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Optimizing Parenting Effectiveness in Families of Children with Asperger's Syndrome

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Abstract
Autistic Spectrum Disorders and Asperger's Syndrome is discussed. Asperger's Syndrome is a neurodevelopmental disorder named after a Viennese physician, Hans Asperger, who first identified the disorder in 1944. Asperger's Syndrome is categorized under Autism Spectrum Disorders. There are differences in diagnosis of Asperger's Syndrome between DSM-IV and DSM-V. The newer edition categorizes Asperger's Syndrome along a continuum of the Autistic Spectrum Disorders rather than a "yes" or "no" decision for each separate disorder. Children with Asperger's Syndrome have near average intellectual functioning, abnormal social skills, repetitive behaviors, heightened sensory perception, and difficulty interacting. Prevalence is given, along with the nature of the disease concerning sensory perception, thought processes, and social skills. Parents of children with Asperger's Syndrome face many stressors. Ratings by mother of quality of life and reported sense of well-being are lower than mothers of children without disabilities and with other disabilities are. There are suggestions about how the family can deal with a child with Asperger's Syndrome. Current approaches for children with Asperger's Syndrome include child-focused, school-focused, and parental-coping interventions. Coping strategies, school interventions, and family support can help promote functional behavior for these children and their family system. It is important to address parental stress. Exploring these concepts and addressing the effectiveness of parenting style is important. There is a need to conduct future research.

Key words: ASD, prevalence, stress, interventions, style

Prevalence of Asperger's Syndrome in the US

Asperger's Syndrome (AS) falls under the category of Autism Spectrum Disorders (ASDs). According to the Centers for Disease Control and Prevention (2012), as many as one in 88 children will have an ASD. ASDs have been identified in all racial and socioeconomic groups and are five times more prevalent in boys than girls. One in every 54 boys and one in every 252 girls are diagnosed with an ASD. On average, children are diagnosed with AS at age 11, compared to an average age of five and a half for autism (Howlin & Asgharian, 1999). According to the 2005 Diagnostic and Statistical Manual of Mental Disorders- Fourth Edition, Text-Revision (DSM-IV-TR) criteria, a diagnosis usually occurs in adolescence, but signs of developmental delay can typically be traced back to before three years of age (Schnur, 2005).

Due to a lack of studies on the specific ASD of AS, data on the prevalence of AS is inconclusive. Gillberg & Gillberg (1989) found that, AS (36-71 per 10,000) is more prevalent than Autism (0.7-21.1 per 10,000); whereas Fombonne (2003) found AS to be occurring at a lower prevalence (2.5 per 10,000) than the total of all ASDs (60 per 10,000). To date, the number of adults diagnosed with AS is indeterminate due to insufficient number of studies on this specific population (Centers for Disease Control and Prevention, 2012). According to Ehlers & Gillberg (1993) and Kadesjo, Gillberg, & Hagberg (1999), AS is present in about 26-36 out of every 10,000 school-aged children. Although the number is indeterminate, the disorder has shown to progress into adulthood (Centers for Disease Control and Prevention, 2012). Despite relatively normal cognitive abilities, AS is a lifelong disorder, characterized by a high level of dependency on primary social support (Mori, Ujiie, Smith & Howlin, 2009).

The Nature of Asperger's Syndrome

Asperger's Syndrome is a neurodevelopmental disorder named after a Viennese physician, Hans Asperger, who first identified the disorder in 1944 (Heiman & Berger, 2008). Asperger's Syndrome falls among the ASDs and is commonly referred to today as "high functioning Autism". Autism Spectrum Disorders include Autism, Asperger's Syndrome, and Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS) (Epstein, Saltzman-Benaiah, O'Hare, Goll, & Tuck, 2007; Toth & King, 2008). The DSM-IV-TR groups the symptoms and related disorders of Autism, PDD, and AS together (Safran, Safran, & Ellis, 2003).

According to the American Psychiatric Association (APA), the DSM-V was released in May 2013, and although AS may no longer be a specified disorder in the new edition, it still exists along the autism spectrum (2012). The new category in the DSM-V is called autism spectrum disorder, which incorporates the disorders of autism, Asperger's, childhood disintegrative disorder, and PDD NOS (APA, 2012). The new DSM-V suggests these disorders represent a continuum, from mild to severe, rather than a yes or no themselves (APA, 2012).

Asperger's Syndrome is similar to Autism in that its symptoms manifest in social awkwardness and repetitive behaviors and interests. Unlike individuals with Autism, those with AS function at an average or above-average intelligence. Deficits typically lie in social communication and language construction (Toth & King, 2008). AS is characterized by repetitive behaviors, preoccupation with certain topics, weak perspective-taking skills, little empathy, and impaired social skills. Sensory perception, social skills, and thought processes are altered in individuals with AS. Comprehending these subtopics may improve understanding and management of AS.

Sensory Perception

Although not currently included as an element of formal AS diagnosis, studies have reported a difference in sensory perception for individuals with AS, compared to children without the disorder (Rogers, Hepburn, & Wehner, 2003). For children with AS, reactions to sensory stimuli (i.e. tactile, visual, auditory, gustatory) "are often intense, painful or uncomfortable, and emotional" (Epstein, Saltzman-Benaiah, O'Hare, Goll, & Tuck, 2007, p. 504). Tasks such as attending an assembly at school or participating in recess after lunch may cause a child with AS to have intense behavioral reactions within 30 minutes, often requiring removal from the environment (Epstein, Saltzman-Benaiah, O'Hare, Goll, & Tuck, 2007).

Social Skills

Children with AS tend to be socially awkward. This awkwardness may manifest as inability to read social cues (Schnur, 2005), appropriately regulate volume of voice, follow standard social etiquette (Safran, Safran, & Ellis, 2003), or understand the characteristics of social interaction (Schnur, 2005). Although they may have full linguistic and verbal abilities, they often have difficulty in the nonverbal aspect of communication (Schnur, 2005), including impairment of eye-to-eye gaze (Heiman & Berger, 2008), tone, volume, gestures, posture, facial expression, distance between others, and rhythm and timing of speech (Safran, Safran,

& Ellis, 2003). They also may have difficulty initiating social interaction and maintaining conversation, despite the fact that they may desire social interaction. Low self-esteem and feelings of isolation and loneliness are often the result of their inability to create and maintain friendships (Safran, Safran, & Ellis, 2003).

Thought Processes

Other characteristics of AS include a restricted range of interest and inflexibility of thought. Individual selections of interests are generally narrow and un-intellectually stimulating, and exclude other individuals. Their thought processes generally involve conceptualizing situations in a systemized, orderly manner. An excessive insistence on a set order of events, compulsion to finish what was started, assertion to rules, and phobias developed from single encounters are other characteristics (National Institute of Health, 2012). Repetitive use of objects or phrases is also characteristic of children with AS (National Institute of Health, 2012). These manners of thought process can be difficult to manage and present challenges for caregivers of children with AS.

Stressors of Asperger's Syndrome on Parents

Research investigating the stressors of parenting children with AS is extremely rare. According to a study of Japanese children and parents by Mori, Ujiie, Smith & Howlin (2009), 67% of the parents of children with AS scored total parental stress at or above the 90th percentile of normal parental stress levels, compared to 57% of parents of children with autism scoring in that same range. The Japanese version of the Parenting Stress Index/short form (PSI/SF) was used to measure stress levels of parents. Thirty-six items were chosen from the full 101 items included on the full-length Parenting Stress Index, and the questions were Likert-scale format. The study found that stress levels of Japanese parents who have children with AS are significantly higher than Japanese parents of children with autism. It thus appears that the prevalence of socially inappropriate behaviors and social deficits, combined with the structural, repetitive, and routine needs of children with AS can lead to unique stress on their parents.

Parents of children with Autism Spectrum Disorders, particularly mothers, suffer more stress and lower levels of well-being than parents of children without disabilities and with other disabilities (Meadan, Halle & Ebata, 2010; Little, 2002). Compared to parents of children with cerebral palsy or mental retardation, parents of children with Pervasive

Developmental Disorders report lower levels of quality of life (Mugno, Ruta, D'Arrigo & Mazzone, 2007). One can logically speculate that the characteristics of AS negatively impact quality of life for caregivers.

Mothers of children with AS have been found to experience significantly more stress themselves than do fathers, and perceive greater levels of stress for their family (Heiman & Berger, 2008; Little, 2002). They are also more likely to seek professional help, take medication for depression, and hold a more pessimistic view about their child's future than fathers of children with AS (Little, 2002).

Although it is known that having a child with an ASD has negative impacts on the parents, there are limited studies about the impact on the marital relationship. While some studies have found having a child with a disability to have a negative impact on marital relationships, others have found no difference between parents with children without disabilities (Meadan, Halle & Ebata, 2010). In addition to traditional care, parents of a child with AS are required to provide a more intensive level of care, including structuring their child's daily routines, developing opportunities for socialization, and further education. In addition to caring for their children's basic needs, parents also take on the responsibility of providing companionship because children with AS lack appropriate social skills and have difficulties developing peer relationships. Support systems for the family typically grow smaller, as parents perceive a lower level of social acceptance surrounding their child's disorder (Heiman & Berger, 2008).

The diagnosis process itself is one of the most stressful periods of time for families with children with AS. According to Heiman & Berger (2008): "The crisis engendered by the diagnosis that something is wrong with their child is probably the parents' most difficult experience" (p.290). Delays in obtaining a diagnosis, multiple medical visits and screening appointments, financial burdens, changes in family cohesion and lifestyle, and social understanding and support systems are all stressors on the family system functioning. Parents of children with AS experience greater marital discord, social isolation, lower locus of control, lower levels of self-esteem, difficulty accepting the diagnosis, perceptions of their child being less accepted by society, and vulnerability to mental health problems, including depression (Mori, Ujiie, Smith & Howlin, 2009). Differences in the parent's views on self-help can further complicate matters, especially straining the marital relationship (Mori, Ujiie, Smith & Howlin, 2009).

Depending on the severity of the child's symptoms, inability to remain in over-stimulating environments, demanding behaviors, abstruseness of symptoms, and dependency and/or lifelong care can negatively impact parents' lives. As described, the impact on parents creates marital stressors, parenting stressors, and social isolation. These demands often necessitate an appropriate intervention plan for the child, the family, and the marital relationship.

Current Intervention Approaches for Children with Asperger's Syndrome

Currently there are three approaches for coping with the problems of children with AS. These include child-focused, school-focused, and parental-coping interventions. Child-based interventions are coping strategies aimed at the individual child with AS. School-focused interventions are strategies currently utilized for the child with AS in a school setting. Finally, there are current approaches to managing parental effects on children with AS through various coping mechanisms and counseling for the parental subsystem.

Child-focused interventions

Current strategies implemented by counselors, teachers, and helpers of children with AS are aimed at improving social skills. These activities include analyzing past situations to improve understanding of circumstances, perspective-taking of others, and consciously observing the visual reactions of others (Safran, Safran, & Ellis, 2003). By attempting to take another's perspective and/or consciously observing emotional reactions of others, children with AS are encouraged to fine-tune their abilities of emotion-recognition, an area where deficits are seen in many children with AS. The introduction of computer programs that are available to help children with AS develop emotion-recognition are additional child-based interventions strategies that are helpful. Computer programs are available to help children with AS develop emotion recognition skills (Silver & Oaks, 2001).

Longhurst, Richards, & Morrow (2010) recommend giving children something tangible to fidget with in their hands while participating in class or group work in order to maintain focus. Silly putty, balls, and cards are a few examples they provide as helpful "fidget tools" to allow children to occupy their hands, as long as the group leader ensures they do not become distracting. These tools can assist in the learning process by helping the child with AS to focus.

School-focused interventions

The repetitive, narrow, and specified interests common for children with AS can make learning other information difficult, as children with AS also have little patience, poor sensory integration, organizational deficits, and low frustration-tolerance. Utilizing their special interests to work to the child's advantage is key to creating a beneficial learning environment. Incorporating the special interests into learning, creating extracurricular peer groups associated with the special topic (i.e. a geology club), or allowing the child to be a "specialist" in the classroom about the topic (i.e. history buff) are strategies identified by Safran, Safran, & Ellis (2003) to utilize potential drawbacks positively and conducive to classroom learning. These activities can help motivate the child and create a safe and healthy environment among peers. A drawback to this school-based intervention that has been identified is that the child with AS may have strange or overly-obsessive interests, in which case the educator would be required to serve as a buffer against ridicule and maintaining relevance for the class (Safran, Safran, Ellis, 2003).

Since children with AS typically have sensory deficits, and visual learning is typically an area of strength, visual representations for learning in the classroom have shown to be helpful (Neihart, 2000; Nielsen, 2002). Examples of visual aids for learning include movie clips, graphic organizers, illustrations, timelines, and drama activities. If possible, a word processer can be used to accommodate those children with AS who have poor motor skills (Nielsen, 2002).

As discussed previously, another deficit for children with AS is appropriate recognition of social and nonverbal cues. Often, indirect learning occurs in the classroom simply by interaction with peers, and gaining an understanding from teachers and general classroom functioning about appropriate social behavior. For the child with AS, this incidental learning can be challenging (Safran, Safran & Ellis, 2003). Switching tasks in the classroom, communicating information between school and home, and getting materials together for an activity are all examples of potential challenges for a student with AS. Approaches to this deficit in school have included teachers notifying a child of changes in the schedule and reiterating those changes. Organization, including recording assignments and due dates in a planner, highlighting key information in readings, and creating graphic outlines of information can assist in the learning (Safran, Safran & Ellis, 2003).

Since children with AS lack typical recognition of social cues and social etiquette, one intervention educators have used is to outline rules and procedures, including "when to listen, how to question, or how to initiate or end interactions" (Safran, Safran, & Ellis, 2003, p.159).

Professionals working individually with the child can practice these skills through role play (Safran, Safran, & Ellis, 2003). Relaxation techniques (Safran, Safran, & Ellis, 2003), self-talk strategies (Marks et al., 1999), and monitoring past situations to develop insight (Safran, 2002) are techniques that have been used to keep stress and anxiety levels down and avoid sensory overloads and intense behavioral reactions for children with AS in the classroom.

Parental coping-focused interventions

The challenges of parenting a child with AS warrant effective coping strategies that can be applied to parenting. Meadan, Halle & Ebata (2010) emphasize the approach-avoidance model and the problem-focused versus emotion-focused models for coping strategies. In the approach-avoidance model, coping responses are categorized according to their focus. Approach-oriented strategies include coping with stressors "by seeking information about it, monitoring it, and trying to resolve it, whereas in avoidance-oriented strategies, a person ignores, denies, minimizes, or diverts attention away from the stressor" (Meadan, Halle & Ebata, 2010, p.24). For a parent of a child with AS, utilizing the approach-oriented strategy, may include understanding the characteristics of the disorder, monitoring behaviors, and seeking interventions to resolve problem behaviors. Conversely, implementing the avoidance-oriented strategy may include minimizing the impact of AS on family life or directing attention to more positive characteristics instead of focusing on the stressors at hand.

Problem-focused versus emotion-focused coping responses are organized according to the function of the response. Using the problem-focused method, one would attend to a stressor by attempting to solve the problem or change the situation. The emotion-focused strategy focuses on emotion regulation and management of emotions produced by the stressor (Meadan, Halle & Ebata, 2010). A problem-focused coping response for parents of a child with AS may include implementing changes in routine in an attempt to change a problematic behavior. An emotion-focused coping response may manifest in the form of a parent controlling his or her emotional reaction to a behavior instead of addressing the behavior triggering the emotion. Approach and problem-focused, rather than avoidance and emotion-focused, strategies are associated with more positive outcomes for managing stress (Meadan, Halle & Ebata, 2010).

Reframing situations to view them more manageably and viewing them in a positive light is known as benefit finding, and has been proven successful as a coping strategy for parents of children with disabilities and medical illnesses. Attempting to view life from the

child's perspective is another example of a coping strategy that can improve relationship between parent and child (Pakenham, Sofronoff & Samios, 2004). Social support through extended family or the community (Little, 2002), creating meaning, and finding strength through spiritual belief systems are other methods that have been applied to help parents of children with AS cope with stress (Meadan, Halle & Ebata, 2010). Sadly, parents of children with ASDs frequently rely on unhelpful strategies that can ultimately detract from the quality of life. Negative, passive, escape-avoidance, and passive religious coping are all associated with greater anxiety outcomes (Meadan, Halle & Ebata, 2010).

A Need to Consider Parenting Style

Currently there are successful strategies that can help parents manage a child with AS. These strategies include a focus at the child-level, school-level, and parental-coping mechanisms. They are necessary when effectively intervening in a family with an AS child, but are not sufficient. Although these interventions are effective, parenting a child with AS remains to be very stressful. Additional approaches regarding parenting styles may be beneficial in managing a child with AS.

Parenting style has been studied as an effective coping intervention for parents of children with autism, ASDs, or behavioral issues of children in general, but parenting style interventions specifically for parents of children AS are extremely rare. The implementation of appropriate parenting styles has proven successful for various children in improving behavior and overall family satisfaction. Therefore determining appropriate parenting style for managing children with AS and utilizing a parenting-style approach to reduce familial stress may be crucial to healthy family functioning.

Parenting Styles and Children's Behavior

Parenting is a compound activity that is a collection of behaviors, working together or separately, that have a direct impact on children's behavior and symptoms of behavior (Alizadeh, Abu Talib, Abdullah & Mansor, 2011). Baumrind found authoritative parents to be more successful than authoritarian parents in avoiding problems correlated with drugs (1991). When parents display responsive and supportive behavior and exhibit certain expectations from their children, less problematic behaviors, high social skills, greater creativity, performance in school, and self-confidence become evident in the child's behavior. Authoritative parenting positively influences a child's behavior into adolescence (Alizadeh, Abu Talib, Abdullah & Mansor, 2011).

Ineffective Parenting and Parental Stress

"Specific parenting behaviors, such as physical punishments, may affect children's development and consequently cause behavioral disorders in them" (Alizadeh, Abu Talib, Abdullah & Mansor, 2011, p.196). Authoritarian parents are generally too strict, rely heavily on punishment (Alizadeh, Abu Talib, Abdullah & Mansor, 2011), and this parenting style is highly associated with delinquency behaviors (Odubote, 2008). Oppositely, permissive parents are responsive but not demanding (Alizadeh, Abu Talib, Abdullah & Mansor, 2011), and exhibit low control and low warmth (Park & Walton-Moss, 2012). Children of permissive parents tend to be passive, unresponsive, dependent, and lack social responsibility (Alizadeh, Abu Talib, Abdullah & Mansor, 2011).

Neither permissive parenting style nor authoritarian parenting styles are recommended for healthy child behaviors and family environment. Because these styles generally elicit negative behaviors in children, parents will most likely have a more difficult time raising the children, and these difficulties will have a negative reciprocal effect on their stress levels.

A Parenting Style-Focused Approach to Asperger's Syndrome

There is a moderate amount of research that exists regarding coping strategies for parents and children, but few studies exist that discuss appropriate parenting styles and techniques for parents of children with AS. Parenting stress and its correlation with children's behavior is not well studied. Park and Walton-Moss (2012) define parenting stress as, "an imbalance between the perceived demands of parenting and the perceived available resources" (p.496). Parenting stress and style has been largely correlated with general behavior of young children and behavior problems in children with chronic illnesses.

"Parenting style has been observed to effect children's emotional intelligence, anxiety, weight gain, and body mass index" (Park & Walton-Moss, 2012, p.495). The three common parenting styles are authoritarian, authoritative, and permissive. These styles are characterized by degrees of warmth and control. Authoritarian parenting is characterized by high control and low warmth. Authoritative parenting is high control and high warmth. Permissive parenting is classified as low control and low warmth. Authoritative parenting is shown to be the most correlated with healthy behaviors in children (Park & Walton-Moss, 2012).

Alizadeh, Abu Talib, Abdullah & Mansor (2011) describe these same three parenting styles in different, yet similar terms. Authoritative parenting is characterized as high responsiveness and high demanding, authoritarian parenting is described as low responsiveness and high demanding, and permissive parenting has high responsiveness and low demanding characteristics.

Optimal Parenting Style for Children with Asperger's Syndrome

Heiman & Berger (2008) report that healthy family support, including acceptance, cohesion, and problem-solving, can positively influence children with a learning disability's adjustment capabilities. Heiman & Berger also found that parents of children with AS viewed their system as more organized, structured, and controlled (2008). Since parents of a child with a disability typically need closer monitoring of general family environment than parents of a child without a disability (Heiman & Berger, 2008), this organized structural system could be important in assisting parents to gain a greater perceived level of control, sense-making, and benefit finding.

The need for organization and structure benefits both the parents of a child with AS and the child. Authoritative parenting style, as Park & Walton-Moss (2012) characterized as exhibiting high control and high warmth, may be the best model, especially for parents of children with AS. The high levels of control provide structure and organization, and the high levels of warmth and care create a sense of belongingness and family unity, as rendered important and effective coping strategies by Little (2003); Heiman & Berger (2012).

Future Research Needs

Future research to determine if indeed authoritative parenting style improves the lives of families of children with AS is needed. Research comparing and contrasting the three main parenting styles and their impact on AS compared to other developmental disorders may provide insight into the most appropriate parenting style for effectively managing behavior. These studies would need to be conducted in a variety of settings, including families with multiple children, single-parent homes, split-family homes, and varying ages and severity of symptoms of the child with AS.

Investigating both maternal and paternal parenting style would also be helpful. Determining differences and/or similarities in the effectiveness of parenting styles, as implemented by mothers and/or fathers would be crucial to striking an appropriate balance of

authority, structure, and warmth stemming from both parents to the child with AS. Longitudinal designs would assist in monitoring effectiveness of various parenting styles within a family over time, as the family ages and adapts to change.

Conclusion

Children with AS present a unique set of characteristics that lead to challenges for the child, the parents, and the school. Although intervening at the school and individual levels with a child with AS is helpful to some degree, additional interventions may be effective in addressing parental stress for parents of children with AS. Supplementing the current interventions with the appropriate parenting style may enhance the overall functional well-being of a child and family with AS.

The parents are responsible for care of the child a majority of the time, so their stress levels, and resulting developmental impact on the child, is vitally important to direct focus. By examining and determining effective parenting styles, suggesting their implementation could help to relieve parental stress through a higher perceived level of control over the situation, healthier behaviors in the child, and a more positive relationship between parents and child.

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