Asperger Syndrome in Adolescent Females
A Review of Assessment Approaches and Intervention Strategies for Educational Practitioners
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Abstract: Asperger Syndrome (AS) is a condition that involves impairment in social relationships, verbal and nonverbal communication (Barnhill, 2001). Individuals with AS experience restriction in social functioning, including a lack of flexibility in thought processes (Gustein & Whitney, 2002). The incidence of AS in child and adolescent populations is of growing concern to schools and community groups faced with the challenges of providing support for individuals diagnosed with AS (Safran, 2002). This paper provides a focus on issues related to adolescent females diagnosed with AS as a means of informing counsellors and other personnel working in educational settings of the current advances in AS research. Discussion includes the delineation of specific assessment approaches and intervention strategies aimed at providing support for adolescents with AS in order to highlight the significant lack of strategies that account for the specific needs of females with AS. Finally, this paper argues that there is a need to expand future directions in AS research in order to challenge existing practices in diagnosis and treatment for females with AS.

Keywords: Asperger Syndrome, Female Adolescents, Intervention Strategies, Assessment Approaches

Introduction

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000) the essential features of Asperger Syndrome (AS) include severe and sustained impairment in social interactions and the development of restrictive, repetitive patterns of behaviour, interests, and activities. There are no clinically significant delays in language or cognitive development for individuals diagnosed with AS.

For teachers and other school personnel working in educational settings, there are significant challenges associated with successfully integrating individuals with AS into regular school contexts (Little, 2003). Ideally, an individual diagnosed with AS is best suited to a small class group where a high degree of structure and individual attention is available. However, many individuals with AS are placed in large school contexts and have limited access to support personnel. As a result, such personnel may spend significant time and energy mediating, re-directing, and intervening in crises for the individual, allowing for limited engagement in supporting the individual in metacognitive learning and acquiring social skills.

For practitioners who are responsible for the care and oversight of female students with AS in secondary school contexts, questions of best practice are ever present. This paper examines the literature on diagnostic assessment, empirical research and suggested interventions for the condition identified as AS, and highlights the need for the development of alternative intervention approaches that are tailored to the specific needs of adolescent females in secondary school contexts diagnosed with AS.

Classification

In 1944, Hans Asperger described a group of 4 boys who had problems with social interaction, communication, and who displayed idiosyncratic patterns of interest. The previous year, Leo Kanner reported on a variant of childhood autism through his work with a group of children who had withdrawn into a psychotic world. Others reported similar cases either as schizoid personality disorders or with a profile consistent with a nonverbal learning disability (Freeman, Cohen, & Candella, 2002). Despite the foundational work of Asperger, Kanner, and other researchers examining autism, interest in AS was slow to develop. However, in the 1980s, research exploring AS began to escalate (Klin, Volkmar, & Sparrow, 2000). In the 1990’s discussion surrounding the identification of AS was facilitated with the American Psychiatric Association (APA) initiating trials for its consideration in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV, American Psychiatric Association, 1994). As a result of such trials AS was included as
one of the categories within the Pervasive Developmental Disorders (PDD) of the DSM-IV.

The essential criteria for AS include qualitative impairment in social relationships; impairment in verbal and nonverbal communication; a restricted range of interests or lack of flexibility in thought; and a lack of any clinically significant delays in language and cognitive development (Barnhill, 2001). However, the criteria continue to create a number of difficulties for diagnosticians. Some experts believe that AS and high-functioning autism are conditions at one end of an autistic spectrum with low-functioning autism at the other. Others hold the assertion that AS is one type of autism included in the classification of Pervasive Developmental Disorder (PDD) that is similar to autism, but should be classified differently (Little, 2002). Further, there are emerging issues surrounding the impact of distinctive gender differences on the classification process for females diagnosed with AS, in contrast to males (Attwood, 1999).

The ambiguities surrounding the classification of AS and the associated dilemmas of diagnosis calls for additional research into the disorder. Existing research projects often fail to differentiate between individuals diagnosed with autism, AS or other diagnoses along the autism spectrum and do not account for differences in diagnosis that are gender specific (Little, 2002; Little, 2003; Shriberg, Paul, McSweeny, & Klin, 2001; Fullerton & Coyne, 1999; Barnhill. Cook, Tebbenkamp, & Myles, 2002; Atwood, 1999).

The Asperger Syndrome Research Project (Griswold, Barnhill, Myles, Hagiwara & Simpson, 2000) attempted to validate the criteria of the diagnosis of AS, to provide a profile of children and youth with AS. Studies within this project investigated intellectual characteristics, academic characteristics (Griswold, Barnhill, Myles, Hagiwara, & Simpson, 2002; Myles, Hilgenfeld, Barnhill, & Griswold, 2002), social and emotional characteristics (Barnhill, 2001; Barnhill & Myles, 2001) and sensory characteristics. However, little attention was drawn to issues surrounding diagnosis and gender. Barnhill (2001) reported a brief overview of current studies focussing on AS. The profile presented by Barnhill (2001) for individuals with AS suggests children and youth with the disorder are generally found to have IQs similar to the general population; a significant differentiation between written and oral language skills; limited ability to problem solve (in contrast to their verbalisations); problems in inferential comprehension; pronounced emotional difficulties recognised by parents and teachers, but not acknowledged by the individual; attributions of a learned helplessness approach; and sensory problems similar to those who cognitively function at a much lower level.

Other research (Shriberg et al., 2001; Harpreet, Dutta & Sinha, 2002) has identified differences in individuals diagnosed with AS that do not fall within the criteria of the DSM-IV-TR (APA, 2000), but indicate there are some features that could impact upon the profiling and treatment of individuals with AS. These features include brain differences and speech patterns. While current investigations have generated findings that serve to increase knowledge relating to the classification of individuals with AS, such findings highlight the limited focus on the impact of gender on the classification process.

### Diagnosis

Although current research surrounding classification of AS is exploratory and inconclusive, there are also concerns within the fields of education and psychology about diagnostic practices. Freeman et al. (2002) outline suggested practices for the clinical diagnosis of AS. They emphasise the necessity for the results of assessment to be coordinated by trained and experienced evaluators who have knowledge of the full range of symptoms in both autistic disorders and AS. Freeman et al. (2002) also recommend that assessment of individuals with AS should indicate diagnosis, the organisation of specific services, measure efficacy of intervention, and provide prognostic information.

Freeman et al. (2002) suggest assessment is required in terms of intellect, communication, behavioural presentation, and functional adjustment and all areas must be evaluated in terms of developmental level. It is interesting to note that issues associated with gender are not formally identified within the assessment process. However, despite this oversight, Freeman et al. (2002) provide a useful framework for practitioners that involves the following:

- **Gathering historical information** by interviewing the primary caregiver, to establish initial concerns and early social communication skills;
- **Utilising rating scales** and questionnaires as screening measures designed to provide structured, systematic methods indicating further investigation. These cannot be used in isolation or as a substitute clinical assessment;
- **Administering medical assessment** to address treatable medical conditions. Such assessment should include medical history, physical examination including auditory and visual processing, neurological assessment, and laboratory studies;

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**Updated by:**

- **Griswold, Barnhill, Myles, Hagiwara & Simpson, 2000**
- **Freeman et al., 2002**
• Conducting psychological assessment that includes testing for cognitive ability (both verbal and non-verbal) and adaptive skills;

• Developing qualitative assessment of communication, including examination of echolalic or pedantic speech and tone, as well as the characteristics of communication such as initiating conversation, attempts at nonverbal communication, making inferences, understanding humour, disturbances in thought or content, or pursuing one topic regardless of the conversation;

• Facilitating occupational and physical therapy assessment to establish motor delays and hypo- or hypersensitivities to sensory stimuli;

• Coordinating family assessment integral to educational and community services;

• Initiating mental status assessment focussing on the individual’s behaviour with familiar and unfamiliar people that attend to the areas relevant for diagnosis and;

• Conducting assessment of social interactions, established through observation and questioning techniques. Once social interaction and communication skills have been assessed, it is necessary to assess whether or not the child has a restricted range of interests and displays unusual behaviours.

Other assessments could include the developmental level of play or leisure activities that appear lower than measured cognitive abilities; and comorbidity of other psychiatric diagnoses.

The prediction that many people with AS still go undiagnosed or are misdiagnosed effects the prognostic value of assessment (Little, 2002; Harprett et al., 2002; Rastam, Gillberg, & Wentz, 2003). Studies of outcomes for people with AS are still inconclusive, due to the recent classification of AS, and therefore provide only limited information to diagnosticians for use in prognosis. Further, the lack of empirical research centring upon the specific peculiarities of classification for females with AS impacts on the diagnostician’s capacity to facilitate a classification process that ensures that females with AS are accurately diagnosed. Despite the identified limitations of diagnosis and classification, outcomes of diagnoses have been recognised as being of significant concern, particularly for parents of individuals with AS (Little, 2002).

Strategies

A number of published resources and strategies based on diagnostic criteria of AS are available to support individuals, families, teachers and other personnel working within school settings. It is important to emphasise however, that the strategies identified in this review provide a general framework for individuals with AS and do not explicitly account for gender differences. The authors of this paper wish to emphasise that, given the differences in the profiles of females with AS compared with males, future advances in AS research must be directed towards the development of programs that acknowledge the impact of gender differences and accommodate the needs of females with AS.

Safran (2002) compiled a list of evaluated print and media resources available to assist educators in understanding and supporting students with AS. Marks, Shaw-Hegwer, Schrader, & Longaker (2003) provide guidelines for classroom instruction. Safran (2002) presents strategies that are primarily focused on the individual with AS. Bock (2001) outlines strategies centred upon social interaction skills. While a range of intervention strategies have been presented in the literature, the effectiveness of many of these strategies is yet to be evaluated.

Asperger Syndrome and Girls

Much research effort has been expended in extending the existing body of knowledge about AS. However, limited attention has been drawn to the identification of gender differences in the diagnosis and treatment of AS. It is imperative that future research in AS explores intervention strategies that are designed to support female students with AS. The majority of studies cited in this report have included sample groups of male to female ratios of at least 4:1. This trend is of significant concern because it does not allow for directions in research that centre upon the effects of AS on female populations. Further, existing findings have not been identified that explore differences between male and female AS profiles.

A recently emerging theory purports that the autism spectrum is an extreme version of normal male intelligence (Cowley, Underwood, Murr, Springen, & Sennott, 2003). For females to meet the criteria of AS and associated disorders, the deficiency in indicators must be more prominent in females compared with males. Further, as girls grow older, the presenting problem may not be associated with the autism spectrum, which may only be evident on close examination and detailed developmental history (Kopp & Gillberg, 1992). Nyden, Hjelmquist, & Gillberg (2000) suggest that girls may be in even greater need than boys for special education and social support.

The case studies of Kopp & Gillberg (1992) provide evidence of misdiagnosis and underreporting of girls with severe social impairments. Only comorbid psychiatric conditions were initially identified, but once treated, allowed for the identification of AS (Rastam et al., 2003). Depression
is the most common co-presenting diagnosis in adolescents and adults with AS (Ghaziuddin, Weidmer-Mikhail & Ghaziuddin, 1998). Given the tendency for ‘sociability’ in females (Nyden et al., 2000) and high rates of depression in the general female population, girls diagnosed with AS are ‘at risk’ of not coping in many aspects of their lives.

Despite a lower incidence of female cases of AS, there is emerging evidence that identification of AS in female populations may be becoming more frequent and accurate. Nyden et al. (2000) indicates the ratio of males to females diagnosed with AS is 5:1. Baker (2002) reports that between 1988 and 1997 the number of cases referred for suspected Autism Spectrum Disorder in the Australian Capital Territory increased 200%, and there has been a decrease in the ratio of boys to girls.

If the number of female students identified with AS is increasing, there is the risk that such students may be under-supported. Based on the profile of the student with AS, it is possible that such a student may be intellectually gifted. However, given the limited support for individuals with AS, it may be difficult for school communities to provide interventions tailored to the students needs (Rowe, 2003; Little, 2002). In mainstream education where little specialist support is available, what possible strategies could be recommended to support such a small percentage of students?

### Support for Adolescent Girls with AS within Mainstream Schools

When working with female students identified with AS in a mainstream school context, a number of initial considerations are paramount. More general conclusions drawn by Levy (2001) about the experience of sharing a diagnosis of AS with individuals and parents, and the questions raised by Baron-Cohen (2002) about whether the need for subsequent intervention should be underpinned by a model of disability or a model of difference are important to consider. Levy outlines three outcomes associated with the communication of an AS diagnosis. For outcome one the individual accepts and is relieved by the diagnosis, understands what AS is and continues on to achieve to her potential. For outcome two the individual accepts and is relieved by the diagnosis and chooses to ‘opt out’ because of the disabilities of the diagnosis. In the third outcome the individual accepts the diagnosis, but finds it difficult to be ‘different’ from others. Baron-Cohen (2002) asserts that the model of intervention should serve to facilitate a response in the individual with AS reflective of Levy’s first outcome. However, a model of intervention that identifies a disability rather than a difference would be more likely to produce outcomes two or three.

Fullerton & Coyne (1999) emphasise the significance of the individual with AS engaging in programs that incorporate components that serve to increase the individual’s understanding of autism. In a program evaluated by Fullerton & Coyne (1999) focussing on self-knowledge, communication and life planning, participants diagnosed with autism reported that the sharing of information about autism seemed to be of greatest benefit. Based on such findings, an adolescent girl diagnosed with AS may need to know more about the features of AS and identify those which she exhibits. One possible means of achieving this goal may be through the initiation of small group personal development programs.

Further, if a student does not identify a problem in a particular area there should be no need to challenge that student’s perception (Baron-Cohen, 2002). It is more constructive to facilitate intervention strategies that aim to relieve the stress of situations creating concerns for students. Further, such strategies should promote experiences of self-determination and success rather than encourage resistance to solving problems that have been imposed by an external source. If time and resources are spent addressing problems identified only by an external consultant, such an approach may prove to be counterproductive to the facilitation of meaningful engagement.

The work of Marshall & Mirenda (2002) also gives insight into a possible systematic approach to developing problem solving skills in adolescent females. The process of identifying negative behaviours and utilising a number of support people within the individual’s system may help develop a new understanding and focus for the young person with AS. Such an approach can be applied to home, school, vocational settings, or social situations and fosters systematic thinking. It can also target a specific behaviour with positive outcomes.

Based on the phenomenon of ‘sociability’ of females and the severity of the disability, it is often considered that females with AS experience significant struggles formulating friendships (Nyden et al., 2000). Often young women diagnosed with AS say they have no friends or are lonely. Carrington, Templeton, & Papinczak (2003) investigated diagnosed adolescent AS students to ascertain perceptions of friendship. While the sample size in the investigation was small, findings suggested that young people with AS have difficulties with the language and the overall conceptualisation of friendship. School based intervention strategies could include specific assistance to AS students in conceptualising
friendship and loneliness as well as practical strategies that serve to promote meaningful peer relationships.

Social skills training is the prescriptive method suggested to provide support in teaching adolescents with AS how to act and respond to promote more appropriate social interactions both in the classroom and in broader settings. Barnhill et al. (2002) evaluated a social skills intervention with adolescents that targeted nonverbal communication. The results indicated that young people with AS and related disorders do not successfully generalize skills across environments and different time periods. However, the program appeared to provide opportunity for participants to experience some social interaction across the intervention period.

Gutstein & Whitney (2002) contribute substantially to the body of knowledge on the development of social competence in young people with AS. They clearly delineate between the conceptualisation of ‘social competence’ and ‘social skills’, and identify that the central deficiency in the young person with AS is ‘experience-sharing’. People with AS also lack the motivation to develop these skills (Gutstein & Whitney, 2002). This has implications for the individual in the home and school context. However, Gutstein and Whitney’s (2002) findings fail to recommend a model for effectively teaching social competence to young females with AS.

Conclusion

AS has only been recognised for a relatively short period of time as a diagnosable disorder. The criteria for identification lack clarity and effective baselines. Consequently, this presents serious implications regarding diagnosis, including individuals being undiagnosed or misdiagnosed. Current research into AS including the efficacy of related intervention strategies are predominantly qualitative and based on case studies. Therefore, empirical research tends to be limited and often inconclusive.

Statistical reports indicate that there are fewer females than males being diagnosed with AS, although the gap is lessening over time (Attwood, 1999). It has been suggested that the diagnostic criteria for AS is an extension of general male abilities and therefore greater deficits in females are needed to meet the criteria for diagnosis. This leads to the speculation that girls and women are more severely affected by social interaction deficits by the time of diagnosis. It has also been established that girls and women with AS are at a heightened risk of depression and other comorbid psychiatric conditions. As a result, women and girls may have greater need for educational and social support.

Outcomes research and prognostic documentation remains speculative given that many adults have not had access to diagnostic and support services. This has implications for practitioners working with female adolescents and adults with AS in educational settings and broader contexts. The majority of existing intervention strategies are based on theoretical models, are lacking in empirical support, and fail to account for the impact of gender differences on treatment efficacy.

The literature reflects the intense work that is being undertaken in the theoretical domain concerning intervention programs for individuals with AS. Existing research agendas appear to be driven by a core group of specialists working from select locations and while recent findings are informative, little knowledge is being generated concerning the specific implications for adolescents, in general, and girls specifically diagnosed with AS.

Based on the present discussion, a number of recommendations can be made that serve to direct future research into AS and its implications for diagnosed adolescent females engaged in regular school communities. First, future investigations need to focus on empirical validation of intervention strategies tailored to the specific needs of female AS students as a means of advancing contemporary educational practice. Recent investigations are predominantly qualitatively based, are not specific to a particular gender group and findings lack empirical support. Second, female adolescents with AS need to be involved in the process of determining the interventions and support required that would be of greatest benefit to them within educational contexts. Contemporary intervention approaches are often administered by expert consultants who fail to include individuals with AS in the process of intervention development and implementation. Finally, future research initiatives should give further attention to the influence of gender in the successful treatment of AS. Future studies could serve to broaden the existing body of knowledge about intervention practices that are best tailored to a specific gender group.

References


