clinicians, for the purpose of this study, were persons who work with individuals with HFA.

Neurotypical

A term initially devised by the autism community to describe those who are not on the autism spectrum. This term later evolved to include anyone without atypical neurology, although used both ways. For the purposes of this study, the term neurotypical denotes persons not on the autism spectrum.

Peer Support Groups

According to research, support groups used in therapy with individuals with ASD are therapeutic [8,11, 18]. A classic support group format is one where groups of people gather and share thoughts and stories, and offer support to one another. For the purpose of this study, a support group directly correlates to the gathering of individuals with similar comorbid complexities, such as autism, to support and discuss issues at hand [30].

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