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The **JOURNAL OF THERAPEUTIC SCHOOLS AND PROGRAMS (JTSP)** is published by the National Association of Therapeutic Schools and Programs and publishes articles that assist readers in providing comprehensive care for adolescents, young adults, and families receiving services from residential and wilderness/outdoor behavioral healthcare treatment programs. Submissions are encouraged that relate theory to clinical practice or provide original research relating to program or treatment outcomes and processes. All rights reserved.

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Preface

Neal Christensen, Ph.D.
Elements Wilderness Program

I have been curious about human behavior since I was very young. I recall asking questions about why people did what they did, and thought about why I did things too. As a youngster I discovered I had a penchant for science and later learned I could study human behavior in college. I pursued a major in psychology and then followed with a master's degree and a doctoral degree in Counseling Psychology. Throughout my early years in college and graduate school, I found myself working with adolescents and young adults across a variety of settings. This developmental period of life continues to be my focus, as well as the myriad of topics with which they struggle and aspire. Undoubtedly, these early experiences influenced my professional path as well as the clientele with whom I have chosen to work. My journey as a psychologist has led me on a fascinating career path, from working with adolescents in remote wilderness settings to serving in the role as guest editor for the Journal of Therapeutic Schools and Programs.

This year's edition of the JTSP focuses on the topic of Neurodiversity. This topic is wide ranging and covers a variety of areas. The authors of the articles of this year's edition cover a multitude of topics on neurodiversity, though certainly not exhaustive. Before I address the articles in this year's edition, I want to speak about the importance of this topic. Difference is at the core of diversity, and diversity is something important to celebrate. Diversity in a species leads to strength and longevity. It's through these differences that people discover new and alternative ways of seeing and doing things. When treating adolescents who experience neurological differences, I find that it is precisely these differences that help them become resilient and persistent in the world in which they live. When misunderstood, people can be unappreciated and mistreated. This has been an unfortunate pattern in human history, and one we as a culture are witnessing in current times. It is our duty as professionals, as well as citizens, that we challenge ourselves to do better and change the future by not repeating the past. This is done through the work of learning and education, conversation, and discussion. In the recent past there have been terrible tragedies playing out in our country and across the world. Unfortunately, tragedy is not limited to the last few

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years. However, these tragedies have generated energy within communities to make important societal changes by embracing diversity, equity, and inclusion in various social demographics. The same movement is important as we work with people who experience neurological differences.

Our professional ethics state that we must strive to treat people benevolently and avoid malfeasance. In the pursuit of professional practice, we must strive to understand things we may not so that we may serve those we treat to live better lives. Neurological differences need to be recognized and understood and individuals with these differences need to be nurtured. Neurodiverse individuals deserve empathy and compassion. Several people come to mind who have made an indelible mark on society and in their respective areas of practice including Dan Ackroyd, Temple Grandin, and Elon Musk. These individuals happen to be on the autism spectrum. Each of these individuals have been pioneers in their respective fields of practice. Each of these individuals have contributed greatly not only in spite of what has been considered a disorder, but because of their syndrome. Each had a gift they gave, though if written off for being eccentric or weird, or allowed to waste away for a belief that these individuals did not have anything to offer, our world would be less for it. Neurodiversity is something to be celebrated and seen for what gifts it has to offer. It is also our responsibility to help people with neurological differences to see their gifts too so they may contribute to the world we all share.

Many of the articles in this edition explore the topic of neurodiversity including two different and yet complementary articles on autism in females and the female phenotype, autism and OCD, and pathological (extreme) demand avoidance. Each of these articles offer new and helpful perspectives on neurodevelopmental conditions, and extend the knowledge base for diagnosticians, clinicians, educators, administrators and supporting staff within the NATSAP community. Other articles go beyond the topic of neurodiversity and explore topics including technology and digital media overuse and family engagement. We know compulsive behaviors such as substance use, video gaming or viewing pornography are ways individuals attempt to cope and get certain needs met. Though these behaviors may be harmful and not without consequence, it is important to understand the individual and the need in which they are attempting to meet, thereby helping them find more adaptive ways of meeting their needs. We know the importance and impact family has for and upon the individuals with whom we work. It is equally important that we continue to see our clients within the context in which they live and grow. It is through the exploration of family engagement that we learn how to support the individuals we treat by engaging those who surround and support our clients. Families come to the NATSAP community seeking help for their loved ones, and it is our duty to serve the individuals and families with benevolence and kindness, professionalism and expertise, and from a space of empiricism.

I want to express my deep gratitude for the Chief Editor, Dr. Ellen Behrens, and Editorial Manager, Ali Kelleher, for all they have done to support me as I served in the role of Guest Editor of the Journal of Therapeutic Schools and Programs. Each of them provided me guidance and support from beginning to end. Their consultation and oversight of this project has been appreciated, and without them this experience would have been far more challenging as a first-time editor. I also want to recognize and give thanks to the many people who reviewed these scientific articles with care and a keen eye for science and professionalism for the mental health community. These peer reviewers played a key role in evaluating and providing important feedback to the manuscripts each read and evaluated. They helped each author elevate and improve the articles contained in this edition.

I learned from my early experience in adventure education to cherish individuals' strengths and contributions, and through collaboration and teamwork the end result is far better. It has been my pleasure for nearly two decades to work with the many clients I have been entrusted with by their families and organizations by which I have been employed. It has been the community, the colleagues whom I have worked alongside, that challenged me and helped me see, learn, and grow as person and a professional. It is the community of colleagues, families, and neurodiverse individuals whom I am truly grateful for. I hope you as the reader of this year's edition is inspired look deeper into yourself, continue learning about differences in humans, and work collaboratively within you teams.

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Autism in Disguise: The Female Autism Phenotype

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Abstract

This article explores the female phenotype of autism including the sex differences in Autism Spectrum Disorders (ASD) between males and females without intellectual or language impairments. We examine the bias associated with considering ASD a "male" disorder resulting in misdiagnosis of females with ASD and the additional challenges associated with diagnosing females. We discuss camouflaging, a strategy that females with ASD use frequently to mask symptoms and how this contributes to diagnostic issues and poor psychological outcomes. Neurobiological differences between males and females with ASD are briefly discussed. Implications for assessment, treatment, and future research are discussed.

Keywords: sex differences, sensory, dysregulation, female protective effect, extreme male brain, neurobiology, camouflaging, female autism phenotype, autism, ASD

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AUTISM IN DISGUISE

The Diagnostic and Statistical Manual of Mental Disorders, or DSM-5 lists autism spectrum disorder (ASD) as a neurodevelopmental disorder characterized by impairments across two major areas. These areas include deficits in social communication and social interaction and restricted and repetitive patterns of behavior, interests, or activities. To obtain a diagnosis of ASD, the symptoms must have been present during the early developmental years (American Psychiatric Association, 2013).

In the DSM-5, ASD is divided into three levels of impairment. In this article, we will be focusing on ASD Level 1, the mildest form of ASD, which includes some individuals previously diagnosed with Asperger Syndrome or Pervasive Developmental Disorder NOS listed in the previous version of the DSM, DSM-IV TR (2000). Individuals with ASD Level 1 require some support (American Psychiatric Association, 2013). Without supports, there are noticeable impairments in social communication, which may include difficulty initiating social interactions, atypical responses to social overtures by others, and what may appear to be minimal interest in social situations. Some of these individuals would like to participate in social interactions/situations but often have poorly developed social skills. Their social skills may be marked by difficulty understanding social cues and/or accurately reading body language. Some may also mask their deficits effectively but become exhausted by their attempts to fit in (Sanchack & Thomas, 2016).

Individuals with ASD Level 1 can engage in communication but struggle with back-and-forth conversations with others. In addition, their attempts to develop and maintain friendships can often fail. They may also display very inflexible thoughts and behavior and have difficulty transitioning from one activity to another. Problems with organization, planning, and other executive functions often interfere with their ability to function independently. Although this is the mildest level of ASD, these impairments significantly affect most aspects of life, and these individuals may still require and benefit from therapeutic intervention and support throughout the lifespan (Matson et al., 2016).

Males with ASD are often identified at a younger age and their social and behavioral impairments are more evident at earlier ages (Giarelli et al., 2010). Females with ASD are regularly treated for other diagnoses, including anxiety, depression or eating disorders (Huke et al., 2013; Lai & Baron-Cohen, 2015, Mandy et al., 2012), because the ASD is not as typical in presentation and therefore not initially identified. Sometimes mental health practitioners speculate that female clients with undetected ASD may have an emerging personality disorder, such as borderline personality disorder. This is likely due to the overlapping symptomatology of emotional dysregulation in both disorders (Attwood, 2007).

Females with ASD can often become easily upset and dysregulated at what appear to be minor disruptions in schedules and/or expectations and may take a long time to calm down. A comparison study of males and females with ASD found that females showed more irritability than males (Frasier et al., 2014). A study of adults with ASD (Lai et al., 2011) showed that females with ASD showed more lifetime sensory difficulties than males with ASD. Females with ASD who have sensory difficulties may have very intense responses to sensory stimulation which can also contribute to higher reactivity to the presence of noise and/or a chaotic group setting.

Diagnostic Challenges

ASD is diagnosed far more often in males than females (Loomes et al, 2017). Historically, males have been thought to be 4-5 times more likely to be diagnosed than females, particularly for those without an intellectual disability (Dworzynski et al., 2012). The DSM-5 states that the prevalence of ASD in males is 4 times greater than females with ASD (American Psychiatric Association, 2013). Dworzynski et al. (2012) suggest that there is a bias against diagnosing females with ASD. Research has shown that ASD, as a potential diagnosis, does not come to the attention of clinicians for females unless they show significantly higher levels of symptomology and more co-occurring difficulties than males. Additionally, females are diagnosed much later than males (Loomes et al., 2017). In a meta-analysis of studies examining almost 14 million participants, Loomes and colleagues (2017) found the ratio between males and females with ASD to be lower than what has commonly been believed, closer to 3:1. Given this finding, Loomes and colleagues (2017) suggest that many females with ASD are not coming to the attention of parents, educators, and clinicians at earlier ages.

Sex Differences

There is a widely held belief that ASD is a “male” disorder. This belief has contributed to well-known ideas regarding ASD, including the belief that individuals with ASD have an “extreme male brain” (Baron-Cohen 2002) and that being a female provides a protective effect (Jaquemont et al., 2014; Skuse, 2000). The “extreme male brain” theory suggests that people with ASD process the world through a “male” lens and take an interest in stereotypically male topics, such as machines, buildings, or vehicles, and that they may have more difficulty with tasks that women are better at, such as understanding social cues. Baron-Cohen (2002) found that the difficulty people with ASD have with social intelligence and the ability to excel at pattern recognition can be explained by the “extreme male brain”. Researchers also suggested that the extreme male brain was associated with higher levels of fetal testosterone (Auyeung et al., 2010; Baron-Cohen, 2002).

The female protective effect proposed by Skuse (2000) and Jucquermont et al. (2014) posits the theory that females are better protected against developing ASD due to chromosomal differences as well as differences in susceptibility to genetic mutations. They concluded that females are “protected” from ASD relative to males with a comparable set of risk factors. These two theories may have fueled inaccurate biases and have been called into question in recent years by Xiong et al. (2020) and Bai et al. (2020), suggesting that we need to consider alternative explanations for higher levels of ASD diagnosed in males.

The diagnosis of ASD in females is sometimes missed by psychological testing and by psychotherapists, particularly clinicians with limited experience with this population. There is growing concern that females with ASD are under-identified and are diagnosed much later in life (Trubanova et al., 2014). Parenting, educational, and clinical practices are heavily influenced by the bias that ASD is a “boy’s disorder” (Estrin et al., 2020). Males are referred for a diagnostic assessment for ASD far more frequently, and parents express concern that their female children may be on the spectrum much later in childhood than their male children

(Begeer et al., 2013). Even when females and males do not demonstrate differences in symptom severity, females are less likely than males to receive a diagnosis.

Whitlock et al. (2020) examined teacher bias in the recognition of ASD and found that primary school educators often missed the signs of ASD in females because of their belief that ASD is a male condition. Thus, they may be less sensitive to the symptoms of ASD in females. An experimental study by Geelhand et al (2019) investigated how people's expectations of boys and girls influence their evaluation of behavioral symptoms as well as their prediction of future behavioral and emotional difficulties. The research participants were all shown the same vignettes of young boys and girls (age 5) engaging in behaviors often displayed in children with ASD. They were asked to rate the vignettes of the 5-year-olds and then imagine the same children at age 15. The results suggested that boys and girls were rated differently. Young boys exhibiting ASD symptoms were expected to continue to have significant behavioral difficulties as they got older. In contrast, while the research participants expressed concern about young females with the same behaviors, they did not expect that the girls would continue to have difficulty as they got older. The research suggests that girls are expected to "outgrow" problematic behaviors, which may provide additional insight into the delayed diagnosis of girls with ASD.

Furfaro (2020) suggested that females are underdiagnosed with ASD because their presentation is qualitatively different from the typical male presentation. Bargiela et al. (2016) described how girls with ASD tend to show a sex-specific manifestation of ASD. Females tend to show higher social motivation and a greater capacity for friendships than males with ASD. In addition, Bargiela and her colleagues (2016) reported that girls with ASD tend to internalize their behaviors rather than externalize them. For example, females are less likely to exhibit behaviors such as impulsivity/hyperactivity and are more likely to suffer from anxiety and depression. Although females and males with ASD have similar underlying characteristics (difficulties with social communication, restricted interests and unusual sensory responses), the behavioral expression is quite different. In an effort to draw attention to the difference in behavioral expression, researchers have begun to use the term "female autism phenotype" (Furfaro, 2020; Hull et al., 2017; Kirkovski et al. 2013). The theory posits that females express the characteristics of ASD in ways that differ from the typical presentation seen in autism spectrum disorders.

Hull et al. (2020) have found that females show higher social motivation and are more interested in friendships compared to males with ASD. They suggest that it is more common for females with ASD to "camouflage" their autism, and they are more likely to internalize their difficulties, resulting in comorbid diagnoses such as anxiety, depression and eating disorders. Additionally, restricted and repetitive intense interests in females tend to be more socially focused or mainstream (reading, pop stars, animals). Bargiela et al. (2016) suggested that since professionals understand ASD within a male population, they are much less aware of how ASD manifests in females, contributing to the diagnostic bias that has been observed in several studies and in clinical practice.

Trubanova et al. (2014) suggest that school age females may appear less socially impaired than males. However, as the social challenges become more complex in adolescence and adulthood, females with ASD start to display greater social impairments. Social impairments in younger girls are often interpreted as anxiety and depression rather than symptoms of ASD. This is supported by Kopp and Gillberg's (1992) research. Trubanova and colleagues (2014) studied several case examples of young adult females with ASD. They all reported that as they entered adolescence, their peer relationships became more intimate and complex, resulting in more severe symptoms of anxiety and depression as well as more extreme behaviors. These behaviors were sometimes diagnosed as personality disorders. Trubanova et al. (2014) suggested that in females, the interplay between deficits associated with ASD and internalizing disorders such as anxiety and depression may contribute to problems with differential diagnosis and delays in receiving appropriate diagnosis and treatments.

When ASD goes undetected, there can be lifelong negative consequences, including greater social isolation, bullying, and a sense of being misunderstood by others. Bargiela et al. (2016) conducted a framework analysis, interviewing women who were diagnosed with ASD late in life and found a high incidence of sexual abuse in the group that was interviewed. Their data showed that young women with ASD can become entrapped in situations where their safety and rights were compromised. These women found it difficult to understand others' intentions and had difficulty understanding if a man was just being friendly or was sexually attracted to them. In addition, the women reported feeling isolated and lacked a supportive friend group that could help them develop strategies to stay safe.

Accurate diagnosis of ASD can lead to effective treatment interventions and services. As a result, a delay in diagnosis contributes to a loss of appropriate support, both for the individual and their family. Late diagnosis of ASD is associated with increased parental stress (Elder, 2016). In addition, it delays early intervention, which is critical to outcomes for individuals on the autism spectrum (Zwaigenbaum et al., 2015). Studies have found that when interventions are implemented before age 4, there are associated gains in cognition, language, and adaptive behaviors, in addition to improvements in social behavior and daily living skills (Dawson et al., 2010; Vivanti et al., 2016).

Taken together, this research strongly suggests that early diagnosis and intervention are crucial for individuals with ASD and plays a strong role in the quality of their lives. Understanding how females with ASD present is critical to providing them with the support and treatment that they will need throughout their life. To expand our clinical understanding and the diagnostic challenges associated with females with ASD, we examined the research on the concept of camouflaging, which is one of the key components of the Female Autism Phenotype and on research surrounding neurobiological differences between males and females with ASD.

The Diagnostic Challenges of Camouflaging

Camouflaging is an adaptive coping mechanism utilized by individuals on the autism spectrum. It is characterized by the suppression of social behaviors indicative of impairment, or the production of social behavior learned to be acceptable regardless of whether the implicit meaning of the social communication is known (Hull et al. 2017; Hull et al. 2020; Lai et al. 2016). Camouflaging is considered to be one of the hallmarks of the female phenotype of ASD (Allely, 2019; Lai et al. 2016). Camouflaging, while also present as a strategy among men with ASD, was found to be more prevalent in women with ASD (Lai et al., 2016). It is hypothesized that this prevalence of camouflaging in women is a cause of misdiagnosis of ASD in females with an average or higher IQ (Allely, 2019; Hull et al., 2017; Hull et al., 2020; Lai et al., 2016). They also found that camouflaging was not significantly correlated with age or IQ, meaning that this is not a strategy associated with improving with age or level of intelligence, further suggesting that it is a sex-specific mechanism in females and/or of neurological origin due to variation in structure or function in the brain (Lai et al., 2016).

Hull et al. (2017) worked on developing a construct for the camouflaging mechanism within ASD. They identified three core areas of camouflaging: 1) the motivation for camouflaging, 2) the process of camouflaging, and 3) the short-term and long-term consequences of camouflaging. Common motivations for camouflaging are a desire to be seen as normal to avoid emotional, verbal, and sometimes physical attacks from peers, to obtain jobs and be more acceptable in higher education and the work force, and to experience social connections (Hull et al., 2017). Their work captures this as a theme of assimilation and a desire to blend in.

The methods by which individuals with ASD camouflage are defined by Hull et al. (2017) as compensation and masking and often include the suppression of ASD-like behaviors or the production of more socially acceptable behaviors. The techniques individuals use include developing specific personas/identities that they use in social situations. These can include creating a character with a name, interests, and history that is separate from the individual in order to present to others as more socially desirable. Other techniques are social mimicking, which include repeating statements that have been said by others, mirroring body language, facial expressions, and other nonverbal gestures. Many times, the individual is producing these social behaviors without knowledge of the social context or implicit meanings. Lastly, individuals with ASD often use a system of rules that they have learned are socially acceptable such as asking questions of the other person, suppressing how much they are talking about themselves, and using routine greetings.

The third domain from Hull and colleagues' (2017) work examines the consequences of camouflaging. For an individual with ASD to camouflage it requires an immense amount of self-monitoring, heightened concentration, constant monitoring of the social world, and tolerance of discomfort. As a result, most individuals who use the camouflaging mechanism often experience severe exhaustion and spend time re-charging and withdrawing entirely from social interaction. Camouflaging individuals also seem to experience anxiety and stress as an outcome due to being uncertain if their techniques were successful.

Tubio-Fungueirino et al. (2020) conducted a meta-analysis of social camouflaging in females. Their findings support camouflaging as a mechanism used predominately by females with ASD and replicated findings regarding the significant negative consequences the utilization of camouflaging can cause on the individual, despite the individuals' intention to be adaptive. Wood-Downie et al. (2021) replicated in their study that females with ASD are using the camouflaging strategy more than males with ASD. Their findings indicate that despite similar levels of autistic traits, females with ASD demonstrated higher social reciprocity than males with ASD indicating use of camouflaging. Wood-Downie and colleagues (2021) postulate that this mechanism may explain the increased difficulty professionals have with recognizing ASD in females and subsequently the lack of support they receive.

Beck et al. (2020) examined camouflaging in females with ASD and found that higher rates of camouflaging are associated with significantly higher rates of psychological distress including anxiety, depression, and suicidal thoughts. The extent to which someone is using camouflaging can help predict when clinicians should be concerned about psychological outcomes and be assessing for ASD if the individual has not been formally diagnosed (Beck et al., 2020). As noted earlier, females with ASD often present with internalizing symptoms that are consistent with the outcomes of camouflaging noted above: high anxiety, depression, social rejection, and difficulty with peers, etc., without manifesting the otherwise observable impairments that would cause a clinician to assess for ASD.

A study conducted by Parish-Morris et al. (2017) looked specifically at linguistic camouflage in females with ASD. The study's findings noted that females with ASD utilized more typically sounding language in conversation as opposed to males with ASD who used more atypical language. They hypothesize that females with ASD are unconsciously mimicking conversational words and lack an understanding of the meaning behind the different social pauses. This study demonstrates additional evidence of camouflaging behaviors associated with a female phenotype of ASD as well as more indicators that distinguish males from females who present with ASD.

A self-report measure, The Camouflaging Autistic Traits Questionnaire (CAT-Q), was introduced in 2018 by Hull and colleagues. The CAT-Q is comprised of 25 questions and is designed to assess the extent to which an individual utilizes the camouflaging strategy overall. The measure evaluates the presence of the three core sub-factors of camouflaging: compensation, masking, and assimilation. Compensation is defined as strategies used to work around social and communication difficulties. It includes copying body language or facial expressions, learning social cues from television, books, or movies, repeating phrases and tones heard by others, and using social skills learned from watching others in interactions. Masking is defined as hiding any observable behaviors or indicators of autistic features such as monitoring one's facial expressions to appear calm and relaxed, feeling pressured to make eye contact, and thinking about the impression one makes on another person. Assimilation is defined as an individual's attempts to blend in during social situations where they are uncomfortable without letting their discomfort be visible. Assimilation strategies including developing a persona, avoiding interactions with others, presenting to be neurotypical, and presenting with an identity thought to be more desirable when socializing (Hull et al., 2018).

Hull et al. (2018) reported high internal consistency for the CAT-Q in its entirety (Cronbach's α=. a94) and the sub-scales (compensation α=. a91, Masking α= .a85, and assimilation α= .a92). The CAT-Q needs additional empirical support to increase the strength of the measurement to help in the assessment and diagnosis of ASD. At this time, it cannot be utilized as a stand-alone measure to diagnose ASD. However, it is a promising measure that can be utilized by an experienced professional in conjunction with additional measures and assessment tools when making a diagnosis. It may also give more insight into the extent to which an individual is utilizing camouflaging strategies.

It is important to note that the CAT-Q measure looks at camouflaging in general and can be used on any individual irrespective of whether they have been diagnosed with ASD. The CAT-Q may be a useful tool to help identify females with ASD, who otherwise may be overlooked or misdiagnosed. It would likely serve to close the gap between the reported higher rates of males than females diagnosed with ASD. This instrument offers females who have ASD, who have gone undetected, a way to report their camouflaging behaviors and their strenuous efforts to camouflage (Hull et al., 2017). Hull and colleagues (2017) recognize that non-ASD individuals also camouflage. However, the experience of the short-term and long-term consequences are different for non-ASD individuals than that of individuals with ASD using camouflaging. Non-ASD individuals who camouflage do not experience the task as requiring as much energy and effort and do not experience the long-term consequences of anxiety, stress, other psychological challenges, or the need for complete social withdrawal (Livingston et al., 2020).

In summary, camouflaging is a strategy utilized predominantly by females with ASD to adapt to social situations without understanding social communication and meaning. This strategy, though apparently somewhat effective to go unnoticed in society as a person with ASD, serves as an impediment to their social and emotional development because they do not receive important resources otherwise offered if accurately diagnosed with ASD at an earlier age. Until more recently, camouflaging has gone under-recognized by many professionals including school professionals, medical professionals, mental health practitioners, and researchers (Hull et al., 2017). It is imperative that clinicians become familiar with camouflaging, incorporate more sophisticated assessment of ASD, such as the CAT-Q, and continue to understand the ASD female phenotype. As outlined in the literature, if a female with ASD is left undetected and a high level of camouflaging is utilized, the individual is at risk for more severe and significant psychological distress (Cage & Troxell-Whitman, 2019; Cassidy et al., 2020; Hull et al., 2021). Interestingly, in Hull and colleagues (2021) found that the camouflaging mechanism was associated with higher psychological risk for autistic adults, regardless of gender. While females tend to use camouflaging more than males, any individual with ASD, regardless of gender, experiences the same increased risk for psychological distress.

Neurobiology, Sex, and Autism

A study by Craig et al. (2007) used magnetic resonance imaging (MRI) to explore brain anatomy of females with ASD. Their use of MRI as opposed to FMRI provided information solely on structure as opposed to structure and activity. This study found structural differences in the neurobiology of females with ASD as compared to a control group. The structural differences of females with ASD found in this study were similar to males with ASD, suggesting that despite differences in clinical presentation and a higher diagnostic rate in males with ASD, both sexes with ASD show structural similarities across brain regions of interest. Furthermore, they call for continued research into sex differences in the neurobiology of males and females with ASD. Craig and his colleagues (2007) suggest that despite the small sample size (19 control, 14 female ASD), the study provided enough evidence to justify further exploration of this topic.

Right Temporoparietal Junction

Lombardo et al. (2010) conducted a study examining the right temporo-parietal junction (RTPJ) and its relationship with social impairments in autism. Lombardo and colleagues (2010) examined the RTPJ due to its involvement with mentalization, the ability to recognize mental states both in oneself and in others. Impairments in mentalization are a core component of ASD and as a result, it is hypothesized that variation in this region would be associated with individuals on the autism spectrum. Lombardo et al. (2010) found that the RTPJ region in the brain responded atypically in individuals with ASD providing evidence of a possible neural underpinning of ASD. Furthermore, they found that the severity of social impairments with mentalizing in ASD individuals was associated with the degree of atypicality in the RTPJ region. The more atypical the functioning was in the RTPJ, the more impaired the individual was with respect to mentalizing. While this study yielded valuable results, the subjects of this investigation were only males with ASD. It will be important to determine if there are similarities in brain structure and function across males and females with ASD.

Prefrontal Cortex

The prefrontal cortex (PFC) is associated with the default mode network and is known to be involved in the processing of social and emotional information as well as self-introspection. (Kennedy & Courchesne, 2008). Kennedy and Courchesne (2008) hypothesized that due to impairments in social and emotional processing with ASD, individuals diagnosed with ASD will show differences in activity and function of the PFC as compared to typically developing (TD) individuals. Their results indicated individuals with ASD had decreased activation in the PFC. The differences of PFC functioning between individuals with and without ASD lends important evidence to help explain presenting symptomatology and where ASD impairments in self-awareness and the processing of social and emotional information are sourced (Kennedy & Courchesne, 2008). Again, it is important to note that only male subjects were used for this study. It will be important to determine if there are sex differences in the PFC of individuals with ASD.

Striatum

The striatum region of the brain is known to be involved with repetitive behaviors associated with psychiatric conditions such as schizophrenia, obsessive-compulsive disorder, and Tourette’s (Langen et al., 2009. Langen and colleagues (2009) discuss the hypothesis that the striatum is involved in ASD due to the region’s association with repetitive behaviors in other clinical conditions. This study found that there was a significant difference in the development of the striatum of individuals with ASD when compared to typically developing (TD) individuals. Specifically, the volume of the striatum was higher in those with ASD than TDs throughout developmental years. Further analysis in the study concluded that faster growth was associated with the severity of the repetitive behavior. This study did not focus on evaluating sex differences in this brain region and it will be important for future research to evaluate whether sex differences exist.

The growing awareness of the Female Autism Phenotype has given way for new research to study the female neurobiology of ASD. This research offers the opportunity to compare the neurobiology of females and males with ASD and whether neurobiological differences may help explain differences in sex-specific behavioral presentations of those with ASD.

Lai et al. (2018) examined neural self-representation and mentalizing responses within two specific areas of the brain, the ventral medial prefrontal cortex (vMPFC) and the right temporoparietal junction (RTPJ), in both males and females with ASD as compared to neuro typical individuals of both sexes. Second, Lai et al. (2018) wanted to understand if any differences between male and female neurobiology were attributable to the camouflaging mechanism.

In contrast to prior research showing decreased activation in key brain regions in males (Kennedy & Courchesne, 2008; Lombardo et al., 2010). Lai et al. (2018) found that females with ASD did not exhibit the same decreased response, and in fact were not significantly different in their activation levels when compared to TD individuals. An additional finding from this study was that in women with ASD, the camouflaging mechanism was associated with a heightened vMPFC response as compared with all other groups: TD males, males with ASD, and TD females. Similar results were found in a study done by Lawrence et. al (2020) where females with ASD were found to have an increased sensitivity to social reward as opposed to their male counterparts who exhibited a hypoactivation to social reward. Lawrence and colleagues (2020) also found that females with ASD do not exhibit hypoactivity of other social brain areas including those studied by Lai et al. (2018).

Jack et al. (2021) conducted a recent study exploring the neurogenetics of female autism and risks for the development of autism in females. The study examined females with ASD and typically developing TD females on measures of responsiveness to human/social motion, which include sensitivity to social cues and non-verbal human behavior, known to be impaired in individuals with ASD. Significant functional brain differences were found between TD females and females with ASD in the putamen, a component of the striatum, during social perception. Females with ASD showed a decreased activation. This information suggests that impacts to the striatum during development may be relevant to the development of ASD in females. This expands on the prior research indicating the striatum's involvement with ASD, and how ASD may present differently across sexes.

The research presented in this article is only a small portion of the research on the neurobiology of ASD and sex-specific neurobiology of ASD and is not intended to be all-encompassing. What is shown through these examples is a connection between both structural and functional differences in neurobiology of individuals with ASD and further, that neurobiological differences exist between males and females with ASD. This is critical evidence that supports the female phenotype of ASD and the importance that neurobiological research on males with ASD should not be automatically applied to females with ASD without further investigation.

Conclusions and Future Implications

As professionals, it is imperative that we continue to educate ourselves on the growing body of research addressing the female phenotype of ASD, including camouflaging as a coping strategy, and the neurobiology of autism across sexes. Improving assessment and diagnosis for females with ASD is critical. We recommend that professionals look for clinical cues and markers of camouflaging in females. These include: reports of having a desire to make friends but struggling to do so, experiencing high levels of stress in social situations, having difficulty reading others' impressions of them during social interactions, and periods of increased or complete social withdrawal following periods of significant social interaction co-occurring with anxiety and depression.

The CAT-Q (Hull et al., 2018) is free and accessible to the public and can be accessed at the following link: https://embrace-autism.com/cat-q/. Psychometric properties for the measure can also be accessed through the website. We recommend professionals use it to assess and quantify the amount of camouflaging being used by an individual and to help determine whether a more comprehensive assessment for autism spectrum disorder is needed. We do not recommend that the CAT-Q be used as the sole tool for diagnosing ASD in females but used in conjunction with other forms of observation and assessment conducted by a professional with expertise in assessment of ASD. Furthermore, professionals need to be cognizant of the psychological distress many females with ASD experience that is brought on by camouflaging, including higher rates of anxiety and depression, stress, and the potential for suicidality. A higher camouflaging score can help lead to further assessment regarding mental health symptoms and assessment of suicide.

Urgency in transmission of this information is crucial in increasing knowledge and information which ultimately improves the lives of females with ASD. Moving forward in our field and our own practices, we need to be cognizant of a female autism phenotype and work towards removing our own biases regarding ASD. Far too often, females with ASD who are undetected or misdiagnosed are often suffering in silence, or worse, receiving inappropriate treatment.

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Conceptualizing and Treating Obsessive-Compulsive Disorder in Adults with Autism Spectrum Disorder

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Abstract

This article aims to increase readers' familiarity with Obsessive-Compulsive Disorder (OCD) in adults with Autism Spectrum Disorder (ASD). There is little clinically oriented material on this specific subject available. OCD in adults with ASD has complexities that require a solid grounding in the basics of OCD and ASD separately, as well as consideration to OCD as an ASD comorbidity to fully appreciate. Accordingly, these topics are covered in succession to provide a context for understanding this clinical subset's nuances. This article draws on the available literature as well as the perspectives of its authors and ends on their concluding thoughts.

Keywords: Obsessive-Compulsive Disorder, OCD, Autism Spectrum Disorder, ASD, Autism, Adults with OCD and ASD, Exposure and Response Prevention, ERP, Treatment Modifications for OCD in ASD.

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The purpose of this article is to examine Obsessive-Compulsive Disorder (OCD) in adults with Autism Spectrum Disorder (ASD) in a way that does justice to the myriad intricacies and challenges of this subject (Postorino, 2017). The organization of the article reflects its authors' viewpoint that knowledge regarding OCD and ASD separately and as comorbid diagnoses is foundational to understanding this compelling but notably challenging population. To illustrate the subject, the article utilizes the available literature as well as the authors' own clinical experiences.

Obsessive-Compulsive Disorder

OCD is neither a quirk nor a noxious personality trait, or behavior that could simply be stopped if the person "really wanted to". OCD is a serious neuropsychiatric disorder affecting one in forty adults and one in two hundred youth; hence, it disrupts the lives of millions of individuals and families worldwide (Stein et al., 2019). The World Health Organization (WHO) ranked OCD in its top ten most disabling illnesses as measured by decreased quality of life and lost income (Murray & Lopez, 1997). OCD is associated with stigma which has been found to be even greater if symptoms incorporate, for example, sexuality or violence (Durna, Yorulmaz, & Aktaç, (2018). It is a debunked myth that people with OCD are not at risk for suicide (Chaudhary et al., 2016). OCD can begin at any age, but peak ages of onset are between preadolescence and early adulthood (Stavropoulos et al., 2017). It impacts males and females about equally overall, however, males with OCD may be over-represented in childhood, while females with OCD may be more prevalent in adolescence and adulthood (Mathis et al., 2011). The presentation of OCD is similar worldwide (Stein et al., 2019).

While its exact cause or causes is considered unknown, OCD appears to have both a neurobiological and learned basis, as well as an association with certain characteristic types of erroneous thought processes (Soomro, 2012). The condition appears to have a genetic basis as well (Alemany-Navarro et al., 2020). OCD has also been related to reactions to infections, such as that observed in PANDAS-- Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections (Sigma et al., 2018), medical conditions including neuroinflammation (Atwells et al., 2017) and head trauma (Berthier et al., 2001). Stress, including major life transitions, can trigger or exacerbate OCD (Adams et al., 2018). However, determining the extent to which OCD is explained by the experience of obsessions as opposed to the reactions to such obsessions remains problematic.

In the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013), OCD was removed from the ‘Anxiety Disorders’ section and described in a new chapter covering ‘Obsessive-Compulsive and Related Disorders’. This change reflected the notion that anxiety is a symptom of OCD rather than its defining characteristic. In the DSM-5, the presence of *either or both* obsessions and compulsions is sufficient to diagnose OCD. In the manual, obsessions are defined as thoughts, urges or images that are usually experienced as distressing, unwanted and intrusive that tend to elicit uncomfortable feelings such as anxiety or disgust, whereas compulsions are characterized as physical actions or mental maneuvers performed to neutralize obsessions. McGuire et al., 2012 suggested that avoidance behaviors and compulsions have similar functionality. Compulsions and avoidance behaviors provide temporary relief but worsen OCD in the long run in a self-perpetuating and progressive negative reinforcement process (Fontenelle et al., 2011).

OCD is also known as “the doubting disease” and the “hidden disorder.” It is called ‘Doubting’, because people with OCD are plagued by uncertainty and do not trust their senses (Ciarrocchi, 1995; Nestadt et al., 2016). It is called ‘Hidden’ because being secretive about OCD symptoms due to shame, embarrassment, or fear is common (Haraldsson, 2015). Another reason OCD might be described as hidden is because many people lack the information needed to recognize its presence (Grant & Odlung, 2008). People with OCD often report feeling stuck in an “OCD trap”, one that resembles an addiction (Grassi et al., 2016). Most individuals with OCD recognize that their obsessions and compulsions are irrational (Fenske & Petersen, 2015). An article by Lewin et al. (2010) stated: “Among adults with OCD, poor insight has been linked to greater symptom severity, increased likelihood of comorbid symptoms, lower adaptive functioning, and worse treatment outcomes.” In the experience of the authors of this article, persons with OCD tend to describe OCD in terms such as having “sticky, endlessly looping and multiplying thoughts” that “catch them”.

OCD symptoms often wax and wane, but some individuals experience this condition as a series of separate “episodes” (Sharma & Math, 2019). Stewart (2008) wrote: “Across the lifespan, OCD patients often experience more than one symptom type at one time, and symptoms also frequently change over the long-term course.” Virtually anything the mind can think or anything the senses can sense can be incorporated into OCD (Hudak, 2011). Symptoms of OCD include compulsive washing, excessive checking, counting, ordering, and arranging, violent, blasphemous or sexual thoughts or images; and perfectionism. Compulsive staring, an extreme need to know,’ need for symmetry, having to ‘prove’ thoughts are true or false, going down philosophical ‘rabbit holes’, excessive reassurance-seeking and needing a ‘just right’ feeling are other examples of OCD symptomatology. Furthermore, people with OCD often appear to have a high need for control (Moulding & Kyrios, 2006). To bring cohesion to its large array of symptoms, OCD has been conceptualized as having various organizing dimensions and clusters (Williams et al., 2013). The authors of this article find that OCD is much more than the sum of its symptoms and has a pervasive and ironically “contaminating” impact upon the impacted individual’s entire approach to life.

Specific erroneous cognitions found in OCD include intolerance of uncertainty, overestimation of threat, overvaluation of the importance of thoughts, inflated sense of responsibility, thought-action fusion (equating thinking about an action with taking that action) and emotional reasoning, in which feeling anxious is equated with the actual presence of danger (Abramowitz, 2006). Individuals with OCD tend to have one or more comorbidities (Pallanti et al., 2011). Per Rintala et al., 2017, aside from ASD, such comorbidities include OCD Related Disorders, a DSM-5 (2013) category which includes Trichotillomania (Hair-Pulling), Excoriation Disorder (Skin-Picking), Body Dysmorphic Disorder, and Hoarding Disorder; as well as Attention-Deficit/Hyperactivity Disorder (ADHD), Tourette Disorder and Tics, Depression, Social Anxiety Disorder, Eating Disorder, Substance Use Disorder, and Thought Disorders.

There is no single, definitive medical or psychological test to diagnose OCD. The Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) is used in assessing the clinical characteristics and severity of OCD symptoms and can also be utilized as one measure of treatment progress. (Storch et al., 2010). OCD treatment optimally incorporates a comprehensive, multi-disciplinary approach (Fineberg et al., 2020). The gold-standard evidence-supported psychological treatment for OCD is a form of Cognitive Behavioral Therapy (CBT) called Exposure and Response Prevention (ERP) (Hazel & Simpson, 2019). This methodology consists of voluntary exposure to feared or discomforting thoughts, images, "urges", or sensations while refraining from compulsions or other avoidance behaviors. Law and Boisseau (2019) suggested that although by no means a panacea, ERP is considered the standard for OCD treatment because its effectiveness has been demonstrated by numerous well-designed studies in different age groups over the course of many years. Moreover, a game-like format can be utilized to make ERP more user-friendly for children (Miranda et al., 2019). Because ERP may be discomforting and counterintuitive, a common concern is that some individuals (or influential family members), or even some clinicians (Keleher et al., 2020), may not find it acceptable. However, a meta-analysis conducted by Johnco et al. (2020) suggested that although it undoubtably occurs, concerns regarding risks of attrition from ERP may be overblown. Since OCD is a progressive condition, early intervention is highly advantageousness but unfortunately very often does not occur (Fineberg et al., 2019).

A long prevailing theory is that ERP works because it promotes habituation to fear (Law & Biosseau, 2019). Another more recent idea, called the inhibitory learning theory, emphasizes how ERP promotes learning new safety information and maximizing ERP's effectiveness (Jacoby & Abramowitz, 2016). Tryon et al. (2017) speculated about the possible mechanisms by which ERP might retrain OCD-relevant neural networks.

Cognitive Therapy (CT) focuses on correcting OCD-related erroneous thinking, as described above. CT may provide a viable treatment option for some individuals who are reluctant to try ERP, with the caveat that it does not have as much empirical support (Wilhelm et al, 2005; Wilhelm & Stekatee, 2006). Acceptance and Commitment therapy (ACT) focuses on increasing psychological flexibility, decreasing experiential avoidance and living a values-based life despite OCD (Philip & Cherian, (2021). Mindfulness-Based Cognitive Therapy (MBCT) focuses on accepting distressing OCD thoughts and staying in the present (Didonna et al., 2019). Motivational Interviewing (MI) helps individuals find internal reasons to challenge OCD-related fears (Simpson & Zuckoff, 2011).

Abramowitz et al. (2013) wrote: “Although OCD is viewed as an individual disorder, it exists in a social and interpersonal context.” For example, Williams et al. (2017) found that cross-cultural factors impact the way that individuals personally experience OCD. Another important context of OCD is the family system. Studies have shown that Family Accommodation (FA) of OCD symptoms, which encompasses facilitating or participating in rituals, providing excessive reassurance and/or aiding and abetting avoidance behaviors, is a common barrier to effective treatment (Lebowitz et al., 2016, Wu et al., 2019). FA is associated with increased levels of depression, low self-esteem, feelings of ineffectiveness and decreased naturalistic learning about how to manage OCD. (Pontillo et al., 2020). The Family Accommodation Scale for Obsessive-Compulsive Disorder (Pinto et al., 2013) is a commonly used measure to assess this problem. Parent training (Sukhodolsky et al., 2013), involvement of family members in treatment (Thompson-Hollands et al., 2014), and couples therapy (Baucom et al. 2012) are often important components of an effective OCD treatment plan. The goals of such modalities include providing education about OCD, improving collaborative communication and problem-solving, as well as reducing over-accommodating behaviors and other non-constructive familial responses (Kobayashi et al., 2020).

A medication-only approach for OCD is discouraged by most experts (Koran et al., 2007). Present clinical guidelines suggest combining CBT/ERP for more severe OCD symptoms (Reddy et al., 2017). The most widely used evidence-supported medication for OCD is a class of antidepressants called SSRIs (Reddy & Arumugham, 2020). Low dose antipsychotics are sometimes used to augment SSRIs and other medications might be used to treat OCD comorbidities that present obstacles to progress, such as stimulant medication for co-occurring ADHD (Pittenger & Bloch, 2014). Agents that target glutamate imbalance, e.g., ketamine, are being investigated regarding their efficacy for OCD (Borue et al., 2015). Treatment of OCD with psilocybin is also presently being researched (Jacobs, 2020). Other emerging medical treatments for OCD include Deep Transcranial Magnetic Stimulation (dTMS), Deep Brain Stimulation (DBS), Gamma Knife (using gamma rays to ablate targeted OCD-related brain tissue) and immunomodulatory therapy (Fineberg et al., 2020). Various forms of psychosurgery have been used as a last resort for treatment-refractory OCD (Roth et al., 2020; Greenberg et al., 2010). The authors of this article are of the opinion that, for highly severe or complex OCD symptoms, intensive outpatient or residential treatment is often the most appropriate option. Additionally, the authors of this article are not aware of any empirical research specifically pertaining to the treatment of OCD in wilderness (outdoor) therapy programs.

Autism Spectrum Disorder (ASD)

Autistic Spectrum Disorder (ASD) is found in the DSM-5 section on Neurodevelopmental Disorders (2013). The ASD category subsumed other autism-related diagnoses, such as Asperger's Disorder and Pervasive Developmental Disorder (PDD), that were present in earlier DSM editions. ASD encompasses individuals with extraordinarily high intellectual ability as well as those with severe functional and intellectual limitations. Deficits in communication, social impairment and restrictive-repetitive behaviors (RRBs) must all appear in early childhood to diagnose ASD. RRBs include repetitive or perseverative motor movements or language, rigid behaviors, intense interests (e.g., maps, LEGO, or facts about U.S. Presidents) and preferred activities (e.g., taking the same route, sitting in a particular chair, eating at a certain restaurant), fixations on parts or whole objects, and sensory issues (Boyd et al., 2010). The prevalence of ASD has increased in recent years but there is no currently accepted theory as to why (Hodges et al., 2020). According to Maenner et al., 2020, one in fifty-four children in the U.S have ASD, more than five million adults in the U.S have ASD, about four times more in boys than girls are diagnosed with ASD and ASD is a prevalent condition across all ethnicities and races and at every socioeconomic level. People with ASD are often stigmatized (Dubreucq et al., 2020).

ASD is further associated with numerous psychological comorbidities and learning disorders (Miot et al., 2019). Due to their social issues, dealing with issues pertaining to sexuality, including gender identity or gender dysphoria, can be especially complicated for individuals with ASD (George & Stokes, 2018). Additionally, there is no “one-size-fits-all” answer to why, when and how to tell any given person they have autism (Dundon, 2018).

Some commonly held beliefs about people with ASD are fallacious. The majority of individuals with ASD are not nonverbal nor minimally verbal (Rose et al., 2016). The authors of this article can attest that they do not always have poor eye contact, and that many enjoy social interactions, form relationships, comprehend metaphors and have a good sense of humor. Additionally, in the experience of the authors of this article many people with ASD demonstrate empathy, albeit at times unpredictably and selectively. Very few individuals with ASD have savant syndrome, which is when a person with a developmental condition also has an exceptional talent or ability (Treffert, 2009).

Individuals with ASD have deficits in understanding and/or accepting social rules, e.g., taking them too literally or seeing no reason to follow them (Jones et al., 2013). Therefore, they may not adhere to rules in a way that is necessarily congruent with family or social expectations. In the authors’ experience, people with ASD might be prone to outbursts or misperceived as having an authority issue and be labeled as “oppositional-defiant” when it is instead their overly literal or limited sense of right and wrong that is the problem. In some instances, oppositionality and OCD may intersect in this population. For example, an individual with ASD could have a compulsion to “prove” their autonomy by doing exactly the opposite of what is asked of them, e.g., engaging in a proscribed behavior a certain number of times.

Some autism advocates have challenged the term “Autism Spectrum Disorder”, considering it to be central to the individual’s identity rather than a disorder. They prefer terms such as “autistic individual”, “autistic person” or simply “autistic"; and do not consider autism a disorder that needs to be fixed, but an example of neurodiversity. The authors of this article have opted to use the term “ASD” for the purposes of this article and do not intend any disrespect to those who disagree with the use of this term.

There are certain evidence-based assessment tools that aid in the diagnosis of ASD, although no one test is definitive (Hyman et al., 2020). The Autism Diagnostic Schedule (ADOS) and Autism Diagnostic Interview-Revised (ADI-R) are measures for assessing ASD (Falkmer et al., 2013). Diagnosing ASD requires a thorough, comprehensive approach integrating direct and reported behavioral observations, developmental history, and multidisciplinary findings. Treatment of ASD is geared toward addressing its core and associated symptoms on an individualized basis. Clinicians providing Applied Behavioral Analysis (ABA), Speech and Language Therapy (SLP) or Occupational Therapy (OT), as well as developmental pediatricians, are often part of the treatment team as no one discipline has been proven to fully resolve ASD's core social and communication symptomatology (Shenoy et al., 2017). Education and training for the family members of those with ASD is important as well (Fuentes et al., 2021). Family Accommodation of RRBs in ASD is like FA of OCD symptoms because it is prevalent as well as counterproductive in the long run (Feldman et al., 2019). However, this may be a confusing concept to parents of people with ASD who are accustomed to providing accommodations in a different sense of the word, e.g., preferential classroom seating.

As noted by Landa (2018), there is "no medical cure or pharmacologic treatment for core social and communication impairments" for ASD. However, in the opinion of the psychiatrist author of this article, medicinal approaches are often helpful to target ASD-associated specific behavioral and psychological symptomatology, including, aside from OCD, anxiety, depression, emotional dysregulation, and disruptive behaviors.

As individuals with ASD age, they appear to be particularly vulnerable to mental health issues such as depression and psychosis as well as medical issues such as gastrointestinal disorders and obesity (Murphy et al., 2016). A few celebrities or technology moguls with ASD notwithstanding, individuals with ASD, including those with very high basic intellectual ability, are at significant risk for unemployment or inadequate employment later in life (Ohl et al., 2017). This is yet another reason why early and effective intervention for ASD cannot be overemphasized (Kasilingham et al., 2021).

OCD as an ASD Comorbidity

There is no prototypical person with ASD that is impacted by OCD. This is a clinical subset that encompasses individuals from all walks of life and levels of ability and success across the gamut of age and other demographic variables. Accordingly, each case must be considered on its own merits, including the degree to which OCD is impacting the individual's life, as well as the lives of their significant others.

OCD has been found to be a notably complex comorbidity in ASD (Leyfer et al., 2006; Meir et al., 2015; Postorino et al., 2017; Martin et al., 2020). Wikramanke et al. (2018) stated that OCD in this population is associated with "greater OCD symptom-severity and poor insight." Meir et al. (2015) wrote: "The high comorbidity, sequential risk, and shared familial risks between OCD and autism spectrum disorders are suggestive of partially shared etiological mechanisms."

Not that long ago, what presently would be diagnosed as OCD symptoms were inherent features of ASD. Today, OCD is broadly recognized as an ASD comorbidity by both the OCD and ASD clinical and research communities. However, to the authors of this article what still seems to be in short supply worldwide are clinicians and treatment programs that are well-versed in addressing OCD in adults with ASD.

Studies regarding the general prevalence of OCD in ASD have produced wide-ranging estimates. Leyfer and colleagues (2006) found a prevalence rate of 37.2%, while Simonoff et al. (2008) reported 8.2% and Martin et al. (2020) 5% rates of prevalence respectively. One possibility is that studies indicating lower prevalence rates may have differentiated OCD and ASD symptoms such as restrictive-repetitive behaviors from obsessions and compulsions to a greater degree than those finding higher rates, Elliot (2018) noted that OCD and ASD symptoms might be defined differently by different researchers. It must be also emphasized that OCD assessment measures were not designed with ASD in mind so they should be administered with caution (Cadman et al., 2015).

Gleaning from the literature and their own experiences, the authors of this article offer the following commentary about teasing apart ASD and OCD symptoms: OCD is all about gaining relief. Compulsions and avoidance behaviors take the person from a negative state triggered by obsessions to a neutral state, albeit a temporary one. In contrast, ASD behaviors, especially RRBs, which can look very similar to OCD, tend to have functions such as regulating stressful or overstimulating external stimuli, preserving a sense of "sameness," or coping with boredom. They can also result in a sense of satisfaction and even gratification. Whereas OCD symptoms are mostly experienced as intrusive upon or in conflict with self (ego dystonic), those of ASD and very notably RRBs generally are self-congruent (ego syntonic).

Individuals with OCD seem to follow "rules" or try to control others by trying to get them to adhere to their "rules" to appease OCD; however, those with ASD seem more likely to "follow the rules" out of habit or because they make sense, feel "justified," or intrinsically feel "right" to them. Of course, the "rule following" of those with both OCD and ASD might fit each of these descriptions. In addition, ASD and OCD symptoms both can make a person appear self-centered, but again for different reasons. In OCD, self-centeredness might be explained as due to being consumed by anxiety. In ASD it is more likely attributable to being inwardly focused.

Family members of individuals with ASD have higher rates of Broader Autism Phenotype (BAP) than the general population (Ruzich et al., 2015), which in the authors' experience can further impede obtaining an accurate developmental history, especially for clients who are now adults (Gerdts & Bernier, 2011). Accordingly, the authors of this article suggest clinicians not settle for first answers to OCD-related questions from either the patient or family member when gathering a clinical history.

Although there are key differences between OCD and RRBs presenting in ASD (Jiujias et. al., 2017), sorting out OCD and autistic obsessions from RRBs might be easier in theory than in practice. As mentioned, certain OCD-related compulsions bear a strong phenotypic resemblance to those of ASD. But a more complicated matter is that they often intertwine. For example, imagine that a person with ASD watches the same video over and over. This could reflect an intense interest or be a source of gratification to ASD. But what if they had to watch it a certain number of times or rewind certain parts to hear it perfectly or prevent something bad from happening? This sounds a lot more like OCD. The authors of this article consider this to be an example of a behavior that appears to have both OCD and ASD aspects. The authors of this article think of it as OCD and ASD symptom fusion that is qualitatively different from either OCD or ASD. Hence, the authors of this article further suggest that to make accurate distinctions between ASD and OCD symptoms, clinicians must be willing to spend an extended period evaluating symptoms, educating caregivers, and learning to "speak each patient's unique ASD language."

For some individuals with significant ASD-associated intellectual deficits, "the cognitive load" of explanations of OCD the clinician uses while conducting ERP should be lower than is typical for conducting ERP with non-ASD persons. The authors of this article further suggest that in designing an ERP plan for this population, there is a great value in conducting a functional assessment to ascertain whether contingencies such as increased attention or avoidance of non-preferred tasks might be reinforcing OCD symptoms

Compulsions are more characteristic of OCD in persons with ASD than obsessions (Bernard-Brak et al., 2021). Further, such compulsions tend to be less connected to neutralizing specific feared consequences than in those with OCD but not ASD (Kerns & Kendall, 2014). Hence, conducting ERP in this population is usually weighted more heavily toward the "response prevention" than the "exposure" side of the coin. Additionally, it may not be productive to require these individuals to rate SUDS (Subjective Units of Distress) levels whilst they challenge their fears, as for many this task might simply be too abstract.

So long as it is appropriately modified, the available research suggests that OCD treatment incorporating ERP can be effective for many individuals with ASD (Kose et al., 2018; Krebs et al., 2016; Nakagama et al., 2019; Russell et al., 2013; Wolters et al., 2016). The menu of OCD specific treatment modifications which may be needed for those with ASD includes: simplifying and using visual aids for rating scales, making instructions clear and specific, structuring sessions more than would be typical than in treating OCD alone, incorporating ASD-related interests into exposures, breaking goals down into smaller steps, using tangible reinforcers that hopefully can eventually be faded-out, providing education in helping identify and communicate emotions, personalizing reasons to be willing to tolerate treatment-related discomfort and using social narratives to support understanding and motivation (Kose et al., 2018). It is further noted that ERP has also been found to be effective in reducing ASD-related RRBs (Boyd, 2012, Lehmkuhl, 2008). However, the authors of this article also take into consideration an article by Tsuchiyagaito et al. (2017) which suggests that those with ASD might inherently be poorer candidates for ERP than non-ASD individuals with OCD because of certain inherent neurological issues.

Counting on IQ to trump social and emotional intelligence to predict outcomes in this population is *not* recommended by the authors of this article nor should IQ be equated with level of functioning in this group. In fact, some of the brightest adults in this population that the authors have ever met were extremely functionally impaired. Similarly, one might understandably assume that highly intelligent individuals with ASD do not need treatment modifications and would more readily understand and accept OCD treatment, but the experiences of the authors of this article suggest otherwise. This should not be construed as treating individuals disrespectfully or “dumbing it down.” Rather, it demonstrates understanding of neurodiversity. A similar caveat also applies to making assumptions about age or any other demographic variable; in the opinion of the authors of this article, factors including readiness and motivation for change, ability to understand OCD treatment concepts and characteristics of the support structure in place tend to be more prognosis relevant.

The authors of this article have also observed that OCD treatment for those with ASD often requires more sessions over longer periods of time in comparison to individuals with OCD alone, and setbacks and longer pauses in progress are typical. Thus, managing the expectations of the identified patient, as well as their family members or significant others early on and periodically throughout the diagnostic and treatment process is key. It is important to understand that ameliorating OCD symptoms is not a cure-all for ASD, although it certainly might improve many of these individuals’ prospects and quality of life. For this population, even greater attention than is usual in the treatment of OCD should be paid to generalizing treatment to different settings and doing so as early in the process as possible. For highly severe or complex OCD presentations in this population, intensive outpatient or residential treatment settings that are “ASD savvy” may be good options (Jassi et al., 2021; Stewart et al., 2009).

Pharmacological treatment of OCD specifically for persons with ASD has received limited research attention. In addition, OCD medications were not developed with those with ASD in mind. Therefore, medication treatment guidelines for this population simply do not exist at the present time. However, since Selective Serotonin Reuptake inhibitors (SSRIs) are the first line psychopharmacological treatment for OCD and are consistent with OCD-treatment protocols, it is generally considered warranted to offer them to ASD patients similar to any other client with OCD (Soorya et al., 2008). If a patient with ASD appears to be vulnerable to agitation or akathisia, a trial of another SSRI may be the best option to see if it is better tolerated (Borue et al., 2015). A slow titration schedule beginning with a very low dosage is often suggested for SSRI-sensitive ASD patients. Combining psychotherapeutic approaches and medication for OCD in those with ASD is the most effective approach, especially for more severe and/or complex cases (Reddy et al., 2017. Additionally, there have been numerous studies that have looked more generally at the treatment of repetitive behaviors in patients with ASD and have reported positive results with SSRIs (Hollander et al., 2012).

Considerations for OCD in Adults with ASD

The authors of this article are not aware of an accepted statistic for the prevalence or treatment outcomes of OCD specifically in adults with ASD. However, they can attest that adults with ASD whose OCD has been successfully addressed in childhood or adolescence certainly do exist. In such cases, these individuals might experience their lives with minimal or no interference from OCD that is in full or partial remission. Some adults in this population might have subclinical OCD that warrants ongoing monitoring, while others might require treatment only during those times when their OCD symptoms are exacerbated.

According to the authors of this article, it’s quite common that persons with ASD that reach adulthood with undiagnosed OCD, late-diagnosed OCD, adult-onset OCD, or improperly treated OCD constitute a highly complex and challenging group for a number of reasons. One reason for this is that unlike children or adolescents, and unless they are under a legal guardianship as adults, they have the right to be self-determining over their mental healthcare decisions. Additionally, as individuals with ASD progress through adulthood, OCD symptoms, as well as other comorbidities, have had more time to progress, synergize with ASD symptoms and impact daily functioning (Pazuniak & Pakrul, 2020). Lastly, the individuals in this group may be extremely different from one another aside from the fact that they have ASD with comorbid OCD. The authors of this article further suggest that it is not necessarily the OCD symptoms that are the major challenge to understand and address in this group, but rather the many other clinical and situational variables that are typically present.

For example, in the authors' experience, the circumstances of referral are important to understand. Some adults with ASD might seek help for OCD on their own or at the behest of a concerned family member or significant other and be motivated and willing to participate in evidence-supported OCD treatment such as ERP. This is ideal and allows for a collaborative treatment approach. Even when this is not the case, however, the authors of this article have found that many initially poorly motivated patients with ASD can be enticed into OCD treatment with an artful, "ASD-aware" approach. In the authors' experience, helping these adults find a personalized and compelling reason for managing the discomforts entailed in challenging OCD can be highly effective.

The clinical impression of the authors of this article is that many adults with ASD, and at all levels of cognitive abilities, do not arrive independently for OCD assessment and treatment. Others tend to be more involved in the therapeutic process for these clients than is typical for adults in general. Therefore, these adults often are accompanied to a first consultation by a parent, spouse or other person in their lives who recognizes and is concerned about their OCD symptoms.

What does a practitioner do when an adult with ASD has OCD and does not see a need for or refuses help? In the authors' opinion, there is no ready-made answer to this conundrum, as there is a plethora of variables to consider. For example, is the client a financially stable, middle-aged, well-educated individual independently living with a spouse or partner?

Or are we speaking about a financially dependent young adult living at home who is unemployed with poor job skills and learning deficits? Is the situation as desperate as described, or is it more that the caretaker(s) have reached the end of the proverbial rope, are exhausted, need respite, or simply “want our life back”? Sadly, in the experience of the authors of this article parents often learn about OCD in the context of ASD only after their relationship with an adult child has been severed and they desperately want to reverse course.

What recourse is there? It is very difficult on many levels to cajole or leverage a resistant adult with ASD into OCD treatment, particularly intensive or residential. The parent or significant other must be ready to accept the risks and emotional impact of an intervention that the adult does not want for all concerned. In such situations, the help of knowledgeable clinicians and placement consultants may be invaluable, with the caveat that even those with the most expertise may not have all the answers, especially given the limitations of guiding research in this area. The authors do not recommend that adults with ASD participate in programs or approaches that seek to treat OCD without consideration to ASD. Costs for getting the proper resources cannot be ignored either. It would be nice to say that high quality, low-cost options for treating OCD in adults abound, but they don’t. The authors of this article have found that resources for older adults in this population seem particularly scarce.

Sometimes adults in this clinical subset have had negative prior experiences with treatment so they are wary of participating in treatment again. They may have even had a positive experience with OCD treatment earlier in their lives but consider themselves “done” with treatment due to having a highly literal perspective. However, in many instances, they have had no treatment at all, and OCD has become an accepted, albeit often distressing and/or limiting, reality of life.

Another hard question is should any adult with ASD be pressured into OCD treatment? Important factors to consider in weighing against any adults right to self-determination include the severity of the OCD symptoms and the presence of risk factors such as potential harm to self or others. Whether such problems as substance abuse and/or gaming or sex addiction is present are other important factors. Considering these factors, the authors of this article would be remiss if they did not mention that in their experience, believing that OCD treatment should be postponed until the adult with ASD is ready and intrinsically motivated seems ideal in theory but is usually not very realistic. Too often, the situation only becomes more severe.

The authors of this article have observed many adults in this population that have had, or still have their OCD symptoms accommodated, e.g., “guilting” the parents or caretakers into participating in their rituals, or making the parents “walk on eggshells” not to trigger them. In certain situations, some of these adults may be engaging in OCD-related symptoms for most, if not all, of their waking hours. At the other end of the spectrum, some individuals in this population may have high levels of career and financial success that mask the severity and impact of their OCD symptoms or give them the wherewithal to “not have to listen to anybody about OCD”.

The authors of this article have often encountered parents that fully acknowledge the severity of an adult child’s OCD but in a very real sense are being held hostage by someone that, for example, threatens to harm themselves (or does in some way) or aggression if the parent reduces accommodating behaviors or seeks treatment for them. In these instances, a thorough and realistic appraisal of the entire situation is a necessity before making any recommendations that might have unintended consequences.

The authors of this article have also found that parents and significant others typically need their own treatment space to evaluate their position as realistically as possible. It is helpful for them to learn effective motivational strategies, consider the pros and cons and their readiness for potential next steps, whether they are best implemented incrementally or more drastically, re-evaluate their role and attachment issues as the parent(s) of an adult child, especially regarding overly accommodating and avoidance-supporting behaviors. Understandably, these sessions may elicit feelings of guilt, uncertainty about whether it will all be worth it in the end, and/or fears that their adult child will no longer love or communicate with them. An important aspect of such assistance is often helping family members not equate treatment, especially ERP, to making their loved one “suffer”. Some parent(s) or significant other(s) may need extensive education and support to step up to the challenge of understanding the important role their behavior can play regarding the long-term OCD-related prospects for their loved one.

Concluding Thoughts

What then, should be the expectations for adults with ASD, or for those who care about them in terms of learning to manage OCD symptoms effectively? As underscored in this article, this is a complicated question, as it depends on so many factors**.** Perhaps the only answer that makes sense lies somewhere between unrealistic and no expectations. What is clear, however, is that this is a daunting clinical subset about which we need a great deal more research and clinical knowledge.

However, the authors of this article have also observed from personal experience that given the opportunity and proper resources, many individuals in this group can make progress. The authors hope that the information they covered in this article will inspire an increased interest in this compelling but under-recognized group in some readers. At the very least, they hope readers will have more background knowledge if they should encounter some of the situations described. A key takeaway from this article is that treating OCD in adults without consideration to ASD is not an effective approach.

Lastly, the authors strongly recommend that most adult clients with ASD be routinely screened for OCD as part of a regular medical or psychiatric check-up. It would be beneficial for mental health practitioners to at least consider ruling it out as a diagnostic possibility when conducting initial clinical assessments and interviews. If the clinician suspects OCD but cannot confirm or rule it out via the self-report of the individual, they would do well to investigate further by, if possible, interviewing their parents, spouses, or other relatives regarding their observations.

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Autism Spectrum Disorder in Girls and Women: Issues with Diagnosis, Unique Experiences, and Intervention

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Abstract

The current article summarizes some of the recent research examining the unique experiences of females on the autism spectrum, and highlights what researchers believe to be the difficulties that contribute to delayed diagnosis or misdiagnosis in this population. At this time, research suggest delayed diagnosis and misdiagnosis in this population relates to an alternative and poorly understood phenotype of females with ASD, and a diagnostic system rooted in a male-centric understanding of the condition. In addition, some of the literature suggests females may be “protected” and are therefore biologically less likely to have autism. Some of the unique experiences described by participants in the cited literature include: 1) greater social motivation, 2) the need to camouflage ASD characteristics, 3) increased sexual vulnerability, 4) fewer repetitive behaviors, and 5) circumscribed interests that are more “typical” or “normal” in females.

Keywords: ASD in females, diagnosing females with ASD, experiences of ASD females, girls and women with ASD.

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AUTISM SPECTRUM DISORDER IN GIRLS AND WOMEN

Autism spectrum disorder (ASD) is a diagnosis in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) characterized by impairments in social reciprocity as well as verbal and nonverbal communication, and the presence of restricted interests and repetitive behaviors (American Psychological Association, 2013). ASD has typically been thought of as being far more prevalent in males, and it has only been over the last several years that autism researchers have turned their attention towards examining gender differences between males and females on the autism spectrum (Halladay et. al., 2015). Although the DSM-5 states that sex differences may exist, it does not provide any guidance on how these differences may manifest (Sedgewick et al., 2016). In general, the literature indicates a ratio of males to females at or near 4:1, with approximately four times as many males being diagnosed with ASD than females (van Wijngaarden-Cremers et. al., 2014). The consistency of this ratio implies there may be sex-specific biological and/or environmental factors underlying the difference in prevalence rates, but the degree of the effect of these factors is not yet well understood.

It appears some biases may affect this ratio, including using the existing ASD diagnostic criteria, which was created primarily using male autistic children, and predominantly sampling males with ASD over females in research studies, referred to as the ascertainment bias (Frazier et al., 2014; Robinson et al., 2013). Some researchers have attempted to account for this bias in their sampling methods and analysis, but still note a higher (though slightly smaller) prevalence of males with ASD over females (Halladay et al., 2015). When mostly male children are sampled and studied in autism research, the unintended consequence is the development and refinement of diagnostic criteria that may overlook females with ASD, and treatment that may not adequately meet the needs of females with ASD. This is concerning given that females on the spectrum are diagnosed less frequently than males even when they score similarly on autism rating scales and diagnostic testing (Robinson et al., 2013). Nevertheless, this male-predominance has, for the most part, held up in the research literature over time, which has led to productive discussion on possible etiological factors, including the presence of neuroanatomical differences between males and females with ASD, as well as differences in the development of brain structures during fetal development (Schaer et. al., 2015).

Researchers who have attempted to account for the diagnostic discrepancies between males and females have generally pointed to two distinct but not mutually exclusive theories (Hull et al., 2020). The first theory posits that females are more likely to develop or present with autism traits than we currently estimate, but that diagnostic biases as well as variations in how females express those characteristics affect a clinician’s ability to identify a female as potentially being on the spectrum. In other words, it is possible that females with ASD present differently than males do (e.g., they have an alternative phenotype) and are therefore missed or misdiagnosed because they do not present similarly to males with ASD. The second theory posits that females, either through socialization or biology, are “protected” from developing ASD traits (called the *Female Protective Effect*) (Robinson et. al, 2013).

Relatedly, the literature also discusses the perceptions of others in the lives of females with ASD, including teachers and parents. For example, teachers tended to interpret social misunderstandings in females with ASD as “lazy” or “rude” rather than attributing social faux pas as stemming from intrinsic social difficulties (Bargiela et al., 2016). Holtmann and colleagues (2007) posited that, because females with ASD can go undetected as being neurodiverse, they are held to a neurotypical standard with regard to their social abilities. In other words, females are held to a higher social standard, or are perceived to have better social skills than males, and therefore others (such as parents, teachers, and employers) may expect more socially desirable behavior from them. Therefore, behaviors such as withdrawing socially or being overly direct in their communication is perceived through a neurotypical rather than neurodiverse lens. Their passive behaviors and lack of significant externalizing behaviors are perceived as being “shy” and “good” as opposed to struggling to engage socially despite a strong desire to do so (Bargiela et al., 2016). The literature also noted issues with being overly passive or assertive. For example, some of the participants in Bargiela et al.’s (2016) study discussed feeling the need to please others and do what they are told to garner acceptance and avoid conflict. However, some females with ASD whose *modus operandi* had been to be passive, experienced damage to their relationships when they switched gears and acted too assertively, as their peers were caught off guard by the sudden assertiveness.

Further complicating accurate identification and diagnosis of females with ASD is the relationship between intelligence and autism traits, and how that affects the identification of higher functioning females on the spectrum. Males are significantly overrepresented among high functioning autism cases, both in sampling for research studies as well as with diagnosis (Robinson et al., 2013). Females who evidence the same or similar characteristics and impairments as males on the spectrum are less often diagnosed as having ASD. The females who are diagnosed with ASD tend to have lower IQ's and more social and functional impairments (van Wijngaarden-Cremers et. al., 2014; Werling & Geschwind, 2013), while females with ASD who are higher functioning go undiagnosed or misdiagnosed. Because repetitive behaviors, restricted interests, and issues with social communication are seen in children with lower intellectual functions (van Wijngaarden-Cremers et. al., 2014), it is probable that intelligence is a confounding factor affecting one's ability to obtain an accurate diagnosis of ASD.

Regardless, when compared to males, females with ASD are at substantially elevated risk of going undiagnosed or being misdiagnosed, as their symptoms and presentation are frequently mislabeled (Bargiela et al., 2016). Oftentimes, females who are later diagnosed as being on the autism spectrum had been initially diagnosed with bipolar disorder, borderline personality disorder, or social phobia, among others (van Wijngaarden-Cremers et. al., 2014). In addition, these females usually receive comorbid diagnoses such as an eating disorder, obsessive compulsive disorder (OCD), depression, and anxiety. Research literature also indicates these females are diagnosed at a much later age, typically in adolescence or early adulthood (Begeer et al., 2013). Consequently, they are overlooked for needed autism-specific services, supports, and intervention.

A Female ASD "Phenotype"?

As previously suggested, it is also possible that females present an alternative phenotype within ASD that is notably different from males, regardless of whether the difference is biological, environmental, or both

(Bargiela et al., 2016; van Wijngaarden-Cremers et. al., 2014). Although the current research presents some disparities regarding clear gender differences in ASD presentation, there is some evidence that females later identified as having ASD exhibited greater levels of social motivation as well as capacity for making friends, especially at younger ages (Atwood, 2007). However, they tended to struggle with identifying and managing conflict in their social circles (Sedgewick et al., 2015). Recent research also demonstrated that girls on the autism spectrum also tend to have more friendships with neurotypical peers, and that these peers helped prevent social exclusion (Dean et al., 2014).

Gender socialization plays a key factor in how a female with ASD may present, and the notion that females are, in general, socialized differently than males is well-researched. Girls are typically taught by their parents from a young age to be social, conflict avoidant, and rule-following (Begeer et al., 2013). They also tend to be socialized towards emotional attunement and social sensitivity (Sedgewick et al., 2016). In addition, gendered play, including pretense play for girls and physical play for boys, is actively encouraged by parents regardless of the child's gender, which can have a positive effect on social functioning (Lindsey & Mize, 2001). The connection between gender socialization as a protective factor and symptom presentation is especially likely given that male and female toddlers in the study by Lindsey & Mize (2001) did not show differences in behavioral features until later in development. This indicates the presentation of these characteristics may be influenced by their environment.

Cumulatively, it is possible that females with ASD are not identified as being on the spectrum partially because they are more socially motivated and have better developed social skills. Some researchers have speculated that, for females, symptoms may not emerge until social pressures change in adolescence (Halladay et al., 2015). This author has noticed in her own assessment of adolescent females on the spectrum that most did not experience notable social difficulties until they entered middle school, when the social environment becomes increasingly complex and nuanced. Beginning around this time, their social milieu exceeded their capacity to "keep up" socially, and they began to struggle with resolving conflict and gaining attention and support in healthy ways.

In addition, females identified as being on the autism spectrum are less likely to exhibit repetitive and stereotyped behaviors, including hand flapping, body rocking, and tics (Frazier et al., 2014; van Wijngaarden-Cremers et. al., 2014). Because these are obvious to an observer and due to the increasing awareness of the characteristics of ASD, it may often be assumed that a child is not on the autism spectrum if they do not display these behaviors. However, Halladay et al. (2015) posited that the nature of repetitive behaviors in females with ASD may be different. They provided a potential example in a woman diagnosed with ASD who carried several books with her wherever she went and read them to the detriment of opportunities for social interaction. Such “quirky” behaviors may go undetected, or it may simply be assumed the female is shy or introverted (van Wijngaarden-Cremers et. al., 2014).

Circumscribed interests, typically described as highly intense and focused interests in specific topics, are one hallmark characteristic of ASD (American Psychological Association, 2013). Frazier et al. (2014) found generally fewer circumscribed interests in females with ASD and suggests this is either reflective of a unique female autism phenotype, or a sex-based protective factor. When circumscribed interests are determined to be present, they tend to involve more “traditional” cisgender female interests, including music, pop stars, dolls, makeup/skincare, and anime. Furthermore, females with ASD exhibit fewer issues with imaginative play but can be controlling and rigid when playing with others, perhaps in an attempt to “follow the rules” or manage expectations in their environment (van Wijngaarden-Cremers et. al., 2014).

Relatedly, some of the research literature (e.g. Werling & Geschwind, 2013) suggests females with ASD exhibit more internalizing symptoms than males, including anxiety and depression, and that males with ASD exhibit more disruptive behavioral problems, which tends to prompt evaluation and treatment. Werling and Geschwind (2013) suggest that intellectual or cognitive impairments may be more likely to prompt evaluation for females with ASD, rather than emotional or behavioral problems. However, the findings of other researchers contradict this notion (Frazier et al., 2014), indicating that females formally diagnosed with ASD present with greater behavioral and adaptive impairments, and thus tend to exhibit greater overall impairment than males diagnosed with ASD.

Female Protective Effect: A Biological Explanation?

There is also the possibility of genuine biological differences between males and females, where females are essentially "protected," or less likely, to present with classic autistic traits and impairments than males (Hull et al., 2020; Werling & Geschwind, 2013). From this perspective, researchers suggest females require a greater familial etiologic or genetic "load" of certain genes in order to present similar autistic characteristics and impairments to males (Robinson et al., 2013). Several researchers are referring to this as the "female protective effect" (FPE), and this theory has increasingly gained traction in the autism research community (Frazier et al., 2014; Halladay et al., 2015; Robinson et al., 2013; Werling & Geschwind, 2013). Certainly, the understanding of sexually dimorphic disease prevalence in certain disorders is not new. For example, autoimmune diseases such as multiple sclerosis has consistently shown a prevalence towards females, whereas certain neurodevelopmental disorders, including ADHD, show a stronger prevalence in males (Werling & Geschwind, 2013).

However, the evidence for the FPE theory is mixed, and there is no actual factor that has been proven in the research to account for a protective effect (Hull et al., 2020). Some researchers have posited that androgens, found in greater quantities among males, may be responsible for many of the autistic characteristics seen in males (Baron-Cohen, 2002). These researchers argue that certain central features of ASD, including issues with emotional expression, empathy, and a strength in analyzing or constructing systems or rules, represent traditionally masculine characteristics; therefore, individuals with ASD are said to have "hypermasculine" or "extreme male" behavioral and psychological presentations (Hull et al., 2020). This is referred to as the *Extreme Male Brain* (EMB) theory, and suggests that females, having generally lower androgen levels than males, manifest fewer of these "male" characteristics. Interestingly, a positive relationship between androgen levels and autistic characteristics in females have been found in the literature (Knickmeyer et al., 2006).

Other researchers have not found that androgen levels during fetal development or early childhood relate significantly to an autism diagnosis (Guyatt et al, 2015). It is important to note that determination of whether or not a FPE exists depends on whether the ratio of males to females on the spectrum are correct and accurate, which is already a key limitation in the autism literature. Ironically, the inherent heterogeneity of autism symptoms (and how they present in individuals) also seems to complicate sampling for autism research, and highlights the need for large sample sizes, a problem often cited in psychological research (Scaer et al., 2015).

Experiences of Females with ASD

In addition to the literature on disparity in prevalence between males and females on the autism spectrum, researchers have also attempted to document the unique *experiences* of girls and women on the spectrum. If there is a genuinely different phenotype of autism that differs based on gender, then it stands to reason that females on the spectrum have different experiences and needs. Perhaps one factor affecting early detection of ASD in girls is their relatively strong social skills compared to boys, which are also mediated by their efforts to behave like others in their social group (Bauminger et al., 2008; Cridland et al., 2014). Many women on the autism spectrum have reported knowing they were different from a young age and feeling confused and unsure as to what kept them from fitting in (Baldwin & Costley, 2016).

Also salient in the research literature is the finding that companionship is a primary social motivator for many adolescent girls with ASD, especially during unstructured time at school such as lunches and recess (Sedgewick et al., 2016). While this is not different than the social needs and motivators of females without ASD, it highlights the notion that what socially motivates non-ASD girls may be similar to what motivates girls on the spectrum. Many adult females with an official ASD diagnosis also appear to make concerted efforts to fit in, yet still struggle to do so, especially beginning in adolescence. For example, Bargiela et al. (2016) documented in their qualitative research that many adult women on the autism spectrum engaged in “masking” or “camouflaging”, which is described as attempts to disguise their autistic traits in order to fit in.

Camouflaging Among Females with ASD

The first reference to camouflaging among females with ASD was mentioned by Lorna Wing in 1981, in an attempt to explain the gender disparity in diagnosis (Hull et al., 2020). Wing hypothesized that females with ASD (that do not have a co-occurring intellectual disability) may not be flagged as having ASD because they appear to have better social communication than males (Wing, 1981). Over time, researchers have attempted to operationalize camouflaging behaviors for the purpose of furthering the literature in this particular area, and there has been some consensus as to what camouflaging entails. This is incredibly important for furthering the research literature in this area, as operationalizing camouflaging as a construct would allow researchers to design quantitative measures and studies to better understand this behavior.

Generally, camouflaging behaviors include conscious and unconscious strategies such as mimicking nonverbal gestures, posturing, and tone. It also involves making use of certain words, phrases, and speech patterns, as well as learning and researching socially acceptable behaviors in popular media and books on social skills (Bargiela et al., 2016; Hull et al, 2020; Milner et al., 2019). In the study by Bargiela and colleagues (2016), participants described "putting on a mask" by deliberately trying to learn and use "neurotypical" social skills as a main form of camouflaging. In order to do so, participants carefully observed their peers and engaged in trial-and-error learning in social interactions. This occurs in response to peers seeing them as different, creating concern they may become excluded from their social group.

For many females with ASD, media sources such as movies, TV, magazines, and social media provided reference material related to body language and personality (Bargiela et al., 2016). Phrases and facial expressions are mimicked in situations that ASD women deemed similar to their own situations. In addition, females with ASD in the research described saying what they felt they were "supposed to say," referred to as *scripting* (Sedgewick et al., 2016). This occurs mostly in relation to emotional expectations, such as repeating, "Don't cry," or "It's alright." However, at times these phrases may miss the mark, and be used in situations where they were ultimately not helpful. For example, this examiner has been told by several of her female testing clients with ASD that the recipient of similar phrases at times felt invalidated or dismissed rather than supported.

The participants in Bargiela's (2016) study noted that their social mimicking was willful and conscious, and therefore took a lot of effort to process people's behaviors and imitate them in other situations. Consequently, they felt exhausted, drained, and confused about their identity after prolonged social interaction. Indeed, other researchers have noted the increased processing time and effort needed for a female with ASD in their social environments, especially when in peer groups that include multiple neurotypical peers (Cridland et al., 2014). This increased time needed adds to the difficulties following and contributing to the fast-paced, dynamic conversation that characterizes adolescent social interaction (Nichols et al., 2009). Oftentimes, females with ASD recalled having "meltdowns" at home when they came home from school (Bargiela et al., 2016). This examiner often hears from parents of adolescent females suspected of having ASD that they seem to keep it together fairly well at school, but "blow up" or have a meltdown once they get home. This perhaps reflects the exhaustive effort of these young women to try to fit in despite their neurodiversity. It is therefore not surprising that females with ASD have a much higher occurrence of co-morbid mental health diagnoses, including but not limited to, anxiety and depression (Cridland et al., 2014).

Increasing Social Complexity in Adolescence and Adulthood

It appears that many female adolescents and adults with ASD (particularly those without a co-occurring intellectual or cognitive impairment) have been able to adequately imitate salient elements of social interaction in earlier childhood, including pretend play and cooperative games; however, they increasingly struggled to manage social interaction and building/maintaining friendships as their social environment became more complex (Cridland et al., 2014).

In addition, adolescent girls have been found to utilize more complex and nuanced forms of aggression during conflict than boys, including gossiping and spreading rumors, ignoring, and exclusion. They also tend to use more non-verbal behaviors, including eye-rolling and giggling (Cridland et al., 2014). These can cumulatively be much more difficult for a female with ASD to understand and respond to. Adolescent female relationships rely heavily on complex social skills that include providing emotional validation and support, advice-giving, and reciprocal sharing. For example, one mother in the study by Cridland and colleagues (2014) noted that their daughter had friends and could play with others when they were younger, but eventually, their daughter was "unable to read what people expected of her." This may be characteristically different than the experiences of male adolescents and young adults with ASD, as male friendships center more around mutual hobbies and "doing" rather than "talking" as a form of relating (Nichols et al., 2009).

Interestingly, adolescent females with ASD have generally reported less relational conflict with their peers in the existing literature (Sedgewick et al., 2016). Nonetheless, they also mentioned a wide range of frequently occurring behaviors indicative of relational conflict, many of which were highlighted by other researchers (Cridland et al., 2014). Behaviors including ignoring, interfering with relationships, and talking behind the person's back were described as having occurred within peer relationships during conflict. The discrepancy between their reported level of conflict and actual conflict highlights potential issues with how accurately females with ASD perceive conflict in their relationships. In other words, females with ASD may not readily recognize conflict in their relationships, and if they do, they struggle to manage this conflict.

Sexual Victimization Among Females with ASD

Research on females with ASD has also documented a shockingly high incidence of sexual abuse, sexual victimization, and issues navigating sexual boundaries and relationships (Bargiela et al., 2016; Brown-Lavoie & Viecili, 2014; Cridland et al., 2014; Milner et al., 2019). In fact, one study found as many as 75% of individuals with ASD have been sexually coerced or abused, with females being disproportionately at risk when compared with males with ASD (Brown-Lavoie & Viecili, 2014). This was partly associated with a lack of sexual knowledge, as peers become an important source of this type of information in adolescence, though parents and teachers are also important sources of information. Because of the core social and communication issues inherent in ASD, females with ASD may not have as many opportunities to obtain important sexual knowledge from these individuals. Instead, they may rely on alternative sources such as television and pornography, which often provide misinformation regarding sex (Brown-Lavoie & Viecili, 2014). In addition, it has also been found that sexual health classes, often provided as part of a school curriculum, may not adequately address the needs of individuals with ASD. As indicated above, having a smaller social circle creates barriers to learning important sexual knowledge and nuanced social skills in a more casual and naturalistic setting (Travers & Tincani, 2010). Therefore, there is perhaps even more importance placed on sexual health classes to provide this information.

In their qualitative study, Milner and colleagues (2019) discussed a common theme of sexual vulnerability among their participants, noting that many felt naïve or gullible, and worried they would get taken advantage of. They also mentioned entering into tense and awkward situations with others as a result of inadvertently sending out the wrong body signals. Brown-Lavoie and Viecili's (2014) study similarly noted the impact of missing social subtleties as well as fewer opportunities for social interaction with peers and highlighted the importance of understanding others' intentions. At times, a female with ASD may miss or misunderstand important cues as well as opportunities to learn appropriate sexual knowledge.

Similarly, some of the mothers of females with ASD in the Cridland and colleagues (2014) study expressed concern that their daughters would be exploited by others. This author has witnessed in her own practice many instances where a female adolescent with ASD was solicited by adult males online. In some instances, this unfortunately culminated in a meeting and subsequent sexual assault. Researchers suggest this vulnerability regarding sexual relationships relates to poor understanding of appropriate boundaries, being overly trusting of others and what they say, and misinterpreting the intentions and behaviors of others due to core social impairments (Bargiela et al., 2016; Cridland et al., 2014; Milner et al., 2019). Brown-Lavoie and Viecili (2014) found, as have other researchers (Ryan et al., 2007), that individuals with ASD lack important sexual knowledge to be able to protect themselves against sexually transmitted diseases (STDs) and engage in safe sexual practices. In addition, they also lack an understanding of appropriate sexual behaviors.

One participant in Bargiela's (2016) study described the potential of copying or mimicking male flirtation or flirting behaviors in general, without fully realizing the implications. Another participant noted it was difficult to tell if a man was flirting or just being friendly. Some participants in Bargiela's study also described not having an adequate point of reference with which to develop strategies to stay safe on dates and reported not knowing that saying "no" to sexual advances was even an option. Other studies mentioned previously (Cridland et al., 2014) echoed these issues, adding that without an appropriate point of reference, a female with ASD may engage in sexual behaviors without necessarily wanting to or feeling comfortable, because they were led to believe engaging in sexual behaviors at that point was "normal" or would culminate in acceptance.

Treatment and Intervention in Females with ASD

It is the hope of this author that readers become more educated on what to look for in the females they work with in hopes of timelier and more appropriate referral for services. In this author's opinion, interventions such as therapy, social skills groups, and other services to account for the secondary issues seen in individuals with ASD (e.g., executive function impairments, anxiety, depression, and other comorbid diagnoses) begins with a psychological or neuropsychological assessment that includes a strong developmental history. Arguably, this developmental history needs to take into account the female's early gender socialization experiences as well as a clear understanding of when social difficulties began to manifest in subtle ways. In addition, interviewing needs to include questions and discussion related to potential camouflaging behaviors, including eye contact, facial expression, tone of voice, or stereotypical phrases the female has learned over time. It can also be incredibly valuable to understand, from the client themselves, their own experience of making and modulating eye contact (versus whether they exhibit appropriate eye contact or not), as well as where, when, and how they learned to fit in with their peers (or whether they have not yet learned how to). This might entail a conversation around, for example, what books, characters, movies/TV shows, or social media influencers the client is exposed to, as well as information regarding the characteristics of their peer group (or an idealized peer group). In addition, a detailed family history of developmental and psychiatric conditions can help a clinician elucidate whether the female client has a positive family history of autism.

Treatment efforts with this population would ideally address risk factors related to sexual abuse and victimization. Researchers such as Cridland and colleagues (2014) as well as Brown-Lavoie and Viecili (2014) highlighted the need for sexual education and support that includes information on developing appropriate boundaries, healthy strategies for sexual expression, and social skills to navigate and negotiate intimacy and sexual behavior. Sexual education topics can include information regarding contraception, STDs, and reproduction. Sexual education should include discussion around how to determine readiness for sexual activity, providing (and revoking) consent, and engaging in safe dating behaviors, both online and in person. Based on the information highlighted in Brown-Lavoie and Viecili's (2014) study, individuals with ASD might also benefit from discussion around safe and unsafe behaviors, understanding others' (potentially) negative intentions, and asserting their own will regarding sexual interaction. For example, teaching young women with ASD to clearly express interest or disinterest, identifying comfort/discomfort with certain physical boundaries, how to pick up on and navigate the nuances of romantic courtship, and understanding the meaning of consensual sexual activity can help as young adult and adult females with ASD begin to navigate the world of dating, sex, and romantic relationships.

As discussed in Kellaher (2015), adolescent and young adult females with ASD may have information regarding sexual *language*, which can create the perception of having greater sexual knowledge than they have and cause them to be overlooked for such intervention. However, recent review of the literature suggests there is no published best practice method of delivering this information to this population (Kellaher, 2015). Nevertheless, this author posits that information needs to be stated concretely and explicitly, with plenty of examples. For example, the participants in Kellaher's (2015) study benefitted from modification of survey items to make them more explicit in their meaning. Rather than asking whether or not a participant had been sexually victimized, the researchers asked about specific situations, such as whether or not they ever had sexual intercourse when they did not want to. They also provided participants with definitions of sexual terms. Because of the inherent cognitive rigidity seen in individuals with ASD, it stands to reason that phrasing information in a concrete, explicit, and literal manner can help the recipients of such intervention better understand the information presented.

As indicated earlier, a central feature of ASD relates to social difficulties, including identifying and interpreting social cues and responding appropriately in social situations. Much of this involves being able to interpret both verbal and nonverbal social cues, which arguably can be more challenging in an online environment. Not only does this pose a risk with regard to being safe on online social media platforms, but also makes it much more difficult for someone with ASD to correctly notice someone’s potential intent in their communication. While this is not necessarily unique to females with ASD, females with ASD are more likely to be the victims of sexual abuse, coercion, or assault (Brown-Lavoie & Viecili, 2014), underscoring the dire need for helping them navigate social interaction both on and offline. Teaching social skills to address a core deficit of ASD should ideally occur as soon as possible and regardless of age. This can include turn-taking, modulating eye contact, appropriate sharing of interests with others, appropriate ways to express emotions, dealing with rejection, and eventually, the concepts of love and intimacy (Travers & Tincani, 2010).

Clinical intervention to address the primary and secondary impacts of camouflaging is warranted, especially given the emotional toll it takes on the female with ASD to try to fit in. As highlighted above, females with ASD attempt to camouflage with their neurotypical peers by mimicking behaviors; even still, there is significant risk they inadvertently mimic behaviors, gestures, and phrases incorrectly, or in situations where it is not appropriate (Bargiela et al., 2016). This “trial and error” method may unknowingly cause peers to distance themselves, for potential bullying to occur because the female with ASD stands out rather than fits in, and for the female with ASD to potentially put themselves in uncomfortable social or romantic situations (Bargiela et al, 2016). This underscores the need for reliable sources of information, such as social skill coaches, therapists, and even peer mentors. Providing guidance and coaching around nuanced social skills and social rules can help the female with ASD more reliably learn appropriate social behavior in order to better relate to their peers. The goal is not necessarily to “hide” the ASD features, but rather to help bridge the social gap between the female with ASD and the peers they seek to befriend.

Whether caused by the exhaustive efforts to try to fit in or not, females with ASD often develop secondary mental and emotional health struggles, such as (but not limited to) anxiety and depression (Cridland et al., 2014). The research on treating such mental health conditions in individuals with ASD is promising, and points to evidence-based treatment modalities such as Cognitive Behavioral Therapy (CBT). CBT can help the individual overcome and reframe the cognitive distortions (irrational beliefs) that affect their self-perception (Wood et al., 2015). This author has found that teaching how to challenge irrational beliefs that contribute to depression and anxiety should ideally be done using an active training approach, where a few important skills are taught and reinforced throughout the day and across different settings. This can help increase generalizability across different situations, which is helpful given the struggle individuals with ASD have in generalizing what they learn from one situation to the next. These skills should be clearly defined and explicitly taught, then modeled. It can then be reinforced in natural settings to encourage mastery.

Conclusion

The following article summarized the state of the literature on females with ASD as well as described the experiences of females with ASD. This article is by no means a comprehensive review of the literature. Rather, it is intended to provide a brief snapshot of the current literature in order to stimulate discussion on this topic. In addition, this author has attempted to provide a “forest through the trees” perspective despite the limited body of literature. However, in some cases, the research literature can be mixed, making it hard to determine patterns that can aid in diagnosis and treatment/intervention planning. Therefore, more research is needed to illustrate patterns and guide clinicians towards more accurate diagnosis and effective treatment.

Regardless of whether males are genuinely more likely to have ASD, or whether the higher prevalence of males with ASD relates to issues with sampling in research and higher likelihood of identification, future research needs to explore the experiences and presentation of females on the autism spectrum. Some of the issues faced by females with ASD are similar to males with ASD, including potential consequences of late diagnosis (Baldwin & Costley, 2016; Cridland et al., 2014); still, this author posits that the experience of females with ASD is unique in this regard, in that they are not as well represented in popular media, let alone in scientific research. Therefore, females with ASD may have the added burden of feeling different without being able to feel a sense that there are others like them.

As discussed in the article by Bargiela and colleagues (2016), late identification and diagnosis may relate to specific features of the potential female ASD phenotype as well as the systems that are designed to identify individuals on the autism spectrum. For example, certain stereotypes, including that all people with ASD exhibit significant social difficulties, are not motivated to make friends, and exhibit obvious repetitive and/or stimming behaviors perhaps contributes to a professional's reluctance to diagnose females as having autism when they do present with some social difficulties. As highlighted above, females on the autism spectrum are more often conceptualized as having another diagnosis, including but not limited to, bipolar disorder, social phobia, and borderline personality disorder (van Wijngaarden-Cremers et al., 2014). In general, females without an accompanying intellectual impairment tend to fall through the cracks in terms of diagnosis, though when they do have an intellectual impairment or lower cognitive function, the research suggests it does increase the likelihood that they receive an autism diagnosis.

Likely, the risk of being on the autism spectrum may be multifactorial, involving a mixture of social, environmental, and genetic factors. While some researchers have pointed to the role of a higher genetic "threshold" for females to develop symptoms of autism, others have focused on the role of female socialization in combination with the generally accepted notion that "girls don't have autism." Nevertheless, the research generally echoes that females with official and unofficial diagnoses of ASD reported engaging in certain efforts to blend in and/or gain acceptance in a desired peer group. Ironically, the ability to camouflage, as well as the higher prevalence of internalizing (versus externalizing) symptoms among females with ASD may increase the likelihood of going undiagnosed or being misdiagnosed, despite camouflaging being an indicator of better social competency and skill (Bargiela et al., 2016; Milner et al., 2019). There was also agreement in the literature that females with ASD tend to exhibit fewer repetitive or “stimming” behaviors; therefore, professionals that are poised to refer for diagnostic testing have fewer “overt” behaviors to go off to justify a referral (Frazier et al., 2014; van Wijngaarden-Cremers et al., 2014).

In addition, the above review highlighted some of the unique vulnerabilities faced by some females with ASD. This included being at risk of sexual exploitation due to difficulties developing appropriate sexual scripts to exercise appropriate boundaries, issues with interpreting flirtation and sexual advances, and mimicking behaviors that unknowingly invite sexual advances from others. Because of the nature of online social media and chat as well as inherent social communication difficulties, some females with ASD may struggle to accurately interpret others’ intention and may take what is said to them at face value. Some authors (Bargiela et al., 2016) have suggested that people with an autism diagnosis have an increased likelihood of being sexually abused and encourage further research in this area.

While society waits for the scientific literature on autism to “catch up” to the identification of ASD in females and their associated experiences, it is recommended that professionals working with this population (whether in the role of therapist or evaluator) educate themselves regarding what is currently understood to be potential signs and symptoms of ASD, especially the more subtle manifestations that may be present in females with ASD. In addition to the reference list below, providers are encouraged to consult the Autism Speaks resource library, the Autism Now website (www.autismnow.org), and the work of Dr. Donna Henderson, particularly her podcasts, presentations, and blog posts, regarding ASD in girls and women (www.drdonnahenderson.com). Undoubtedly, the dearth of research studies on this topic, and relatedly, lack of knowledge from teachers, therapists, parents, educational consultants, and even psychologists, contributes to delayed diagnosis and a delay in receiving needed services in females with ASD. For many reasons, this is not acceptable. Therefore, added training, discussion, and research will be necessary to better meet the needs of this population.

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Discovering and Treating Pathological Demand Avoidance in the Wilderness

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Abstract

Pathological demand avoidance (PDA) was first observed and studied in the United Kingdom in the 1980s by Elizabeth Newson and her colleagues, developmental psychologists specializing in pervasive developmental disorders. PDA reminded these psychologists of autism, though it differed in important ways, including obsessive resistance to daily demands, 'surface sociability,' and imaginative play (Newson et al., 2003). This topic has drawn significant attention and has been debated as to whether PDA is a unique diagnostic profile within the autism spectrum or merely an over-pathologizing process of individuals' autonomy and independence (Milton, 2013; Moore, 2020). PDA has an established following of professionals, family members and individuals. The discussion of this topic is of critical importance so that individuals affected by PDA who are being treated in outdoor behavioral healthcare (OBH) settings, also called wilderness therapy, and residential treatment settings in the United States are not misdiagnosed or treated inappropriately, thereby experience harm due to a misunderstanding on the part of professionals and parents.

Keywords: pathological demand avoidance, PDA, autism spectrum disorder, ASD, pervasive developmental disorder, PDD, outdoor behavioral health, OBH, wilderness therapy

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DISCOVERING AND TREATING PATHOLOGICAL DEMAND

Outdoor behavioral healthcare (OBH) is an emerging field of behavioral healthcare which treats adolescents and adults (Russell & Hendee, 2000). A recent meta-analysis of wilderness therapy studies (Bettman et al., 2016) found that wilderness therapy produced moderate effect sizes of improved mental health and behavioral outcomes. DeMille et al. (2018) demonstrated that participants who attended an OBH treatment program were, as reported by their parents, functioning significantly better than the treatment as usual (TAU) comparison group one year following the program. Wilderness therapy, a residential form of OBH, has been employed to treat adolescents struggling with a variety of mental health and developmental disorders (Christensen, 2008; Cahill & Stireman, in press). The outcomes for clients with an autism spectrum disorder (ASD) diagnosis were not as favorable. Savidge (2020) investigated treatment effects of adolescent and adult clients who presented with an ASD diagnosis while attending an OBH program. Her results demonstrated mixed results for ASD adolescent clients. She related that with the adolescent sample studied; 49% reported ‘recovered’ or ‘improved,’ while 22% reported ‘no change,’ and 29% reported ‘deterioration’ in their functioning and symptoms.

Mental health practitioners in OBH face two primary responsibilities while working with young people. The first is a thorough examination of the diagnostic profile of the participants, and the second is formulating effective treatment strategies and implementing appropriate interventions based on diagnoses (Hoag et al., 2014). If one is not clear about what a client is struggling with, either the treatment will be less effective, or worse, may harm the client and create confusion for the family, and alienate the client from seeking mental health treatment in the future. Over the last year, the authors have become aware of another proposed diagnostic entity, that of pathological demand avoidance (PDA), and have begun to consider its presence and prevalence among clients who are treated in OBH programs. In review of the DSM-5 (American Psychiatric Association, 2013), there are clear cut demarcations of conditions and diagnoses, while in practice these clear boundaries are frequently blurred and diagnostic clarity is not always so evident. Additionally, despite the value added by the DSM-5 and ICD-11 (World Health Organization, 2019) categorization of diagnoses, it is a common understanding that these resources do not encompass all conditions that mental health and developmental professionals encounter and treat. Internet addiction, problematic internet use, and digital media overuse (Cahill & Stireman, in press; Dahl & Bergmark, 2020); and non-verbal learning disorder (NVLD) (Rubinstien, 2005) are profiles that come to mind. Diagnosis and treatment approaches continue to advance, and it is important to evolve with these.

History and Description of PDA

In the early 1980s, Elizabeth Newson, a British developmental psychologist, and her colleagues began seeing young people, referred for assessment, diagnosis, and treatment who reminded referring professionals of autism but differed in important ways (e.g., sociability and imaginative play) (Newson et al., 2003). It became clear to Newson and her colleagues a behavioral profile emerged in these young people that was not described by any diagnostic category at the time. They proposed a separate diagnosis named pathological demand avoidance (PDA) within the general diagnostic category of pervasive developmental disorders. Newson et al. (2003) defined PDA by eight key characteristics, including:

1) an obsessive resistance to everyday demands and a tendency to use a range of ‘socially manipulative’ strategies to subvert requests (e.g., distraction, targeted shocking behavior, threats),

2) ‘surface sociability’—a superficial ability to manage social interaction, but with little evidence of a normal sense of social identity (e.g., believing themselves to be on a par with or superior to adults), and a lack of pride or shame, evident in socially shocking behavior viewed as infantile or bothersome by peers,

3) lability of mood and impulsivity motivated by an obsessive need for control,

4) comfortable in role play and pretending—often adopting borrowed roles when interacting with others (e.g., relating to peers in the manner of a teacher or other scripted roles),

5) early language delays due to passivity,

6) obsessive behavior often targeted at particular people or their characteristics,

7) a passive early infancy history of delayed developmental milestones, and

8) neurological involvement (e.g., delayed milestones, clumsiness, and seizures).

At the time Newson et al. (2003) believed PDA to be within the spectrum of pervasive developmental disorders, but still different from autism and Asperger syndrome. They believed it required a separate diagnosis to capture its unique presentation and criteria. PDA has been studied and discussed over the last four decades and was presented in a recent review of mental health problems affecting children and adolescents (Ogundele, 2018). Despite the active discussion and following there has been some question about the actual existence of PDA as a profile of specific pathology (Malik & Baird, 2018; O'Nions et al., 2016), with some expressing concern about pathologizing appropriate resistance and individuality (Milton, 2013; Moore, 2020). Though debate on the topic continues, professionals in the UK have been assessing and treating individuals with PDA, a cluster of symptoms which lead to significant difficulty with daily functioning (Newson et al., 2003; O'Nions, Viding, Greven et al., 2014).

Currently PDA is not recognized by the DSM-5 or the ICD-11, and therefore has not been considered within the dominant OBH community. Researchers and clinicians familiar with this condition have characterized PDA within the spectrum of pervasive developmental disorders (Newson et al., 2003), and more recently, as a subtype or sub-group of ASD (O'Nions & Eaton, 2020). However, there is no agreed diagnostic algorithm to determine who should meet criteria and no consensus about whether PDA is a good candidate for inclusion as a sub-category within ASD in the future (O'Nions & Eaton, 2020).

Lord et al. (2012) conducted a large study examining whether categorical diagnostic subtypes of ASD could be supported. Results from the study supported the move from existing subgroups (e.g., autistic disorder, PDD-NOS, and Asperger's syndrome) to a dimensional description of core features of social affect and fixated, repetitive behaviors, together with characteristics such as language level and cognitive function. O'Nions and Eaton (2020) suggest that "thinking about PDA or extreme demand avoidance (EDA) dimensionally is useful in drawing parallels with the wider international research literature on demand avoidance in ASD." Considering PDA as relating to and a variation of ASD dimensions can be useful. The reason for this is that PDA presents differently than prototypical autism (e.g., sociability and imaginative play), though PDA is found more frequently in individuals with ASD than in the general population (Gillberg et al., 2015).

Of significant note, the prevalence of PDA across sexes is believed to be roughly 1 to 1 (Newson et al., 2003), which is significantly different from prevalence rates of ASD across boys and girls, 4 to 1 (American Psychiatric Association, 2013). Clinicians and researchers continue to explore and study young people with these challenges so that they can better define the profile of PDA, determine accurate prevalence rates, and assess its presence through diagnostic measures (O'Nions, Christie, Gould et al., 2014; O'Nions, Viding, Greven et al., 2014).

One of the reasons it is important to consider and discuss this profile is that the symptoms overlap with other disorders that may lead to PDA being missed or incorrectly diagnosed and therefore inappropriately treated. Given the overlap in symptomatology of PDA with other mental health issues, it can be confused with oppositional defiant disorder, bipolar disorder, attachment disorder, personality disorders, dissociative disorder, and other behavioral presentations (Eaton & Weaver, 2020; O'Nions, Christie, Gould et al., 2014; O'Nions, Viding, Greven et al., 2014). It is relevant to note, Newson et al. (2003) argued that PDA is developmental in nature, presenting early in life. They state behaviors commonly seen within PDA are driven by one's attempt to reduce anxiety and distress triggered by real or anticipated demands rather than from other etiologies, including trauma, biochemical, willful position, or poor parenting.

Presence and Risks of PDA in OBH

Mental health professionals unfamiliar with this condition may not easily distinguish PDA from other behavioral or perhaps personality-based disorders from its neurodevelopmental nature (Eaton & Weaver, 2020). The diagnostic journey for individuals with PDA can be similar to the one with ASD. It is common for people with ASD to be evaluated but not diagnosed early in the evaluation process (Davidovitch et al., 2015), due to the evolving nature of the ASD profile. Similarly, it is important for individuals with PDA to be accurately diagnosed, otherwise they will not receive appropriate treatment. As OBH and other residential therapy professionals become familiar with the key characteristics of PDA, one diagnostic category to consider is: Other Specified Neurodevelopmental Disorder associated with Extreme (Pathological) Demand Avoidance (F88). It is also important to evaluate whether these individuals meet the criteria for ASD, as well as PDA. In this case, clinicians should diagnose ASD and add a specifier of PDA, drawing attention to these unique traits. Additionally, the specifier can be helpful to draw attention to a condition which has been described as not responding well to general autism guidelines and need appropriate modifications (Newson et al., 2003).

Positively, there have been efforts made to assess PDA by developing measures to identify and differentiate PDA from other disorders. O’Nions, Christie, Gould et al. (2014) developed the Extreme Demand Avoidance Questionnaire (EDA-Q), a parent completed, 26-item measure designed for research purposes rather than as a diagnostic tool. This instrument demonstrated promising psychometric properties with a high level of internal consistency. The EDA-Q provides cut-off scores to assist in evaluating the presence of PDA and differentiating between different disorders were also determined. These cut-off scores maximized both sensitivity and specificity to detect individuals with PDA. Similarly, O’Nions et al. (2016) evaluated the use of a clinician-rated measure for PDA by selecting 11 items from the Diagnostic Interview for Social and Communication Disorders (DISCO) (Wing et al., 2002). Subjects who scored high on these items were found to have a lack of cooperation, engage in what appeared to be manipulative behavior, and at times choose socially shocking behavior. They were also found to have difficulties in their relationship with other people, experience anxiety, and demonstrate sudden behavioral changes moving from loving behavior to aggression. O’Nions et al. (2016) suggest that these surveys provide useful clinician-rated measure of to assist in the diagnosis of PDA.

In OBH and other therapeutic residential environments, the risk of treating professionals seeing individuals with PDA through a purely behavioral or personality-based lens is significant. As a result, this could impact the way individuals affected by PDA are evaluated in their overall engagement of the program. The misunderstood young person with PDA will be left feeling confused and uncertain about what to do and how to engage in a process that seems insurmountable for them. As Savidge (2020) indicated in her investigation of ASD adolescent clients in OBH programs, 51% reported no change or a deterioration through the course of treatment. It could be theorized that at least some of these individuals may have had PDA in addition to ASD, and unfamiliar therapists and field guides did not know how best to approach and treat these individuals. Additionally, it is likely that for individuals with undetected PDA, their treatment plans would have been poorly designed and ineffective in treating their symptoms, leading to poorer outcomes.

Stress and Its Effects in PDA

Newson et al. (2003) described that anxiety interferes with individuals with PDA desire to exercise agency in moments of avoidance. Resistance to feared stimuli can be mistaken for defiance and willfulness. During these times, uninformed or misinformed adults and peers may move quickly to their own reactivity, including providing consequences and punishments for the undesirable behavior by the individual with PDA. The young person with PDA lacks flexibility in navigating daily expectations, and also struggles to manage their emotions and behavior in functional and adaptive ways (O’Nions, 2016). This is likely to impact their lives significantly and further contribute to poor interpersonal relationships. In working with young people with PDA, it is important for parents, teachers, paraprofessionals, and other caregivers to appreciate the underlying anxiety and how this drives the avoidance of perceived demands (Newson et al., 2003). Being clear about where this anxiety and avoidance originates will be helpful in addressing the emotion and reactiveness in a supportive, understanding, and effective manner.

The primary issue for individuals with PDA involves resisting or avoiding daily expectations and real or perceived demands. Those with PDA find it anxiety-provoking and stressful to face things like waking up, going to school, eating, keeping a schedule, or even doing the things they enjoy doing (PDA Society, 2021). As these individuals confront everyday demands, they can experience significant mood changes and what appear to be disruptive and problematic behaviors (Newson et al., 2003). Newson and her colleagues (2003) indicate that behavioral consequences are not effective in the same way as when working with prototypical ASD without

PDA. Individuals with PDA may perceive the demand as worse than any positive or negative consequence provided to them, and it is often seen as impossible to cope with or meet expectations or demands. Like many anxiety-based presentations, people with PDA are quickly reinforced for avoiding these stresses or everyday expectations or demands. It is helpful to consider the abundance of demands encountered in an OBH program, including social, emotional, cognitive, physical, sensory, and daily demands. It is likely that OBH programs unfamiliar with this condition would apply commonly used behavioral methods with these individuals, which will be largely ineffective with PDA clients (O'Nions & Eaton, 2020). It is important for OBH programs to consider other types of therapeutic approaches as they encounter individuals with PDA.

Treatment Considerations

O'Nions and Eaton (2020) relate: It is helpful to remember that children with a PDA profile are not deliberately difficult. If the socially strategic behaviour is seen for what it is - a scripted and limited strategy for ensuring predictability and control, rather than labelled as 'manipulative', the child's behaviour can be reframed in a more compassionate way (p. 8).

It is important that professionals not view behavior as willful or defiant (e.g., oppositional defiant disorder), rather view it as an inability to act. The PDA Society characterizes PDA as a tug of war between the brain, heart, and body (PDA Society, 2021). Individuals with PDA may want to perform the task/expectation in front of them, which is what differentiates them from behavioral disorders, but their brain tells them they can't, and their body shuts down due to their fear (defensive) response. Given the anxiety and stress individuals with PDA experience, the activation of their autonomic nervous system is likely implicated in their response to stress (Porges & Carter, 2017), and will need to be addressed.

Newson et al. (2003) posited that individuals with ASD only do not follow the same treatment patterns as those with ASD and PDA. Specifically, familiar and practiced routines are often helpful to individuals with purely ASD. However, for individuals who also experience PDA, those routines are often perceived as stressful expectations and demands, producing a fear response and shutting down through avoidance behavior. As a result, individuals with PDA need some modifications, as well as an approach which supports their path towards greater level of functioning in the face of anxiety-provoking demands (Newson et al., 2003).

The PDA Society references the 'PANDA' approach for caregivers and professionals who work with, treat and support individuals with PDA (PDA Society, 2021). PANDA stands for **P**ick battles, **A**nxiety management, **N**egotiation and collaboration, **D**isguise and manage demands, and **A**daptation. This approach involves seeing the person, exploring their interests, and positive engagement. For more information on this approach, refer to https://www.pdasociety.org.uk/about-us-landing/our-ambassador/. This society suggests that relationships with people with PDA should be 'person-centered' and based on a partnership of trust, flexibility, and collaboration. They suggest careful consideration of the words and language used, as well as a balance of demands when speaking with an individual with PDA.

Other practitioners have also noted the importance of a calm and collaborative process with an individual with PDA (Sherman & Vincent, 2021). Creating a sense of control for the individual is an important aspect of the treatment approach and avoiding the parent or task-oriented role. The authors note that the person with PDA will react with rigidness to a sense of being told what to do, and it is helpful for requests to be worded indirectly and avoid the word 'you'. Creating a sense of teamwork, and suggesting, "We are on the same team! Let's work together" is important. One should be prepared for the individual to react and resist, work with the young person's ambivalence, and not react to failure. Sherman and Vincent (2021) further suggest framing things as a race or challenge or using humor by directing demands to other people or objects in the room.

While there is no specific treatment that has been empirically tested and validated for clients with PDA, practitioners have looked to the PDA Society to understand, assess, and treat this developmental condition in individuals. It is critical that OBH programs and other residential treatment programs learn how to best approach and treat this group of individuals. Practitioners need an understanding of how this clinical issue manifests and what conditions it may be similar to, so by extension, professionals can provide safe and effective treatments to this unique population.

Identifying Applicable Clinical Theories and Approaches

This section will review a variety of theories and approaches when working with people with PDA and their families. Given the lack of research on specific clinical empirically supported treatments for individuals struggling with PDA, the authors will discuss approaches that treat aspects of PDA to assist professionals encountering and treating this profile (PDA Society, 2021).

Greenspan and Weider (1999) discuss addressing ASD from a developmental approach. Developmental approaches are relationship-based, child-centered, and play-based, which help to teach individuals with ASD skills in social relationships and engagement (Wagner, et al., 2014). Features and characteristics of PDA are common across the autism spectrum. These include lack of co-operation, changes in mood, blaming others, poor social awareness, rigidity, and anxiety (O’Nions et al., 2016). Given the overlap of ASD and PDA, developmental approaches could be useful when designing treatment interventions for individuals with PDA.

Individuals with PDA struggle with global functioning, impaired by their anxiety and fear of demands, their desire for control of situations they find stressful, pathologic avoidance of stressful situations, and cognitive rigidity. Given the myriad of issues that present with these complex individuals, professionals will more effectively serve individuals with PDA when a comprehensive treatment planning approach is taken, including: anxiety management, anger management and emotional regulation skills, distress tolerance skills, social skills training, psychotropic intervention, sensory integration techniques, mind-body awareness techniques, cognitive therapy, behavioral therapies, healthy lifestyles, and family therapy (O’Nions & Eaton, 2020; Sherman & Vincent, 2021).

PDA shares characteristics of anxiety disorders, wherein both general and specific fears are experienced. Individuals with PDA are hyper-focused on their fear of demands and anticipated outcomes, and rigid about their avoidance of situations and people they perceive as placing these demands on them. Over-control is also a feature of PDA, a struggle to deal with uncertainty, similar to that of individuals who experience ASD and OCD. There is high comorbidity in developmental disorders, anxiety disorders, and neurocognitive; American Psychiatric Association, 2013;

Hoffman, 2012; Hoffman and Hudack, in press). Clinical treatments addressing these conditions may be fruitful to explore.

When confronted with demands, individuals with PDA can become highly emotionally dysregulated, similar to aggression observed in some individuals with ASD (Kanne & Mazurek, 2011). If these individuals are unable to escape through avoidance, individuals may mobilize a ‘fight or flight’ response to regain a sense of control (O’Nions & Eaton, 2020). Behavioral and psychological approaches addressing emotional dysregulation are important to practice (Lucyshyn et al., 2015; Porges & Carter, 2017), and psychopharmacology intervention may also be important to consider (McDougle, et al., 2003; Parikh, et al., 2008).

Related to the issue of emotional and behavioral dysregulation, family members and professionals may accommodate the individual in an effort to soothe the person or avoid the fallout from high levels of dysregulation (O’Nions & Eaton, 2020). Though, in so doing, they reinforce the problem behaviors and the belief that one cannot cope with stress (Hoffman, 2012). The family system is important to consider while treating these individuals in order to help others avoid reinforcing maladaptive ways of coping.

Given that individuals with PDA experience stress responses to feared stimuli, leading to an activated sympathetic nervous system, it is important to consider interventions and conditions that help to regulate the autonomic nervous system (ANS). One such related theoretical approach is the Stress Reduction Theory (SRT) (Ulrich et al., 1991). Ulrich and colleagues (1991) found that individuals exposed to natural environments experienced health benefits by engaging the parasympathetic nervous system. This leads to calming a dysregulated ANS, leading to improved recovery of the ANS, contributing to behavioral regulation, emotional regulation, and increasing cognitive flexibility.

The Polyvagal Theory (PT) described by Porges and Carter (2017) discusses three systems of the ANS as being behaviorally linked to three global adaptive domains of behavior: 1) social communication, 2) defensive strategies of mobilization, and 3) defensive strategies of immobilization. They theorize that body and mind are intimately connected, and both need to be considered when working with people experiencing states of stress and displaying defensive strategies. This appears consistent with the behaviors of individuals with PDA. This theory suggests it is important to help people find safety through their bodily experience, along with helping them cognitively. The PDA Society conducted survey research of individuals with PDA, and they found that respondents describe a neurological tug-of-war between brain, heart, and body (PDA Society, 2021), which seems to tie to PT well. Given this survey data, the description of anxiety and need for control, and connection to the ANS and stress response, mind-body therapeutic techniques would appear to be an effective treatment strategy with PDA. Meditation, breathing exercises, chants, and body posture exercises are all suggested methods to help regulate the vagal system (Porges & Carter, 2017). Voluntary regulated breathing practices have been shown to be effective with anxiety disorders, stress, and depression (Brown & Gerbarg, 2005).

Additionally, the PT suggests that the vagus nerve is involved in what is called the Social Engagement System (SES) (Geller & Porges, 2014; Wagner, 2016). Geller and Porges (2014) suggest that the SES is a proposed third part of the ANS, which has previously been considered a two-part system. The SES has a more nuanced response than the sympathetic and parasympathetic nervous systems. This theory describes the neural mechanisms through which physiological states communicate safety and threat to oneself and others (Porges & Carter, 2017). The SES allows individuals to engage effectively with those around them when positively activated while sensing safety. When an individual senses safety, this system allows for greater flexibility in coping styles, including positive social engagement and initiation and general openness and problem solving. When an individual senses threat, this system leads to more rigid and maladaptive ways of behaving including ‘fight or flight’ behaviors, and shutting down (Porges & Carter, 2017). Teaching individuals with PDA ways to engage the SES ‘state of safety’ may lead to increased cognitive flexibility and willingness to engage demands previously experienced as stressful and avoided. Additionally, practitioners engaging with individuals with PDA can aid in the positive activation of the SES through a present, client centered therapeutic relationship (Geller, 2018). This type of relationship is likely to lead to a ‘state of safety’ which will aid individuals with PDA to be more relaxed, more open to learning, and practice new behaviors introduced by their practitioners. The practice of present, client centered therapeutic relationships the PT promotes is consistent with the PANDA approach suggested by the PDA Society (PDA Society, 2021).

Mindfulness and acceptance-based therapies including Dialectical Behavior Therapy (DBT; Linehan, 2014), Acceptance and Commitment Therapy (ACT; Hayes et al., 2012), Acceptance Based Behavioral Therapies (ABBT; Roemer & Osillo, 2020; Treanor et al., 2011) and Radically Open Dialectical Behavior Therapy (RO DBT; Lynch, 2018) could be useful with these individuals to more effectively regulate their ANS, and challenge their beliefs about demands and their need for control over uncertain situations, thus helping them feel safe. Mental health professionals have applied these approaches to individuals who have ASD, OCD, Anxiety Disorders, and BPD; each of which share characteristics with PDA.

Case Example

Kevin was a 16-year-old male who presented for treatment as a result of academic failure due to severe school avoidance and unwillingness to do schoolwork. This pattern of behavior had escalated over several years. Of great concern, Kevin displayed aggression in the home when confronted about academic avoidance and parents' expectations to wake up and go to school. These confrontations triggered him to be physically aggressive with his father and threaten his father with a knife as well as to harm himself. Instead of engaging with his personal and academic responsibilities, Kevin was engrossed with online gaming, often playing throughout the night. If his gaming was restricted, it often led to threats, blowups, and property damage. Kevin had attended a therapeutic boarding school and had returned home for 6 months before his parents reached their threshold and sought more intensive treatment. His parents expressed some dissatisfaction with the previous therapeutic boarding school as "they didn't seem to push him hard enough" and encouraged the wilderness therapy program to challenge him more consistently to "break the pattern of avoidance of almost everything."

Early in treatment, it was thought that a precipitating event for Kevin's decompensation following his previous treatment was his parents' divorce. Kevin described feeling like being in treatment was the cause of his parents' separation. He said that the divorce was a traumatic and upsetting event for him. Early in his wilderness experience, the therapeutic process explored the divorce as trauma or loss, and how it contributed to his struggle to meet daily expectations. At that time, Kevin had undergone psychological testing and was diagnosed with ADHD, ODD, and Major Depressive Disorder. While being evaluated, it was noted that Kevin demonstrated at least a superficial sense of social skills, reciprocity in social communication, at least when it was a topic of interest, ruling out ASD. His parents described him as having an active fantasy life growing up, playing with imaginary friends, and enjoying adventure stories with wizards and witches. Kevin had a strong attachment to the Harry Potter and Percy Jackson series. As a child he was described as stubborn and preferred to be alone unless his peers played games in the way he wanted. His parents described him as "controlling" of his friends while growing up. This pattern of behavior also seemed to lead to a loss of various friends over the years. Once Kevin discovered online gaming, his social engagement changed dramatically. He rarely engaged with people in real life except when at school.

Upon arriving at the wilderness therapy program, he reluctantly greeted his field guides and was outfitted with his gear. He appeared notably unhappy and nervous but was cooperative upon admission into the program. However, on Kevin's second day, he refused to get up, spending much of the day in his sleeping bag, and even though there was a great meal that day due to a holiday, he appeared uninterested in attending the celebration.

Initially, the therapist and field guides followed through with the parents' requests and challenged Kevin to meet daily expectations by being firm and sharing clear expectations. It quickly became clear that was not an effective way to interact with Kevin. In fact, it seemed to push Kevin further away, as he withdrew from his guides and other students. He appeared agitated and retreated, though he did not display aggression with anyone in the program.

This pattern largely ensued for many weeks, where Kevin refused to participate in most aspects of the program. For example, soon after joining the group, Kevin spent the first 12 days in the same campsite, often refusing to get out of bed, staying in his sleeping bag most of the day, not eating or drinking adequately, and missing or refusing his medications. At times, it seemed as though the demands of the day and the group reduced in size, Kevin would come out of his sleeping bag and attempt to connect, albeit minimally. Other times, Kevin found something that the field guides or students said upsetting, off-putting, or demanding, and as a result, he returned to his sleeping bag.

One of the turning points in his engagement during the first month of the program seemed to coincide with spending time with an especially kind, caring, and patient field guide. This field guide seemed to connect well with Kevin and encouraged him to hike two times during that week. The field guide took time with Kevin to listen and foster a relationship while also learning about Kevin's interests. The field guide attempted to make the experience and expectations of the day more fun by engaging in fantasy and banter. This was seen as a significant success, and other field guides made future attempts to mirror this approach. For several weeks the group was able to hike as often as three times a week. Kevin began to complete more therapeutic assignments and treatment goals, fulfilled many of his daily expectations, and overall demonstrated more effort. It seemed like he had turned the proverbial corner. As he showed more focus and engagement, more was expected of him. However, this increased effort was not sustained, and his pattern of withdrawal and avoidance returned. Staff wondered if the encouraging approach became less effective, or if the increased demands placed on Kevin led him to revert to old patterns of avoidance.

Over the next few weeks, the progress seemed to disappear as Kevin returned to 'digging in his heels' and resisting meeting daily program expectations, including not meeting his own basic needs like eating or drinking. It seemed that as pressure increased and more was expected of him, Kevin withdrew. Regularly, when guides, other students, and his therapist attempted to engage with him and encourage him to do his part, he would share, "I can't." Due to the significant interference his behavior had on the rest of the group, the therapist designed an intervention where Kevin worked with two dedicated staff, essentially creating a group of one. This intervention was used as an opportunity for him to practice the daily skills without the pressure of the group and general program structure.

While on this individualized intervention, an especially engaging and gregarious field guide stepped in as the lead guide for the week. Over the course of the week, Kevin and his assigned field guides hiked 22 miles, which was more than he had hiked in the previous six weeks that he had been in the program. During this hike he shared many stories and events of personal shame. Kevin shared that he wanted to do well academically but could not get himself to go because he felt overwhelmed much of the time. He expressed feeling guilty and ashamed about his trouble, and when his father [or others] pressured him, it made it worse. Kevin expressed that it felt like he was cornered and didn't know how to cope.

As the individualized intervention came to a close, he returned to the group. It was immediately clear that Kevin had more skills in managing daily expectations and was more invested in his therapeutic process. However, it soon became clear that a level of 'stuckness' was still present with Kevin, as his resistance continued to present intermittently for what seemed like no apparent reason. He struggled to make strong connections to the group, and he seemed to avoid or appear agitated with field guides that were direct, loud and demanding.

During his last month in the program, it was discovered that the most successful way of approaching Kevin was to involve him in a system that utilized incentives that he was personally interested in. Prior to this, a variety of arbitrary rewards and consequences were attempted, and most seemed ineffectual in helping him shift his behavior. In many ways, the relationship we had developed with Kevin allowed us to take some steps with him. As the therapist brainstormed this incentive idea with him, it was initially presented as something the therapist was not attached to, and also did not think would work. Kevin had shared that he enjoyed playing Dungeons and Dragons (D & D), a role-playing game, and wanted to play it while in the wilderness. As they discussed this opportunity, the therapist shared that he could earn some character sheets or printouts from the different D & D books or other things that interested him. They discussed that Kevin did not want to do a 'token economy' intervention as he already tried that at a previous program. However, they discussed that it would be different, only focusing on positive behaviors. This allowed Kevin to focus on prosocial behaviors and successfully complete Activities of Daily Living

(ADLs). He expressed reluctance but was willing to try this because he was excited about playing D & D with the other students and field guides.

This weekly incentive system was a collaborative effort with Kevin and often followed a discussion-oriented to, ‘What do you want to earn this week?’ The goals and point system were within reach because he designed the point system himself. Initially, he wanted to earn a drawing pad, then a comic book. Over time he earned additional personal items, including D & D character sheets, sections of the D & D player’s handbook, and finally, some dice. Each week he became more eager to discuss things he wanted to earn than the previous week. The discussion of earning rewards dominated the early part of therapy sessions. Kevin identified which behaviors were worth various amounts of points, often at a rate lower than what the guides and his therapist would have expected. Each week he added behaviors that he thought were relevant to his overall growth areas.

Kevin tracked his points each day over the coming weeks. Having him earn points for positive behaviors only took away the temptation to ‘give up’ after getting stuck with one part of the day, which helped him recover from a ‘bad morning’ or a ‘bad day’. Nonetheless, he continued to struggle with typical daily responsibilities, including cleaning his cup, helping with chores, and hiking. At times, it was important to negotiate a way forward as not to fully withdraw or selectively pick the expectation or activity for which he would engage. Kevin often seemed to do better with positive support and when distracted by talking about things he enjoyed (i.e., D & D, video games, and favorite books and movies).

Previous attempts at rewards or reinforcements seemed ineffective because frequently, by the second day, Kevin would give up, which looked like not getting up for the day or hiking with the group. Ongoing points for positive choices or behaviors, rather than removing points for not completing a task, seemed to provide a reason to care about the next part of the day, as he could still earn points even when periods of regression or resistance occurred. At the end of each week, Kevin would proudly list the number of points he had earned, and for the last four weeks he was in the wilderness program, he set record after record for his efforts.

As noted above, the idea was to empower Kevin to want to do things, push through his anxiety, or practice ways of managing it more effectively, so he could join in more of the daily expectations and group activities. Focusing on the positive seemed helpful for him, especially when it appeared to be his idea. As it became clear that he typically resisted increasing demands and expectations, the therapist and field guides approached this part of him differently and began working on anxiety management and helping him regulate and work on acceptance of stress while changing his thoughts about various tasks.

While Kevin was not a typical wilderness therapy participant in many ways, more of these students are presenting for treatment for the same reasons. Being creative and finding ways to connect seemed to help him complete the program on an upswing and with significant pride and hopefulness. Kevin still had days when he avoided, withdrew, and shut down, sometimes having difficulty articulating the trouble he was having, and yet he engaged more fully in the program more consistently.

Conclusion

The diagnosis of pathological demand avoidance (Newson et al., 2003), a proposed subtype of autism spectrum disorder, has been observed and discussed for four decades. While it is still not recognized as a disorder in the DSM 5 or the ICD 11 (American Psychiatric Association, 2013; World Health Organization, 2019), we have begun to experience it and see it in OBH programs. It is vital that professionals at OBH and residential therapy programs become aware of this symptom presentation and not just see PDA as a behavioral or personality-based issue. Accurate diagnosis and understanding are critical to design an effective treatment plan for clients with whom mental health and associated professionals work (Hoag et al., 2014). It is not helpful to over pathologize a person, believing a problem exists where it does not (Milton, 2013; Moore, 2020); while it is equally unhelpful to not address a problem which causes significant interference in multiple aspects of one’s life (American Psychiatric Association, 2013). A lack of understanding can lead to misdiagnosis, inappropriate treatments, and ultimately treatment failure.

Working with clients who have PDA, as described in the case example, requires significant effort, creativity, and flexibility on the part of the treatment professionals. In the absence of research regarding empirical treatments for PDA, the authors suggest utilizing therapies that target similar symptom presentations. Therapeutic interventions applied to individuals with pervasive developmental disorders and other mental health disorders are not going to ‘fix’ the problem, and improvements are often not consistently sustained. Training or retraining of the brain and its associated neurological systems takes time and repetition (Hoffman, 2012; Porges & Carter, 2017; Roemer & Osillo, 2020). The PDA Society (www.pdasociety.org.uk) provides many helpful resources, information, and ways of connecting with others who experience PDA and work with and treat clients with PDA.

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Disconnect to Reconnect: Adolescents with Digital Media Overuse in Outdoor Behavioral Healthcare

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Abstract

Digital media overuse is a growing concern in a world increasingly dependent on technology. Mental health professionals seek effective treatment modalities for adolescents believed to be struggling with this issue. The objective of this study is to understand if Outdoor Behavioral Healthcare (OBH) has a similar positive impact on Youth Outcome Questionnaire (YOQ) scores of both students with and without digital media overuse. The sample studied was composed of attendees of an OBH program over a four-year period who had completed the Youth Outcomes Questionnaire (YOQ) at intake and discharge ($n = 473$). Therapists identified students according to the presence of Digital Media Overuse (DMO) or not (non-DMO). Our analysis found that, on average, both groups studied showed clinically significant improvements and reported YOQ total scores near or below the clinical cutoff at discharge. Further, no statistically significant difference in YOQ outcome scores was found between the two groups; indicating that both DMO and non-DMO participants benefited from OBH treatment and did not differ significantly in the positive effect experienced. These findings suggest that OBH is effective in producing positive mental health functioning outcomes, as measured by the YOQ, for students who may have digital media overuse issues.

Keywords: Internet Addiction, Digital media overuse, Problematic Computer Use, Treatment, YOQ, Wilderness Therapy, Outdoor Behavioral Healthcare (OBH), Therapeutic Outcomes, Adolescents

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DISCONNECT TO RECONNECT

Beginning in the 1990s, increased attention and writing has focused on adolescent technology use and concerns about the consequences accompanying the benefits of the digital age. Undeniable benefits from the rise of the digital age have been paralleled by possible negative consequences to society, specifically to adolescents. According to Twenge and colleagues (2019), there has been a steady increase in adolescent digital media use from 1976-2016, with a reported 4-6 hours of average daily use, as of 2016. This includes time on the internet, gaming, texting, video viewing and visiting social media sites. This cultural shift and the ubiquity of mobile handheld devices creates concern about adverse effects on society, especially high usage individuals. Although there is no universal term used to describe the cascading problems identified with too much technology use, many suggested terms have been put forth in the literature. Internet Addiction was first proposed by Young (1998) and modeled after diagnostic criteria for Pathological Gambling. Since then, a variety of terms such as Problematic Internet Use (Spada, 2014), Internet Addiction (Young, 1998), Compulsive Internet Use (Greenfield, 1999), and Digital Overuse (Montag & Walla, 2016) have been used to describe a burgeoning modern phenomenon that is clinically relevant and deserving of increased attention. In this article, we will primarily use the umbrella term Digital Media Overuse (DMO) to encompass all types of excessive or compulsive behaviors associated with digital media use. Digital Media Overuse better represents a wide range of different digital activities involving all types of media and mass communication regarded collectively, not only on the internet.

Classifying a New Disorder

The American Psychiatric Association has included Internet Gaming Disorder (IGD) under the “Conditions for Further Study” section of the DSM-5 (American Psychiatric Association, 2013). Due to its similarities with substance related and addictive disorders, IGD is proposed to be included with Gambling Disorder as a non-substance related disorder. Although IGD is a tentative disorder not intended for clinical use, defining this phenomenon offers consistent language for clinicians and researchers, while also highlighting the need to clarify diagnostic criteria, prevalence, and treatment. A key component of IGD includes the persistent and recurrent use of video games leading to significant impairment or distress. While criteria for IGD are similar to the DSM-5 Substance Use Disorders, Substance Use Disorders require a minimum of only two of the eleven criteria to be considered a disorder while impairment or distress related to IGD requires a patient meet a minimum of five of the nine listed criteria within a 12-month period, making the threshold for IGD comparatively high. One large, international study of young adults indicated a prevalence of IGD in 0.3% to 1% of the sample and a potentially dysfunctional gaming prevalence of 2.4% (Przybylski et al., 2017). An earlier meta-analysis of pathological gaming indicated an overall prevalence of 3.1% (Ferguson et al., 2011). A large study of adolescents from primarily European countries found 1.6% of participants meet full criteria for IGD (Müller et al., 2014). The inclusion of IGD in the DSM-5 as a condition meriting further study establishes diagnostic criteria consistency and serves as a starting point to develop consensus on one type of digital media overuse.

In the latest edition of the International Classification of Diseases, 11th revision (ICD-11), the World Health Organization (WHO, 2018) included Gaming Disorder (GD) as a disorder due to addictive behaviors. To qualify for a diagnosis of GD, a person must display three symptoms including impaired control, increased priority to gaming that takes precedence over other interests or activities, and continuation or escalation of gaming despite negative consequences. Gaming must result in marked distress or significant impairment in important areas of functioning for at least 12 months. Criteria such as withdrawal and tolerance are not included in the definition of Gaming Disorder (World Health Organization, 2018). Since Young's (1998) initial formulation of Internet Addiction, most attempts at conceptualizing, understanding, assessing, and treating have been adapted from substance and behavioral addiction studies. The introduction of IGD and GD to two widely recognized professional sources has further validated the field of study and level of concern.

The APA (2013) and the WHO (2018) identify gaming as the single focus of IGD and GD; excluding excessive use or the inability to control use of other digital media technologies such as social media, texting, video viewing, shopping, and pornography. There is currently no widely recognized diagnosis to encompass multiple types of digital media overuse. In one recent meta-analysis, researchers identified 65 studies using varying definitions and measurements of digital media overuse (Dahl & Bergmark, 2020). Another study, which reviewed interventions for adolescents with internet addiction, included six studies, each using different diagnostic tools and criteria (Malinauskas & Malinauskiene, 2019). Dienlin and Johannes (2020) described digital technology use as an umbrella term and highlighted the complexity of the topic, the different forms, the functionality, and types of use, along with explaining the lack of consensus on a definition of overuse. Despite this lack of consensus on diagnostic criteria, there is wide agreement that adolescent digital media overuse is a problem. A definition of addiction put forth by Heather (2016) incorporates the most basic features of the concept:

> "a struggle in which one keeps having trouble quitting a repeated behavior, despite awareness of harmful consequences, and where repeated behavior is guided by disordered choice; positioned somewhere in between the voluntary and involuntary, coming both from inside the individual and as a reaction to external structures" (p. 426).

Elements frequently found in describing and understanding the problem of digital media overuse often include preoccupation, prioritizing, mood altering effects, trouble limiting use, negative consequences, compulsive use and deception, and tolerance and withdrawal. Many studies highlight the lack of a common definition and agree on the necessity of developing consensus on the definition of this developing issue.

Problematic Internet Use (PIU), Digital Media Overuse, and addiction are widely written about, yet prevalence rates of these issues vary greatly due to the lack of a common definition and methodology. Studies incorporate multiple different assessment tools and varying sample groups, which creates problems predicting and understanding the prevalence of digital media overuse in adolescents. In a review by Dahl and Bergmark (2020) which focused on prevalence and change over time, the authors concluded prevalence findings are scattered and should be interpreted and compared with caution due to the lack of consensus regarding methods and definitions. Mihara and Higuchi (2017) found prevalence rates to range from 0.7% to 27.5%. Other recent meta-analysis and reviews verify the prevalence of DMO as hard to assess, ranging from 1% to 26.8%, and dependent on age, culture, and geographic location (Dahl & Bergmark, 2020; Dienlin & Johannes, 2020; Pluhar et al., 2019; Sussman et al., 2018).

Alongside DMO, other co-occurring disorders such as autism, ADHD, depression, and substance use exist. The discussion surrounding causation or correlation of these co-occurring disorders is highly debated and overall unanswered. Some describe the relationship between DMO and comorbidities as a vicious cycle with no clear cause and effect order: digital media overuse exacerbates other issues in an individual’s life and life’s problems lead to increased digital media use to manage problems or escape them (King & Delfabbro, 2018a). In a meta-analysis and literature review, Dahl and Bergmark (2020) concluded that PIU tends to be associated with anxiety and depressive symptoms and other co-occurring disorders and social difficulties. While the correlation between PIU and associated co-occurring disorders seems to be well documented, the source of causation is unclear and may be best understood in terms of circular causality which focuses on the reciprocal relationship between two events. In a recent review, depressive disorders were the most frequent co-occurring disorders with internet and video game addiction. The prevalence of internet and video game addiction is higher in adolescents with comorbid impulsivity, ADHD, and autism spectrum disorders (Sussman et al., 2018). In a systematic literature review, Mihara and Higuchi (2017) concluded that co-occurring psychiatric disorders are common and act as both risk factors for and consequences of IGD. Similar to later studies, the researchers highlighted ADHD as a risk factor; while sleep problems, depression, social and school dysfunction may more likely be consequences.

OBH Model

Outdoor Behavioral Healthcare (OBH), previously referred to as wilderness therapy or adventure therapy, is often an alternate approach to traditional residential care used for adolescents with co-occurring mental health conditions. Programs vary in length and model and participants often have prior mental health treatment experiences (Bettmann et al., 2016). A key feature of OBH is “the prescriptive use of wilderness experiences by licensed mental health professionals to meet the therapeutic needs of clients” (Gass, 2014, p. 1). According to Gass (2014), the main components of OBH include:

- Extended backcountry travel and wilderness living experiences long enough to allow for clinical assessment, establishment of treatment goals, and a reasonable course of treatment not to exceed the productive impact of the experience.
- Active and direct use of clients’ participation and responsibility in their therapeutic process.
- Continual group living and regular formal group therapy sessions to foster teamwork and social interactions.
- Individual therapy sessions, often supported by the inclusion of family therapy.
- Adventure experiences utilized to appropriately enhance treatment by fostering the development of eustress (i.e., the positive use of stress) as a beneficial element in the therapeutic experience.
- The use of nature in reality as a metaphor within the therapeutic process.
- A strong ethical base of care and support throughout the therapeutic experience.

There is growing outcomes-based research demonstrating the effectiveness of OBH for adolescents. Recently, Gass et al. (2019) compared treatment as usual (TAU), no structured treatment (NST), and OBH for post-acute adolescents diagnosed with a substance use disorder and a comorbid diagnosis. TAU consisted of clinical recommendations to more traditional forms of outpatient care, intensive outpatient, and residential care. Students in OBH demonstrated more significant outcomes than TAU. Another study using a TAU comparison group strengthened findings, showing significantly better rates of change for adolescents completing an OBH program when compared to those in the TAU group. While both groups in this study demonstrated significant improvements from admission to discharge, treatment gains from one-year post treatment were three times larger in the OBH group (DeMille et al., 2018). In a meta-analysis by Bettman et al. (2016), researchers found medium-sized effects after participation in OBH programs in six areas: self-esteem, locus of control, behavioral considerations, personal effectiveness, clinical measures, and interpersonal measures. A slightly earlier study by Tucker and colleagues (2014), highlights OBH as effective for adolescents with a variety of presenting problems, complexities, and co-occurring diagnoses. These studies continue to support the evidence that OBH is a viable and effective option for adolescents experiencing a variety of co-occurring mental health and substance use concerns. Data consistently shows improvement for youth, reducing symptoms of distress and effectiveness to improve overall function.

Methods

Data Collection

The data used in this study was collected between January 1, 2017, and March 30, 2021, from a privately funded OBH program licensed by the Utah Department of Licensing and accredited by the Association for Experiential Education. The OBH program administers the Youth Outcomes Questionnaire (YOQ) to its clients upon intake and at discharge. This program also administers this instrument to parents of the clients at each of those instances, with parents being instructed to fill out the questionnaire reflecting on their child. The differences between the intake and discharge YOQ scores were compared for both the client self-report and the parent completed questionnaires.

In addition to the two mentioned self-report measures, all clients and parents are also asked to fill out the NATSAP questionnaire, which is used to collect client demographic data. Clients and parents are further asked to fill out forms consenting to the use of their data in research. The results reported in this paper comprise only the individuals who consented to the use of their data for research purposes.

At the completion of each client's stay, therapists complete a three-part discharge report, including a summary of the treatment, recommendations for future treatment, and a list of the clinical diagnoses along with their corresponding DSM code. The diagnosis data used in this report was collected manually from the discharge summaries of the participants. All participants had two or more listed diagnoses. The specific diagnoses listed on the discharge summaries were sorted into 10 diagnostic categories:

- Depression (including mood dysregulation disorder, adjustment disorder, bipolar disorder, and self-harm and suicidal behaviors).
- Anxiety (including OCD and eating disorders).
- Family Issues.
- Substance Abuse.
- ADHD (and other executive functioning deficits).
- ODD (conduct disorder, impulse control, disruptive behavior disorder).
- Learning Disorders (academic problems, developmental coordination, slow processing speed, and specific learning disorders).
- Trauma (developmental trauma disorder, trauma-related disorder, history of sexual abuse).
- Autism (autism, nonverbal learning deficits, neurodevelopmental disorder).
- Other (personality disorders, Tourette's disorder, and other neurodiversity, reactive attachment disorder, etc.).

Diagnosis data was collected for the entire sample of digital media overuse students enrolled from January 1, 2017, to March 30, 2021 (n = 75). Diagnosis data was also collected on a sample of students without digital media overuse issues with discharge dates between February 11, 2019, and September 24, 2020, (*n* = 199).

To determine digital media overuse, therapists reviewed their student list from 2017-2020. Therapists identified students with “digital media overuse” if that student’s interaction with technology prior to arriving to the program was preoccupying, excessive, interfered with functioning, hard to control, continued/increased despite negative consequences, and was a major contributing factor to their reason for being enrolled in the OBH program. These behaviors were reported by both parents and students. The two groups defined by this process will be referred to as digital media overuse (DMO) and non-digital media overuse (non-DMO) individuals.

Measures

The Youth Outcomes Questionnaire (YOQ) is a standardized clinical outcome instrument to measure treatment progress in youth populations receiving mental health intervention (Burlingame et al., 2019). The YOQ measures six factors that encompass the various issues adolescents struggle with (Ridge et al., 2009). These factors are: **intrapersonal distress (ID)**, which measures anxiety, depression, fearfulness, hopelessness and self-harm; **somatic (S)**, measuring physical and somatic distress a child or adolescent may be experiencing; **interpersonal relations (IR)**, relating to issues in a client's relationship with their family, adults and peers; **social problems (SP)**, assessing troublesome social behavior; **behavioral dysfunction (BD)**, relating to a client's ability to organize tasks, concentrate, handle frustration, etc. and; **critical items (CI)**, which describes issues which may need immediate inpatient services like suicidal thoughts or self-harming behaviors (Burlingame et al., 2019). The YOQ also provides a total score by aggregating each of the subscores. The range of total scores is 16 to 240. A higher score indicates a more severe condition. The YOQ provides a “clinical cutoff” to determine an individual’s need for a clinical intervention. A score below the clinical cut-off indicates an individual in the normative range, while a score above the cutoff indicates an individual in need of a clinical intervention. The cut-off score for parent reports is

46, while the cut-off score for student self-report is 47 (Burlingame, et al., 2005).

A change that is statistically significant is not always considered clinically significant. Clinical significance is a measure of whether a treatment has a real, genuine, palpable, and noticeable effect on someone's life (Jacobson & Truax, 1991; Kazdin, 1999). The reliable change index (RCI) is the criteria used to evaluate if a clinically significant change has occurred. The RCI for the YOQ Youth Self Report is a change of 18 points, while the RCI for the YOQ Parent Report is a change of 13 (Burlingame et al., 2019).

Sample

Participants completed an Outdoor Behavioral Healthcare program accredited by the Association of Experiential Education. The program utilizes traditional forms of therapy, such as Cognitive Behavioral Therapy and Dialectical Behavioral Therapy, while immersing students in a backcountry wilderness setting. Participants experienced an expedition backpacking model and received mental health treatment, substance abuse treatment, and general health care services. The average length of the program is 10 weeks (*M* = 76.72 days, *SD* = 16.62).

The data set used in this analysis consists of students enrolled in the OBH program between January 1, 2017, and March 30, 2021 (*n* = 473). Each individual case will have scores reported by the student (*n* = 411), and/or by one or more of the parents (*n* = 463). For example, an individual case could have no student reported data, but two separate entries from each parent. Only survey responses with paired data points at both day of admission (DOA) and day of discharge (DOD), as well as verified consent forms, were included in the data set.

Of the 473 individual cases in the dataset, 67 students (14.16%) were identified as having digital media overuse and 406 (85.84%) were not. The overall mean age of the participants was 15.72. The mean age of the students identified as not having an overuse issue was 15.78, while the mean age of DMO students was slightly lower at 15.44 years old.

From the samples of diagnosis data described above, the percentage of students who fell into each of the ten diagnostic categories was calculated and is shown in Table 1. Since all participants have more than one co-occurring diagnosis, the total percentage will add up to more than 100% for each of the two groups.

Table 1

Presence of Comorbidities

Diagnosis	**Non-DMO** ***n* = 167**	**Non-DMO** **%**	**DMO** ***n* = 81**	**DMO** **%**
ADHD	101	60.48	60	74.07
Anxiety	115	68.86	58	71.60
Autism	26	15.57	25	30.86
Depression	145	86.83	68	83.95
Family Issues	118	70.66	60	74.07
Learning	36	21.56	12	14.81
ODD	36	21.56	12	14.81
Substance Use	128	76.65	23	28.40
Trauma	35	20.96	9	11.11

Note. Table includes all participants surveyed in the time period specified, not just those with paired data points at admission and discharge.

Results

Paired t-test of Digital Media Overuse Outcome Scores

The average decrease in YOQ total scores for individuals deemed to have digital media overuse, when reported by both parents (*M* = -52.38, *SD* = 31.90) and students (*M* = -22.47, *SD* = 33.87), was found to be statistically significant; (parents: *t*(73) = 14.13, *p* < .001, and students: *t*(59) = 5.14, *p* < .001) as well as clinically significant because both the change means fall within the parameters of the Reliable Change Index. Cohen’s d was calculated to measure effect size. This test indicated a large effect size for parent DMO scores (*d* = 1.68, 95% *CI* [1.32, 2.05]) and a medium effect size for student scores (*d* = 0.75, 95% *CI* [0.42, 1.08]).

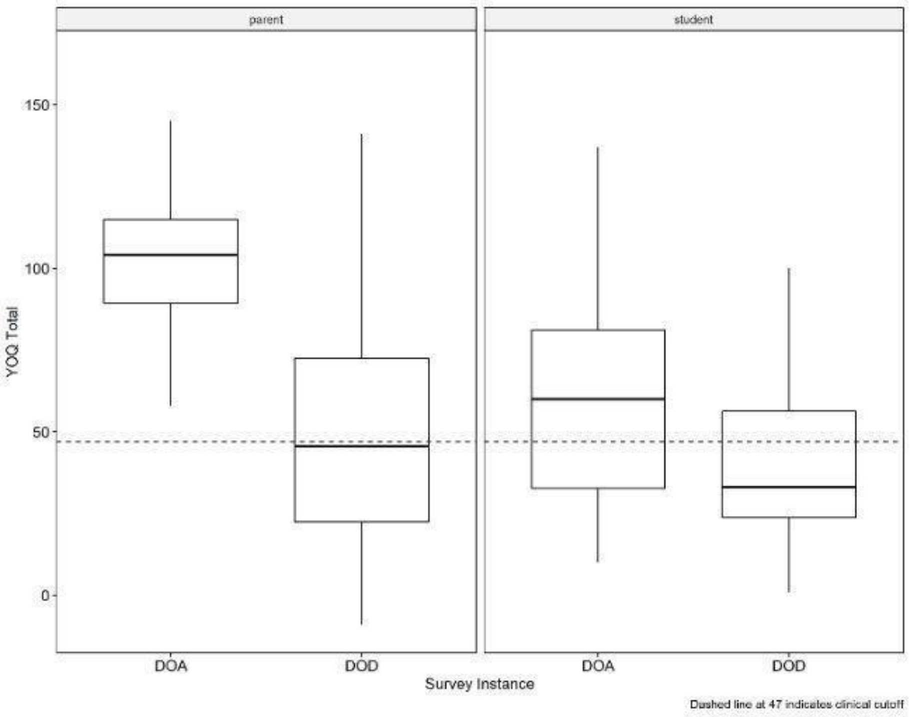
Figure 1 shows paired data of parent (*n* = 74) and student (*n* = 60) reported YOQ total scores of participants with digital media overuse issues at day of admission (DOA) and day of discharge (DOD). At the time of discharge, the mean total score for students was below the cutoff score of 47 (*M* = 39.08, *SD* = 25.31), but slightly above the cutoff for parents (*M* = 50.09, *SD* = 34.91). However, the median score for both groups was below the cutoff as indicated in Figure 1.

Paired t-test of non-Digital Media Overuse Outcome Scores

The average decrease in YOQ total scores for the individuals who were not deemed to have digital media overuse for both parents (*M* = -53.86, *SD*= 36.66) and students (*M* = -21.48, *SD* = 34.28) was found to be statistically significant; (parents: *t*(388) = 28.97, *p* < .001, and students: *t*(350) = 11.74, *p* < .001). Further, the mean decrease of both parents and students met the parameters of the Reliable Change Index indicating clinical significance as well Cohen's d indicated a large effect size for non-DMO parent scores (*d* = 1.77, 95% *CI* [1.57, 1.96]) and a medium effect size for student scores (*d* = 0.68, 95% *CI* [0.56, 0.81]). Figure 2 shows paired data of non-digital media overuse participants from both parent (*n* = 389) and student (*n* = 351) reported YOQ total scores at day of admission (DOA) and day of discharge (DOD).

Figure 1

Digital Media Overuse Outcomes, Parent and Student



Dashed line at 47 indicates clinical cutoff

Paired t-test of non-Digital Media Overuse Outcome Scores

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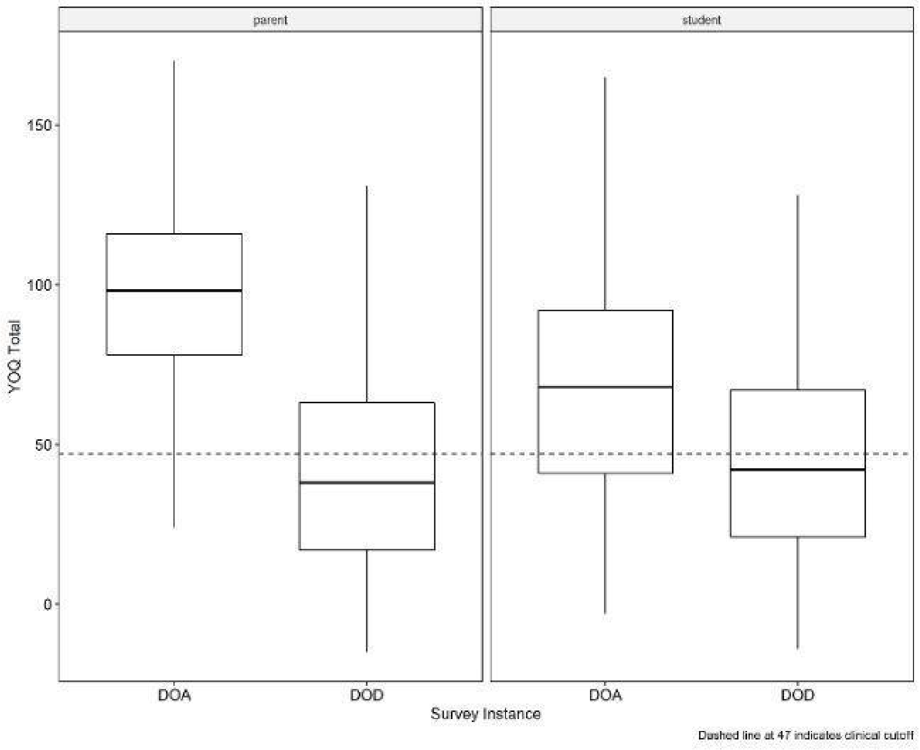
389) and student (*n* = 351) reported YOQ total scores at day of admission (DOA) and day of discharge (DOD).

Figure 2

Non-Digital Media Overuse Participant Outcomes

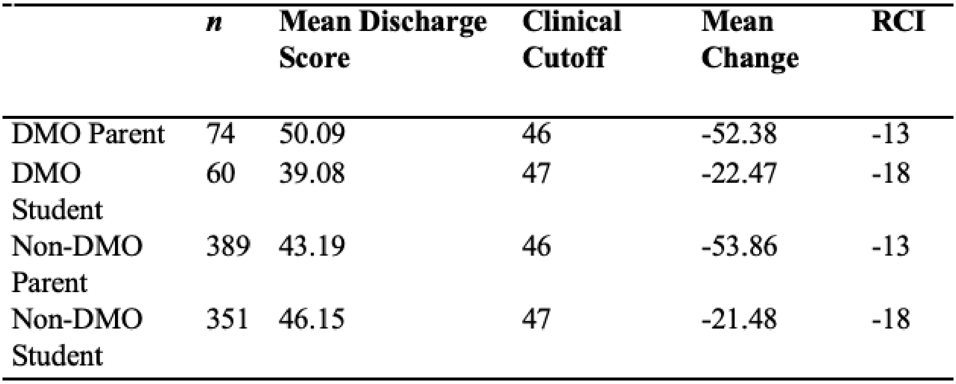


Dashed line at 47 indicates clinical cutoff

The change in mean scores for both parent and student reported scores of DMO and non-DMO individuals indicates that the Outdoor Behavioral Healthcare intervention on average benefits all groups of participants (Table 2). This significance holds true for both self-reported student scores, as well as parent scores reporting on their child. The only group that had a mean discharge score above the clinical cutoff was parents of DMO students (*M* = 50.09). While this group experienced significant improvement through the program (a mean change of -52.38 points), this result may partially be because this group entered with the highest YOQ total mean score of any group (*M* = 102.47, *SD* = 25.07).

Table 2

Outcome Scores and Comparisons for DMO and Non-DMO participants



	n	Mean Discharge Score	Clinical Cutoff	Mean Change	RCI
DMO Parent	74	50.09	46	-52.38	-13
DMO Student	60	39.08	47	-22.47	-18
Non-DMO Parent	389	43.19	46	-53.86	-13
Non-DMO Student	351	46.15	47	-21.48	-18

Table 3

Youth Y-OQ Self Report Total Score

Change Category	**Reliable Improvement**	**No Reliable Change**	**Deterioration**
Y-OQ-SR Change	**18 or more**	**1-17**	**0 and below**
	% (*n*)	% (*n*)	% (*n*)
DMO	53.33 (32)	25.00 (15)	21.67 (13)
Non-DMO	53.56 (188)	18.23 (64)	28.21 (99)

Table 4

Parent/Guardian Y-OQ Total Score

Change Category	**Reliable Improvement**	**No Reliable Change**	**Deterioration**
Y-OQ Change	**13 or more**	**1-12**	**0 and below**
	% (n)	% (n)	% (n)
DMO	82.43 (61)	10.81 (8)	6.76 (5)
Non-DMO	82.01 (319)	12.34 (48)	5.66 (22)

Independent t-test of DMO and non-DMO Student Reported Outcome Scores at Admission and Discharge

After running a series of Welch two sample t-tests, the difference between individuals with digital media overuse (parent n = 74, student n = 60) and individuals without digital media overuse (parent n = 389, student n = 351) was found to not be statistically significant at any of the following instances: parent scores at admission ($t(107) = -1.69$, $p = .094$), student scores at admission ($t(79) = 1.31$, $p = .193$), parent scores at discharge ($t(100) = -1.57$, $p = .120$), or student scores at discharge ($t(90) = 1.94$, $p = .056$). This indicates that the Outdoor Behavioral Healthcare intervention had the same impact, statistically, on both groups of students.

Further, to achieve a more in-depth understanding of how the two groups were affected by the treatment, reported scores were placed into groups determined by their pre-treatment/post-treatment change score: reliable improvement, no reliable change, and deterioration. Student Y-OQ-SR scores are recorded in Table 3, while parent Y-OQ scores are recorded in Table 4. A chi-squared test of independence showed there was not a significant association between the distribution of change scores and

DMO status for either student scores, X2 (2, *N* = 411) = 2.02, *p* = .36, or parent scores, X2 (2, *N* = 463) = 0.25, *p* > .88.

Presence of comorbidities

As shown in Table 1, some diagnoses occur in similar proportions in both groups (depression, anxiety, and family issues) while others are different. A chi-square test of independence showed that there was a significant association between diagnosis and DMO status, X2 (9, *N* = 248) = 28.39, *p* < .001. Notably, the presence of autism is almost twice as high in DMO students (30.86%) versus non DMO students (15.57%); ADHD is higher in DMO students (74.07%) versus non (60.48%); while substance abuse is much lower in DMO students (28.4%) versus non DMO students (76.65%). This finding is consistent with the existing body of research. Other research has found social problems and school problems to appear more frequently in DMO individuals (Dahl & Bergmark, 2020; Mihara & Higuchi, 2017; Sussman et al., 2018). Due to these issues not being specifically measured in the available dataset, comparison is not possible in this study.

Discussion

This study found that treatment in an OBH program resulted in a positive change in mental health functioning for both participants with digital media overuse, as well as those without. For both DMO and non-DMO participants, parents of enrolled individuals, as well as the individuals themselves, reported clinically and statistically significant improvements when measured from the day of admission to the day of discharge. The mean change scores of all groups exceeded the minimum requirements of the Reliable Change Index. The only group which did not meet the clinical cutoff at discharge were parents reporting on digital media overuse students, who reported a mean total score of 50.09. However, DMO parents reported a very similar and significant change score to non-DMO parents (DMO *M* = -52.38, non-DMO *M* = -53.86), indicating that the program had a similar level of relative effect despite the DMO parents rating their adolescent slightly more severe at admission.

The difference in outcome scores between the overuse individuals and the non-overuse individuals proved to not hold statistical significance at any of the time points tested. This finding indicates that the OBH intervention is effective at improving general mental health functioning in adolescents with digital media overuse and adolescents without digital media overuse. A participant's digital media overuse status does not result in a significant difference in them experiencing a positive impact change, as measured by the YOQ due to the intervention.

Similarities to Existing Treated Diagnoses

One possibility for this result could be because OBH has been shown to be helpful to diagnoses that often co-occur with DMO, including mood disorders, ADHD, and autism. Similarities between digital media overuse and substance use disorders may also contribute to the observed result. Outdoor Behavioral Healthcare has been found to be effective for students with substance abuse issues. According to the National Institute on Drug Abuse (2018) and the Substance Abuse and Mental Health Services Administration (2020), substance use and its co-occurring issues are complex and require holistic treatment approaches that target the overarching and interdependent origins of such behavior.

Behavioral addictions, including DMO, are similar to substance use in this way, given that the presence of co-occurring mental health conditions is overall a rule rather than an exception. There is also no panacea when it comes to intervention, modality, or treatment plans for these complex issues. Correspondingly, treatment plans for behavioral addiction are often modeled after those for substance use disorders (Sussman et al., 2018). In a recent review, researchers concluded that despite limitations and criticism of the field, internet and video game addictions are both clinically relevant and overwhelmingly similar to substance use disorders (Sussman et al., 2018).

In addition to its similarities with substance use disorders, some researchers argue that the addictive use of the internet is most similar to Pathological Gambling disorder (Young, 1998). In the DSM-5 (2013), Pathological Gambling was moved from an impulse-control disorder and is now categorized as an addictive disorder, under the diagnosis of Gambling Disorder (American Psychiatric Association, 2013). In a recent systematic review of Gambling Disorder findings from the National Epidemiological Survey of Alcohol and Related Conditions (NESARC), adult prevalence rates of 0.42% in the United States are reported with variability across some groups. Men have a slightly higher prevalence rate than women. Similar to substance use disorders, Gambling Disorder rarely exists independently without co-occurring problems and diagnoses (Loo et al., 2019). The findings from Loo et al. (2019) support a prior reported prevalence rate of 0.6% for Pathological Gambling. Variability was also found in the sub-groups studied, showing young men to have higher prevalence rates. Overall, when Pathological Gambling was detected, there was a consistent finding of mental health and substance use disorder diagnosis comorbidities present (Kessler et al., 2008).

Prevalence rates of Gambling Disorder are potentially comparable to current rates of digital media overuse. Those affected by Gambling Disorder follow treatment protocols that parallel substance use disorders. If Internet Gaming Disorder continues to be included as a non-substance behavioral addiction, like Gambling Disorder, digital media overuse is likely to be approached in the same way. As a relatively new field, DMO displays considerable overlap as a non-substance behavioral addiction. Therefore, when combined with the growing body of evidence supporting OBH as beneficial when treating substance use disorder (Gass et al., 2019), it is not surprising that the results of this study show that OBH is an effective treatment to improve mental health functioning of individuals struggling with digital media overuse or a behavioral addiction to internet or technology use.

Benefits of Treatment Outdoors

Another potential reason for the improved mental health functioning of DMO individuals seen in this study relates back to the vicious cycle described earlier: an individual’s overuse of digital media can have a negative impact on their mental health functioning, which in turn leads to increased overuse. Conversely, life problems or mental health issues can lead to increased digital media use. Engagement in an OBH program breaks this cycle by preventing all digital media use, except in therapeutically appropriate medical appointments or family therapy. Further, the experience of OBH students being disconnected from all digital devices may intrinsically foster a reconnection to oneself and to others (Gass et al., 2012). A period of abstinence or digital detox can support assessment and potentially be part of a larger, integrated intervention. A digital detox could also be useful as an intervention to interrupt unrestrained or poorly controlled digital media use. Abstinence or detox may reduce negative impacts caused or correlated with digital media overuse and interrupt the vicious cycle, thus allowing a student the opportunity to enhance insight, and learn and practice coping skills, while receiving therapeutic support.

In a review by Fernandez et al. (2020), researchers highlight the differences in short- and long-term abstinence and argue that short term abstinence does offer promise as an intervention for some problematic behaviors. The researchers stated a cautiously optimistic conclusion of the potential positive effects of short-term abstinence as a specific or integrated intervention for behavioral addictions with the strongest evidence being found when applied to mobile phone, social media, gaming, and pornography use. Increasingly, controlled use rather than long term abstinence, is becoming the dominant recommendation in the field of behavioral addiction (Fernandez et al., 2020). Similar to other behavioral addictions, digital media overuse and long-term abstinence is likely unrealistic for most, and arguably not possible, in a world increasingly reliant on technology, especially with the identifiable benefits to health and day-to-day living of digital media use. The impact of intentional, short-term abstinence from behavioral addictions is largely underrepresented in the literature when compared to substance related addiction and abstinence.

Limitations

There are several limitations to this exploratory study. Many limitations mirror criticism already present in the field. These criticisms include a lack of consensus in the definition, assessment, and etiology of digital media overuse as a diagnosis and consequently a difficulty in consistently identifying its prevalence in adolescent participants across research studies. In order for research in this field to develop, consensus must be reached regarding the above-mentioned items. This study is further limited by the subjective, post hoc method used to identify DMO students. Although the level of involvement each therapist has with their clients increases the likelihood of this being a useful assessment, it is not an unbiased or standardized rating of digital media overuse. A significant limitation to this approach was that it was not possible to measure the severity of DMO in the sample studied. This left the researchers with the useful, but limited, binary definition of DMO being either present or not present. It would be useful to administer a standardized measurement tool, such as the Internet Addiction Test (IAT), to unbiasedly assess which individuals suffer from digital media overuse, as well as differentiate between the different types of problematic technology usage. The authors suggest OBH programs begin to collect data from a measurement tool such as the IAT. This will be valuable information to have as adolescent digital media overuse is likely to increase. Although this limitation is significant, it does not invalidate the findings of this study.

In addition, this study used data from only a single OBH program and is not representative of the entire field of OBH, nor is it a representative sample of adolescents. More broad reaching studies will only be possible if OBH programs begin to use standardized measurement tools to collect data on presence and severity of digital media overuse issues within the population they work with. Also, this study only tracked data from admission to discharge. A longitudinal study that accounted for data points at six months and one year post discharge would offer insights into whether the impact measured was sustained. Longitudinal data would be particularly important to verify parent YOQ scores. A significant limitation with only utilizing admission and discharge data is when parents fill out the discharge YOQ, they have likely only had minor interactions with their child and have not yet experienced the child settling into their home or next setting.

The diagnosis data reported in Table 1 did not include the entire available data set of non-DMO students. This diagnosis data was time intensive to collect because it required manually reviewing each student’s discharge summary. The researchers were only able to gather diagnosis data for 167 of the entire 473 individuals in this manner. Although diagnosis data is also collected on the NATSAP staff questionnaire at intake, this survey only collects information on primary and secondary “reasons for referral”. The authors chose to not use this data source for three reasons. First, the “reasons for referral” do not necessarily reflect actual diagnoses assessed by trained mental health professionals. Second, this survey only collects information upon a student’s arrival in the program and frequently does not show a true representation of their diagnostic profile after assessment. And finally, only two diagnoses are collected while some students have up to 10 diagnoses reported on their discharge summary. Using diagnosis data from the NATSAP questionnaire would significantly limit and alter understanding of the interplay of comorbidities.

Further, the assessment of mental health functioning used, the YOQ is dependent on self-report of the participants. Self-report is limited by individuals reporting a biased view of their own experiences. Evidence for this can be seen in the difference between the scores reported by students of their own experience and by parents of their child’s experience. One way the data from the YOQ survey cuts down on this bias is by collecting data from the parents as well as the students. The combination of these two scores can hopefully provide a more accurate depiction of outcome scores for these participants despite the aforementioned limitation on parents' YOQ discharge scores.

Conclusion

As technology becomes an increasingly integral aspect of society, concerns about the impact it may have on people's well-being follows. This may be particularly true for adolescents and adolescent development. In order to respond to this burgeoning trend, the field of adolescent mental health care must work to establish a consensus on the definition and understanding of digital media overuse. Additionally, it is important to identify potential treatment options for adolescents that develop issues related to technology and digital media overuse. The results of this exploratory study show adolescent boys with DMO experience a similar level of improvement in the mental health items measured by the YOQ as adolescent boys without DMO after participating in an Outdoor Behavioral Healthcare program. Further information is needed to understand if the positive impact measured is sustained by the client after discharge, as well as if OBH directly impacts the specific issues associated with digital media overuse.

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The Importance of Parent Engagement in Outdoor Behavioral Health Programs for Youth

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Abstract

The benefits of parent engagement are well established for youth outpatient treatment, but little is understood about parent engagement in more intensive treatment settings. In this study, relationships between parent engagement, family functioning, and global health of youths attending outdoor behavioral therapy programs were examined. The findings indicated that improvements in family functioning mediated the relationship between youth outcomes and two types of parent engagement activities: homework assignments and number of parent visits.

Keywords: Youth treatment, wilderness therapy, parent engagement, youth treatment outcomes

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THE IMPORTANCE OF PARENT ENGAGEMENT

It is imperative to optimize the effectiveness of therapy for youths in treatment for mental health, behavior, and relationship issues. The involvement of parents is known to benefit youths in outpatient therapy (Filges et al., 2018; van der Stouwe et al., 2014) and thus the uptake of parent involvement should naturally extend to more intensive approaches, yet information in this area is lacking. The purpose of this study is to advance knowledge about parent engagement with their youth's outdoor behavioral (OBH) therapy experience.

Parent Treatment Engagement

Treatment engagement may be defined attitudinally (i.e., belief that therapy will work) or behaviorally, involving treatment seeking and attendance, communication, and active and meaningful presence and effort (Staudt, 2007). Active and meaningful engagement is ideal; simple attendance and beliefs in treatment effectiveness may not optimize outcomes (Clarke et al., 2015; Mauro et al., 2017). Active and meaningful engagement of parents in therapy for their child is called Parent Participation Engagement (PPE; Haine-Schlagel & Walsh, 2015) and is the focus of this article.

Quality PPE is a dynamic and fluctuating treatment process (Kim et al., 2012) that includes contact with the care team, attendance at family sessions, participation in treatment planning, attending to therapist recommendations, homework compliance, and connection with other supports (Fawley-King et al., 2013). PPE also spans emotional involvement, integrating therapeutic learning into daily living (Staudt, 2007), and a healthy and open alliance between parents and therapists in terms of trust, agreement, and effort (Mauro et al., 2017). These parent-oriented efforts combined with intrinsic motivation are thought to foster a healthy foundation for sustained post-therapy problem-solving, family functioning, and skills to support youth's healthy development. Indeed, Haine-Schlagel and Walsh (2015) examined 24 studies and found that the intensity of PPE was associated with symptom reduction and improved functioning for youths who attended outpatient care. When parent engagement is fundamental to the treatment protocol, then, optimal youth outcomes should be expected.

Family-oriented treatments typically take an ecological approach to therapy by working on issues central to individual clients as well as the family and community systems in which they live. This approach is known to benefit youths and their families who attend outpatient treatment. Indeed, simply contacting and engaging family members can increase youth engagement (Kim et al., 2012) and retention (Hendriks et al., 2011) in home-based and community treatment settings. Tanner-Smith et al. (2013) conducted a meta-analysis of 45 outpatient studies and found that family therapy was more effective at reducing youth substance use than other approaches.

Multidimensional Family Therapy and Multisystemic Therapy address youth health and behavior in the context of, and including, the family and community systems in which they are embedded. Several reviews have found these eco-systemic approaches more effective than interventions that focus solely on the youth across domains of client retention (Rigter et al., 2013), therapeutic alliance (Hogue et al., 2006), criminality (van der Pol et al., 2018), externalizing behavior (Schaub et al., 2014; van der Pol, 2017), internalizing symptoms (Schaub et al., 2014), substance use, psychiatric symptoms, family functioning (Henderson et al., 2010; Hendriks et al., 2011; Schaub et al., 2014), delinquency, substance use, psychopathology, and peer relationships (Baldwin et al., 2012). Given the success of these eco-systemic approaches for outpatient approaches, it is important to expand our understanding of system-based work in more intensive treatment settings.

There is insufficient research exploring the impact of parent engagement in out-of-home treatment. So far, there is some information indicating that clients and families *feel* that parent engagement is important: two studies found that youths, parents, and staff reported that parent engagement was a key benefit to residential treatment (Coates, 2016; Gogel et al., 2011). Parent engagement is also key to treatment process and retention; Sunseri (2001) found that frequency of home visits predicted youth residential treatment completion. Another study at a Canadian combined wilderness and residential treatment center found that the degree of clinician-rated PPE predicted treatment progression and completion (Uliaszek et al., 2019). In terms of outcomes, one study found that frequency of family contact predicted improvements on mental health and behavior for youths who attended residential treatment in Florida (Robst et al., 2013). Hair (2005) reviewed studies on out-of-home care and found that family engagement with youth in residential care was associated with sustained treatment gains but the author noted methodological concerns and limited available research. Further, all literature relating PPE to youth out-of-home treatment outcomes focus predominantly on residential approaches; no literature was found specific to wilderness or OBH treatment. Clearly, the literature on parent engagement in OBH treatment has yet to convert anecdote into evaluation-informed best-practice. This study will help to build a knowledge base about PPE in relation to OBH treatment.

Family Functioning Impact on Therapy Process and Outcomes for Youth

Little is understood about the explanatory pathway that explains the relationship between parent engagement and youth outcomes. One possible pathway is that PPE impacts general family functioning, and that improved family functioning acts as a catalyst for youth improvement. Family functioning can be understood as the capacity to work together, resolve conflicts, communicate openly and honestly, and respect each member’s roles and boundaries (Olsen, 2000). Several studies examine the direct relationship between family functioning and youth residential treatment processes and outcomes. For example, two large-scale studies found that baseline family functioning predicted program completion among youths in residential treatment (Sunseri, 2004; Sunseri, 2020). In a review of 98 studies of predictors and moderators of youth anxiety, baseline family functioning consistently predicted youth outpatient treatment outcomes (Compton et al., 2014). Youth continued care has also been related to baseline family functioning; youths with higher baseline family functioning experienced more profound health improvements and required less intensive aftercare (Sunseri, 2001). Sunseri (2020) also found that improvements in family functioning predicted successful discharge, particularly among families who entered residential treatment with low functioning families.

Sunseri's (2020) findings of family functioning as a predictor for change in mental health and behavior is compelling. Sunseri notes that the reasons for family functioning improvements were unknown but presumed to be related to intervention during the child's course of therapy. To build on Sunseri's supposition and expand knowledge about parent engagement with youth OBH treatment, the research question addressed in this study was: '*does parent engagement predict youth OBH treatment outcomes, and is this relationship mediated by changes in family functioning?'*.

Method

Participants

Eighteen OBH therapy programs were members of the National Association of Therapeutic Schools and Programs Practice Research Network. Members of this Network administered research and evaluation surveys to clients, caregivers, and staff before, during, and after treatment, and electronically submitted data to a central database managed by the University of New Hampshire (UNH). For this study, UNH provided data that were anonymized at client and program levels. With data anonymized at the program level, the spectrum and variety of treatment frameworks, therapeutic underpinnings, program-specific length of stay, location, and other program elements could not be defined. A general description of OBH therapy is an intervention where clients are immersed in nature for extended periods while mental health professionals facilitate travel and experiential adventure. Clients engage in individual and group work that focus on self-reflection, responsibility, coping mechanisms, interpersonal communication, physical and mental challenges, identity development, and hard skill development (Gass et al., 2019). Only clients who consented (if 16 or over), or who assented with an associated parent consent, to contribute to research were included.

The sample was drawn from a sample 3,660 youth participants whose programs collected and contributed data to the network between 2017 and 2021. Of these, 1,385 had complete data on all relevant variables. Schuirmann's Test of Equivalence (Schuirmann, 1987) was used to examine whether the participants were a biased subset of the total sample. Using a conservative (0.25-*SD* and α =.05) criterion, the results indicated that at the time of admission the sample group and the non-sample group were equivalent on age, youth global health, and family functioning.

Youths in the sample were an average of 16 (*SD = 1*.3) at admission, 67% were male, and 17% were adopted. Youths were generally affluent, with 54% coming from homes with family income over $200,000 per year and only 17% with income less than $100,000. At intake, staff identified clients' two primary reasons for referral and indicated high prevalence of depression (42%), anxiety (39%), and substance use disorder (29%).

Measures

Surveys were administered within seven days of admission and seven days of discharge.

Clinician-Rated PPE

The three elements of behavioral PPE are Global (attendance), Specific Therapeutic Interactions (engagement and contribution), and Homework (Haine-Schlagel & Walsh, 2015; Staudt, 2007). Our indicators of PPE were clinician-rated Global PPE and Homework. Specifically, program staff (i.e., mental health professionals providing direct services to the client) reported on PPE and homework on Discharge Summary surveys at the time of client discharge. PPE and homework related questions from the Summary were:

1. How frequent were your therapeutic contacts with the parents? *less than once per month* (1), *monthly* (2), *twice per month* (3), *weekly* (4), *twice weekly* (5), and *three or more times per week* (6).

2. How much time on average did you spend on family therapy per contact? *none* (0), *30 minutes* (1), *1 hour* (2), *1.5 hours* (3), *2 hours* (4), and *more than 2 hours* (5).

3. How many assignments did you give to parents to complete outside of therapy? *none* (0), *1-2* (1), *3-5* (2), *6-9* (3), *10-14* (4), *15-20* (5), and *more than 20* (6).

4. How many times did the parents come to visit during treatment? (*numeric entry*).

5. On average, how long did the parents stay during each visit (hours)? (*numeric entry*).

6. While visiting, on average how many hours did the parents participate in therapy with their child? *none* (1) *1 hour* (2), *2 hours* (3), *3-4 hours* (4), *5-7 hours* (5), and *8 hours or more* (6).

This collection of questions did not form a 'factor' of PPE (unacceptable Cronbach's α; <.5) and so each was explored in independent mediation analyses.

Youth Outcomes Questionnaire Change Scores (Δ YOQ). The Youth Outcome Questionnaire Self-Report 2.0 (YOQ) is a 64-item Likert-type assessment of global client health, calculated from seven domains: depression and anxiety symptoms, somatic problems, interpersonal relations, social problems, behavioral dysfunction, and critical items such as paranoia and suicidal ideation. The YOQ is widely used and has well established reliability (0.96) and validity, along with benchmarks for clinically problematic functioning (scores 47 or higher) and for meaningful clinical change (change of 18 or more) (Ridge et al., 2009; Wells et al., 1999). Scores from admission were subtracted from discharge score for a change score: Δ YOQ.

Family Functioning Change Scores (Δ Y-FAD). The McMaster Family Assessment Device, General Functioning Scale, youth-report (Y-FAD) is a

12-item Likert-type assessment of family member's acceptance and agreeableness with each other. It is widely used and shows >0.70 reliability (Ryan et al., 2005) and good validity (Sperry, 2012). The North American 'healthy' family scores range from zero to two, with higher scores indicating higher dysfunction (Ryan et al., 2005). Individual Y-FAD mean scores at admission were subtracted from individual Y-FAD mean scores at discharge to determine an individual change score: Δ Y-FAD.

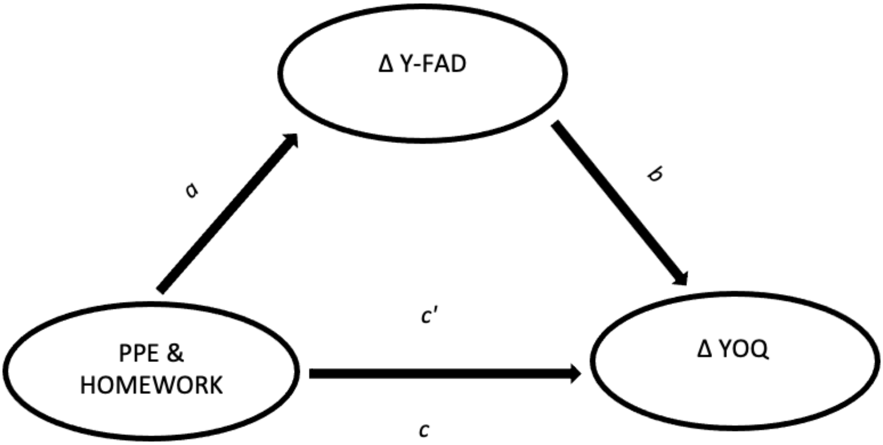
Analyses

Frequency and univariate ANOVA procedures were used to examine the landscape of PPE and homework and changes on youth health and family functioning. Baron and Kenney's (1986) procedure with Sobel's (1982) test was used in mediation analyses. The Baron and Kenney (1986) procedure aims to discover if a (moderator) variable explains the relationship between two other variables (i.e., the independent on outcome variables). In this study, the mediating variable (Δ Y-FAD) is expected to underlie the relationship between PPE / Homework and changes in youth health. The Baron and Kenny method is performed by first regressing the outcome variable on the independent variable (*c*). Then, the mediator is regressed on the independent variable (*a*). Finally, the outcome variable is regressed on the independent variable, controlling for the effect of the mediator (*c'*). The fundamental question in mediation is whether the strength of the initial direct relationship, *c*, is significantly reduced when the intervening variable is introduced. Sobel's (1982) test is used to determine whether any reduction between *c* and c' is statistically significant, using $\frac{(aa*bb)}{\sqrt{bb^2*ss_{aa}^2+aa^2*ss_{bb}^2}}$.

Figure 1 depicts the theoretical mediation model for this study. The research question suggests that the relationship, *c*, between parent participation and youth health outcomes will be reduced (*c'*) when the mediator (Δ Y-FAD) is introduced. In other words, changes in family functioning are proposed to underlie the relationship between PPE and youth health.

Figure 1.

Model of Δ Y-FAD Mediating Relationship Between Independent Variables and Δ YOQ



Results

PPE & Homework.

Most parents engaged in therapeutic contact with the clinician weekly for an hour. Parents typically visited the program once and stayed either the better part of a day or overnight and engaged in therapy with their child for two hours while visiting (Table 1). Parents were typically assigned between 3 and 14 assignments, with more assignments predictable by longer treatment duration ($F_{(1382)} = 19.204$, $p < .001$; $R^2 = 0.014$).

Changes on Youth Health & Family Functioning.

Youth global health improved from pre- to post-treatment. The mean pre-treatment YOQ score changed from 68.4 to 47.9, a significant improvement with large effect size ($F_{(1384)} = 491.93$, $p < .001$; $\eta^2 = 0.26$). Youth family functioning scores also improved significantly (with large effect) from 2.3 to 2.0 ($F_{(2,1384)} = 396.47$, $p < .001$; $\eta^2 = 0.22$).

Table 1.

Elements of OBH Parent Engagement (Clinician-Report)

	Response Options	Mean or Percent
Number of days in program		78.4 (25.3) Med = 78
Number of parent visits		1.1 (1.0) Med = 1
Duration of visit		17.8 (14.3) Med = 16
Time in Therapy with Child During Visit	None	7%
	1 hour	20%
	2 hours	26%
	3-4 hours	18%
	5-7 hours	12%
	8 or more hours	15%
Frequency of Contact with Clinician	Monthly	<1%
	Twice per month	<1%
	Weekly	85%
	Twice weekly	14%
	3+ Times Per Week	1%
Time per Contact with Clinician	None	0%
	30 min	2%
	1 hour	81%
	1.5 hours	14%
	2 hours or more	3%
Number of Assignments	No assignments	<1%
	1-2 assignments	4%
	3-5 assignments	30%
	6-9 assignments	14%
	10-14 assignments	28%
	15-20 assignments	19%
	20+ assignments	4%

Mediation Analysis.

The relationship between Δ Y-FAD and Δ YOQ, path *b,* was significant ($F_{(1383)} = 312.93$, $p < .001$, $\beta_{(unst)}=24.7$, $SE_{(unst)}=1.4$, $R^2 = .18$); the more FAD changed, the more YOQ changed. Specifically, for every unit improvement on FAD, estimate a 24.6 unit improvement on YOQ. These *b* path coefficients were the same across all mediation analyses.

Each of the PPE and Homework variables was examined in a separate mediation analysis. The unstandardized β and *SE* for each pathway is shown in Table 2, with the Sobel test statistic and its standard error.

Parent Visits.

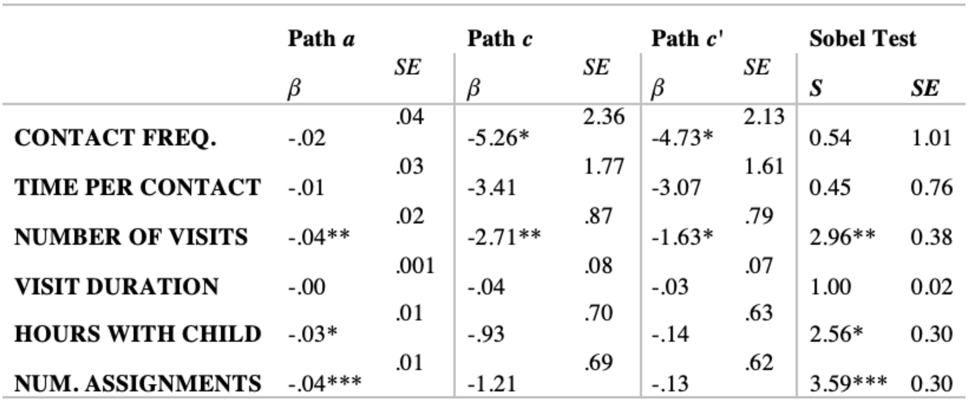
Typical mediation analyses seek significant paths *a, b, c,* and Sobel statistic. The model with Number of Parent Visits as the independent variable met these criteria, with a significant reduction in the β coefficient from *c* to *c'*. This finding indicates that the more parents visit the program, the more impact it will have on family functioning and changes in family functioning underlie the relationship between parent visits and youth outcomes.

Parent Assignments.

A significant direct path *c* is not a requirement to support a mediation model (see for example Hayes, 2009). As such, another finding of interest is the model including Number of Assignments as the independent variable. Here, path *c* was marginally significant ($p = .08$) and path *a, b,* and the Sobel statistic were strong. Thus, the relationship between the number of parent homework assignments and youth outcomes was mediated by Δ Y-FAD. In other words, the more homework assigned to parents, the more health improvement youths experienced, and this relationship is explained by improvements in family functioning.

Table 2.

Individual β and SE for Paths and Sobel Test in Mediation Analyses.



	Path *a*		**Path *c***		**Path *c*'**		**Sobel Test**	
	β	*SE*	*β*	*SE*	*β*	*SE*	***S***	***SE***
CONTACT FREQ.	-.02	.04	-5.26*	2.36	-4.73*	2.13	0.54	1.01
TIME PER CONTACT	-.01	.03	-3.41	1.77	-3.07	1.61	0.45	0.76
NUMBER OF VISITS	-.04**	.02	-2.71**	.87	-1.63*	.79	2.96**	0.38
VISIT DURATION	-.00	.001	-.04	.08	-.03	.07	1.00	0.02
HOURS WITH CHILD	-.03*	.01	-.93	.70	-.14	.63	2.56*	0.30
NUM. ASSIGNMENTS	-.04***	.01	-1.21	.69	-.13	.62	3.59***	0.30

*Notes: ***p < .001; **p < .01; *p < .05*

Discussion

The objectives of this project were to advance knowledge about parent engagement in youth OBH treatment and to determine whether improved family functioning was the mechanism by which parent engagement impacted youth health outcomes. The findings show that parent engagement, well known to benefit youth outpatient outcomes, also benefits the outcomes of youths in OBH settings. Specifically, the number of parent visits and the amount of homework assigned predicted youth health improvements, and these relationships were mediated by improvements in family functioning.

Mediation models were not significant for the other criterion variables: contact frequency, amount of time per contact, hours with child, and duration of visit. In terms of contact frequency, 85% of clinicians reported weekly contact and more frequent contact was related to better youth outcomes, but not to improved family functioning. The number of hours spent with the child during a parent visit had an impact on family functioning, but not on youth health changes. Neither the amount of time per contact nor the duration of parent visits were significantly related to the youth health or family functioning. These findings highlight the importance of myriad elements of parent engagement, via direct relationships, but are not criterion variables in the specified mediation model. Parent visits and assigned homework, however, were criterion variables that help to understand that changes in family functioning are the process by which improvements in youth health are related to parent engagement.

Sunseri (2001), Sunseri (2004), and Sunseri (2020) pioneered work that showcases the importance of family functioning for youth outcomes and our work helps to affirm his supposition that intentional parent-oriented intervention is a catalyst for improved family functioning and related youth health improvements. Our findings should encourage treatment providers to incorporate parent engagement activities as key elements of the treatment process.

Limitations

The concept of PPE as rated by clinicians in terms of assigned homework or parent visits has limitations. Notably, these activities are prescribed by the program and not a function of parent initiative or intrinsic motivation. Also, the amount of PPE reported by clinicians seems to indicate a ‘high’ parent engagement, especially given that the parents and child are not physically together during the bulk of therapy. With no established benchmarks for PPE, however, it is difficult to define or assume levels of engagement. More needs to be understood about how to measure PPE, who should assess PPE, and when it should be assessed. Openness to change is in the realm of Specific Therapeutic Interactions domains of parent engagement (Haine-Schlagel & Walsh, 2015) and warrants the development of valid and reliable tools to measure Interactive Engagement. Some work is being done in this area, specific to parent participation in community child mental health services (Haine-Schlagel et al., 2016) and in the education field, but these advances have yet to reach OBH settings.

Another limitation is that there are several characteristics of youths that would help understand the homogeneity or heterogeneity of the clients and may have contributed even more in-depth knowledge about the findings. For example, understanding whether the mediation model was moderated by client race would more profoundly advance knowledge. Many such demographic variables were not included in the data. Likewise, the differences from program to program would help deepen our understanding and foster targeted recommendations; however, the data de-identification process eliminated this line of inquiry.

Finally, the data analyzed included information from pre- to post-treatment and did not extend to post-discharge, which would assess sustained treatment gains and the relevant impact of parent engagement and family functioning. This should be an important consideration in future studies.

Conclusion

Our results suggest that engaging parents in their youth's OBH therapy by hosting parent visits and assigning homework fosters improvements on family functioning, which is a catalyst for youth mental health and behavioral improvement. Treatment providers are encouraged to strategically incorporate behavioral parent participatory engagement into their youth work and to continue to measure parent engagement and youth outcomes.

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Manuscript Topics

The *Journal of Therapeutic Schools and Programs* (JTSP) is published by the National Association of Therapeutic Schools and Programs and publishes articles that assist readers in providing comprehensive care for adolescents, young adults, and families receiving services from residential, wilderness/outdoor behavioral healthcare, and transition treatment programs. The editors welcome manuscripts that are the original work of the author(s), have been approved by an Institutional Review Board when data was collected, and follow APA style as presented in the seventh edition of the *Publication Manual of the American Psychological Association*. Manuscripts may include, but are not limited to, case studies, topical clinical articles, literature reviews, qualitative research and empirical research. Submissions are encouraged that relate relevant theory to clinical practice or provide original research relating to program or treatment effectiveness.

Submitting the Manuscript

Electronic submission is required at www.natsap.org. **Author/s must submit an abstract, keywords, and author bio/s along with the manuscript.** Authors are required to reveal any possible conflict of interest in the conduct and reporting of research (e.g., financial interests in a test procedure, funding provided by program) when their manuscript is submitted.

Manuscript Evaluation

Submitted manuscripts will initially be reviewed and evaluated by Dr. Ellen Behrens or a Guest Editor. After the initial evaluation, manuscripts will be sent to a Review Board who will forward their recommendations to Dr. Behrens or the Guest Editor. The JTSP management team reserves the right to edit or to require editing of content, format, or style, or to make other revisions before accepting a manuscript for publication. Dr. Behrens will make final decisions regarding publication status.

Manuscript Format

All manuscripts should be submitted in a form that allows blind refereeing (see *APA guidelines – 7th edition*). The author's name and any identifying information must be visible only on a detachable front page. Manuscripts will be retained by the JTSP Editorial Board and will not be returned to the author(s).

Manuscripts should be formatted to 8 1/2" x 11" paper as follows:

- Font to be used is "Times New Roman – Size 12"
- Italics and Underline are accepted
- Document must be in black text only
- 1-inch margins are required on all sides
- Double line spacing is required
- Pages are to be numbered in the top right-hand corner
- Submit manuscripts in the following order: 1) Title Page (de-identified), 2) Abstract (no more than 100 words) and keywords, 3) Text, 4) References, 5) Figures (Tables, Charts, Graphs).

Total manuscript length including abstract, tables, and references should ordinarily not exceed 20 pages. The entire manuscript including footnotes, references, and quoted material and figures/illustrations should conform to the style specified in *The Publication Manual of the American Psychological Association –7th Edition*.

Images depicting aspects of the contribution are strongly encouraged. Insertion notations for figures, tables, and images should be included in their preferred place within the document though the actual figures, tables, and images along with appropriate captions should be appended to the end of the submitted manuscript. Please attach original camera-ready art or jpeg/gif files for figures and images.

Use of Inclusive Language

Writing must be free from bias, stereotypes, colloquialism, reference to dominant culture and/or cultural assumptions. Consistent with APA Style, the journal requires the use of gender-neutral language, which can often be accomplished by using plural nouns (e.g., “clinicians, “students”, “clients"). Furthermore, when an individual’s pronouns are not known, the journal require the use of the singular ‘they”, “them”, “theirs”, which is also consistent with APA Style. These guidelines are meant as starting point but are by no means exhaustive.

Publication Ethics and Publication Malpractice Statement

It is necessary to agree upon standards of expected ethical behavior for all parties involved in the act of publishing: the author, the journal editors, the peer reviewers, and the publisher. Our ethic statements are based on COPE’s Best Practice Guidelines for Journal Editors.

Journal Management

The National Association of Therapeutic Schools and Programs (NATSAP) Board of Directors has engaged Ellen Behrens, Ph.D. for the editorial and managerial responsibilities for the *Journal of Therapeutic Schools and Programs* (JTSP).

Publication Decisions

The editor of the journal is responsible for deciding which of the articles submitted to the journal should be published. The editor may be guided by the policies of the journal’s editorial board and constrained by such legal requirements as shall then be in force regarding libel, copyright infringement, and plagiarism. The editor may confer with other editors or reviewers in making this decision.

Fair Play

An editor will at any time evaluate manuscripts for their intellectual content without regard to race, gender, sexual orientation, religious belief, ethnic origin, citizenship, or political philosophy of the authors.

Confidentiality

The editor and any editorial staff must not disclose any information about a submitted manuscript to anyone other than the corresponding author, reviewers, potential reviewers, other editorial advisers, and the publisher, as appropriate.

Disclosure and Conflicts of Interest

Unpublished materials disclosed in a submitted manuscript must not be used in an editor's own research without the express written consent of the author.

Use of Inclusive Language

Writing must be free from bias, stereotypes, colloquialism, reference to dominant culture and/or cultural assumptions. Consistent with APA Style, the journal requires the use of gender-neutral language, which can often be accomplished by using plural nouns (e.g., "clinicians, "students", "clients"). Furthermore, when an individual's pronouns are not known, the journal require the use of the singular 'they", "them", "theirs", which is also consistent with APA Style. These guidelines are meant as starting point but are by no means exhaustive.

Duties of Reviewers

Contribution to Editorial Decisions

Peer review assists the editor in making editorial decisions and through the editorial communications with the author may also assist the author in improving the paper.

Promptness

Any selected referee who feels unqualified to review the research reported in a manuscript or knows that its prompt review will be impossible should notify the editor and excuse themselves from the review process.

Confidentiality

Any manuscripts received for review must be treated as confidential documents. They must not be shown to or discussed with others except as authorized by the editor.

Standards of Objectivity

Reviews should be conducted objectively. Personal criticism of the author is inappropriate. Referees should express their views clearly with supporting arguments.

Acknowledgement of Sources

Reviewers should identify relevant published work that has not been cited by the authors. Any statement that an observation, derivation, or argument had been previously reported should be accompanied by the relevant citation. A reviewer should also call to the editor’s attention any substantial similarity or overlap between the manuscript under consideration and any other published paper of which they have personal knowledge.

Disclosure and Conflict of Interest

Privileged information or ideas obtained through peer review must be kept confidential and not used for personal advantage. Reviewers should not consider manuscripts in which they have conflicts of interest resulting from competitive, collaborative, or other relationships or connections with any of the authors, companies, or institutions connected to the papers.

Duties of Authors

Ethical Oversight

Authors are required to have full oversight and approval from a recognized Institutional Review Board (IRB) for any human subjects’ data collected as part of a research study, whether that study be qualitative or quantitative.

Reporting Standards

Authors of reports of original research should present an accurate account of the work performed as well as an objective discussion of its significance. Underlying data should be represented accurately in the paper. A paper should contain sufficient detail and references to permit others to replicate the work. Fraudulent or knowingly inaccurate statements constitute unethical behavior and are unacceptable.

Data Access and Retention

Authors may be asked to provide the raw data in connection with a paper for editorial review and should be prepared to provide public access to such data (consistent with the ALPSP-STM Statement on Data and Databases), if practicable, and should in any event be prepared to retain such data for a reasonable time after publication.

Originality and Plagiarism

The authors should ensure that they have written entirely original works, and if the authors have used the work and/or words of others that this has been appropriately cited or quoted.

Multiple, Redundant, or Concurrent Publication

An author should not in general publish manuscripts describing essentially the same research in more than one journal or primary publication. Submitting the same manuscript to more than one journal concurrently constitutes unethical publishing behavior and is unacceptable.

Acknowledgement of Sources

Proper acknowledgment of the work of others must always be given. Authors should cite publications that have been influential in determining the nature of the reported work.

Authorship of the Paper

Authorship should be limited to those who have made a significant contribution to the conception, design, execution, or interpretation of the reported study. All those who have made significant contributions should be listed as co-authors. Where there are others who have participated in certain substantive aspects of the research project, they should be acknowledged or listed as contributors. The corresponding author should ensure that all appropriate co-authors and no inappropriate co-authors are included on the paper, and that all co-authors have seen and approved the final version of the paper and have agreed to its submission for publication.

Disclosure and Conflicts of Interest

All authors should disclose in their manuscript any financial or other substantive conflict of interest that might be construed to influence the results or interpretation of their manuscript. All sources of financial support for the project should be disclosed.

Fundamental Errors in Published Works

When an author discovers a significant error or inaccuracy in their own published work, it is the author’s obligation to promptly notify the journal editor or publisher and cooperate with the editor to retract or correct the paper.

The National Association of Therapeutic Schools and Programs Ethical Principles

Members of the National Association of Therapeutic Schools and Programs (NATSAP) provide residential, therapeutic, and/or education services to children, adolescents, and young adults entrusted to them by parents and guardians. The common mission of NATSAP members is to promote the healthy growth, learning, motivation, and personal well-being of our program participants. The objective of all our therapeutic and educational programs is to provide excellent treatment for our program participants; treatment that is rooted in good-hearted concern for their well-being and growth; respect for them as human beings; and sensitivity to their individual needs and integrity.

When applying to become or continue as a member of The National Association of Therapeutic Schools and Programs, the program / school Executive signs the Ethical Principles stating that *our organization supports and follows the NATSAP Ethical Principles*.

1. Be conscious of, and responsive to, the dignity, welfare, and worth of our program participants.

2. Honestly and accurately represent ownership, competence, experience, and scope of activities related to our program, and to not exploit potential clients' fears and vulnerabilities.

3. Respect the privacy, confidentiality, and autonomy of program participants within the context of our facilities and programs.

4. Be aware and respectful of cultural, familial, and societal backgrounds of our program participants.

5. Avoid dual or multiple relationships that may impair professional judgment, increase the risk of harm to program participants, or lead to exploitation.

6. Take reasonable steps to ensure a safe environment that addresses the emotional, spiritual, educational, and physical needs of our program participants.

7. Aspire to maintain high standards of competence in our areas of expertise and to be mindful of our limitations.

8. Value continuous professional development, research, and scholarship.

9. Place primary emphasis on the welfare of our program participants in the development and implementation of our business practices.

10. Manage our finances to ensure that there are adequate resources to accomplish our mission.

11. Fully disclose to prospective candidates the nature of services, benefits, risks, and costs.

12. Provide informed, professional referrals when appropriate or if we are unable to continue service.
13. NATSAP members agree to not facilitate or practice reparative therapy.

National Association of
Therapeutic Schools and Programs
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