Autism Spectrum Disorders and The Family Impact

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Introduction

The family is often described as the basic unit of society, with the implication that it is within the family that individuals first grow and develop, and in turn become influential members of society. From this foundational concept, it can be deduced that any positive change to the familial unit has a direct impact on society as a whole. Thus, research related to the development of positive family environments is of great importance. According to the Center for Disease Control & Prevention (2015), 1 in 5 adults in the US has a disability. Given the high levels of familial stress associated with having a family member with a disability (Duarte, Bordin, Yazigi, et al., 2005), research related to decreasing familial stress will directly benefit society. Specifically, the current paper aims to present the impact of the family environment on the behavioral phenotype of individuals with Autism Spectrum Disorders (ASD), the model of a family psychoeducation program to facilitate a positive impact, and the current research surrounding multi-family psychoeducation interventions entitled “Transitioning Together” and “Working Together” (Smith et al., 2008).

Autism Spectrum Disorders (ASDs) are classified as lifelong developmental disorders and are defined by three primary symptoms: (1) repetitive behaviors and restricted interests, (2) impairment in reciprocal social interaction and (3) impairments in communication (Lord, Rutter, & Le Couteur, 1994). According to the CDC (2014), ASD affects 1 in 68 children in the US. The prevalence of Autism Spectrum Disorders has continuously increased with the newest estimate about 30% higher than the estimate for 2008 (1 in 88) and about 60% higher than the estimate for 2006 (1 in 110) (CDC, 2014). Although the exact cause for the trend in prevalence is still unclear, it can be hypothesized that advancements in identification and diagnosis of ASD influence the trend. The increasing prevalence of ASD prompts for continuous research to expand the current understanding of the causes, characteristics and effective treatments of this developmental disorder.

Background

Extensive research has been done to assess the levels of stress experienced by parents and families of children with ASD (Duarte, Bordin, Yazigi, et al., 2005, Monte & Halterman, 2006). It has been found that parents of such individuals experience higher levels of stress, particularly stemming from the problem behaviors associated with ASD (Hastings, Kovshoff, & Ward 2005). Research conducted by Smith, Greenberg, & Mailick (2014) concluded mothers of adults with autism demonstrated significantly more physical health symptoms such as joint pain, fatigue, headaches, and gastrointestinal problems, than mothers of adults without disabilities. This study also found that mothers of adults with ASD displayed significantly hypoactive cortisol levels, an indicator of chronic stress often displayed in individuals with caregiver burnout and posttraumatic stress disorder (PSTD). As can be inferred from these findings, the emotional impact of raising a child with a disability is high for mothers and in turn, high for the family unit.

1 Under the supervision of Leann E. Smith, PhD
However, the limiting of our focus to the correlation between problem behaviors of a child with ASD and increased levels of familial stress can quickly lead to an unhealthy view of the child with a disability as a “problem” within the family unit. As is clear, an individual’s dignity and value does not stem from his or her external actions or behaviors but from the mere fact that he or she exists. In research involving individuals with ASD, it is from this premise that a study is conducted, always recognizing the individual for who they are as a human being. Further, through such research the goal is to expand the knowledge base of science and society so as to increase the quality of life of individuals with ASD and to strengthen the family unit by decreasing familial stress. Although significant research has been done to qualify the external behaviors associated with ASD and to demonstrate the correlation between such behaviors and levels of familial stress, it was not until more recently that the reverse direction was studied. Current research points to the significant bidirectional influence between the family environment and the behavioral phenotype of autism. Smith et al. (2014) highlighted the centrality of the family in maximizing the quality of life of individuals with ASD and the need to identify characteristics of family environment that are associated with the reduction or exacerbation of problem behaviors.

In regards to such research, it is probable that many researchers were hesitant to study the effects of family environment and stress levels on the external behaviors associated with autism given that a positive correlation in this direction may lead one to blame families for the problem behaviors of their child. Although this is a real concern, this is the point in which the aforementioned premise of each individual’s inherent dignity and value becomes incredibly important. Research related to the effects of family environment assumes that each individual with autism is cared for and loved for the mere fact that he or she exists, but recognizes that helping families decrease the natural stress experienced will increase quality of life and strengthen the family unit. Thus, it is of great importance to study the effects of family environment on the phenotype of ASD so as to provide families with concrete tools that will decrease stress, provide supports, and foster positive family environments.

The Family Impact on Child Development

Given the central role of the family in the life of a child, it is not surprising that family environment and parenting practices have a significant impact on the development of a child (Borkowski, Ramey & Bristol-Power, 2002, Bornstein & Bradley, 2003). Studies have shown the effect of positive parenting practices on the socio-emotional and cognitive-linguistic outcomes for typically developing children and children with disabilities alike. In their study, Mahoney & Perales (2003) found a clear correlation between maternal responsivity and improved socio-emotional functioning and social interaction skills in young children with ASD. Further, Siller & Sigman (2002) demonstrated a link between responsive, sensitive parenting and better language trajectories for children with ASD. Although the role of the family is evident during the developmental period of a child, research has also indicated that the effects of family environment and parent-child relationship, especially for individuals with ASD, continue past childhood. A longitudinal study of mother-child dyads of adolescents and adults with autism done by Smith et al. (2008) concluded that high initial levels of maternal warmth and positive remarks were associated with reductions in autism symptoms and behavior problems 18 months later. Within the same sample, high levels of criticism were predictive of increased problem behaviors. Smith et al. (2008) highlight the impact the family environment has on the behavioral development of individuals with ASD, which in turn impact society as a whole.
To classify characteristics of family environment which influence the phenotype of individuals with a disability, the concept of expressed emotion (EE) has been greatly explored. The five aspects of EE include criticism, hostility, emotional over involvement, warmth, and positive remarks. These five aspects originated in the work done by Brown et al. (1972) with adults with schizophrenia. To conceptualize EE, the Camberwell Family Interview was administered (Leff & Vaughn, 1985). In their analysis of relapse rates for these individuals, it was found that the EE aspect of criticism played a decisive role in predicting symptomatic relapse. Further studies provided similar conclusions indicating the link between high levels of EE and the exacerbation of problematic symptoms in individuals with mood disorders, eating disorders, Alzheimer's, asthma, diabetes, Parkinson Disease (Hooley, 2007, Wearden, Tarrier, Barrowclough, 2000), intellectual and developmental disabilities (IDD) (Beck, Daley, Hastings, 2004), and typically developing children and adolescents (Kwon, Delaney-Black, Covington, et al. 2006, Wedig, Nock, 2007). Kwon et al. (2007) found that both typically developing children and children with IDD displayed increased problematic behaviors when their family atmosphere was marked by higher EE levels of parental criticism.

A 13 year longitudinal study investigating the influence of the distinct aspects of EE on the behavioral phenotype of adolescents and adults with autism was conducted by Smith et al. (2014). The aim of the study was to identify characteristics of the family environment, particularly positive dimensions of family life (i.e. warmth, positive remarks), which play a significant role in decreasing problem behaviors in individuals with ASD. Based on the Camberwell Family Interview done by Brown et al. (1972), the Five Minute Speech Sample (FMSS) (Magana, Goldstein, Karno, et al. 1986) was administered to the mothers of the adolescent or adult with autism. In this task, the mother is asked to speak for five minutes, describing her child with autism and expressing her thoughts and feelings about her child. The verbal content and vocal tone of the FMSS is then coded for EE (criticism, emotional overinvolvement, warmth, and positive remarks).

Over 7 years, in addition to the Five Minute Speech Sample (FMSS), the Problem Behavior subscale of the Scales of Independent Behavior-Revised (SIB-R) (Bruininks, 1996) and the Autism Diagnostic Interview-Revised (ADI-R) (Lord et al., 1994) were administered on four separate occasions to explore the link between the family environment and the behavioral phenotype of ASD. Bidirectional influences between the family environment factors and child functioning were found, however the primary direction of effects was from the family environment to the child’s expressed behaviors. In their first study including 149 mothers with an adolescent or adult with ASD, Greenberg, Seltzer, Hong et al. (2006), found that high levels of criticism predicted an increase in the severity of internalizing and asocial behavior problems as well as in repetitive behaviors and restricted interests over the 18-month period, controlling for prior levels of problem behaviors and autism symptoms. A parallel study was conducted with 122 mothers of individuals with Fragile X Syndrome (FXS), a genetic developmental condition causing intellectual disability. This study concluded similar results indicating that higher levels of maternal criticism are related to an increase in externalizing and total problems in children with FXS.

In the reverse direction, high levels of maternal warmth and positive remarks were significantly related to decreased expression of problem behaviors, repetitive behaviors, and restricted interests in adolescents and adults with ASD and in adults with FXS. This is indicative of a strong influence in the direction of family environment/maternal EE to child behaviors. It was not found that initial levels of behavior problems and autism symptoms were predictive of levels of maternal warmth and positive remarks 18 months later, indicating a weak influence in the direction of child behavior to parent EE response.
The Family Impact: Model of Family Psychoeducation Program

With the aforementioned research as the basis, a strong case can be made for the need of an intervention aimed at reducing familial stress through providing support, increasing parental warmth and decreasing criticism. One such family-based intervention approach is that of Family Psychoeducational programs. These programs typically provide families with information about what is known about the cause, course, and outcome of the condition; effective interventions and treatments; community supports and resources; how the family is affected; behavior management; and vocation and residential planning (McFarlane, Hornby, Dixon, et al., 2002).

Studies by McFarlane, Dixon, Lukens, et al. (2003) have demonstrated the effectiveness of Family Psychoeducational Programs in improving the overall family environment and reducing behavior problems and symptoms in individuals with schizophrenia. Additionally, studies have shown similar effects in individuals with mood disorders (Colom, Vieta, Martinez-Aran, et al., 2003, Miklowitz, Georg, Richards, et al., 2003, Rea, Tompson, Milowitz, et al., 2003). The key finding behind such studies is that changing the family climate and context can potentiate changes in the mental health and adaptive outcomes of the individual with the disability (Smith et al. 2014).

“Transitioning Together and Working Together”

Research involving Family Psychoeducational Programs with adolescents with an autism spectrum disorder and their families was conducted by Smith et al. (2012) through a program they developed entitled “Transitioning Together”. Their basis for studying adolescents with autism was founded in the fact that familial stress is greatly increased during transitional times, such as adolescence, when reorganizations in the family system are taking place (Smith et al., 2002). “Transitioning Together” involved two individual joining sessions to establish goals followed by eight weekly sessions for parents and the youth with ASD. Session topics for the eight weekly sessions included transition planning, risks to independence, community involvement, health and well-being, and legal issues (Smith and Anderson, 2013). Data from their pilot work suggested that the program can improve the parent-child relationship and increase parental expressions of warmth as well as increase parental knowledge of the disability and the service system (Smith et al., 2014, Smith et al., 2012).

Given the surge in the number of diagnosed individuals with ASD who are entering adulthood, it is important to look at the provision of services for this age group. Smith et al. conducted a series of focus groups, concluding that the partnership and collaboration between adult service providers and family members was often lacking. In a study by Taylor & Seltzer (2011), over 25% of adults with ASD without Intellectual Disability (ID) are disengaged from work or post-secondary education. Given the correlation between meaningful work and quality of life, it is clear that the quality of life for these individuals is at risk. With the high proportion of adults with autism whom reside at home within the familial unit and the lack of appropriate formal supports for these young adults, the burden of supporting them falls on the family, consequently increasing familial stress.

The current research being done by Smith and colleagues is looking at the effects of a Family Psychoeducational Program, entitled “Working Together,” designed for young adults with autism (aged 18-30). Given the previously mentioned outcomes with related populations, it is hypothesized that a multi-family group psychoeducational intervention will lead to positive changes in family climate which in turn will influence adult behavior functioning and engagement in the community.
Conclusion

The family is the environment in which an individual first learns, grows, and develops. Thus, the centrality of the family within society is evident. Any positive change to the familial unit has a direct impact on society as a whole and research related to the development of positive family environments is of great importance. With the growing proportion of individuals in society with autism spectrum disorders (ASD), the need for research surrounding the impact of family environment on the phenotype of ASD and the quality of life of individuals with ASD is of great importance. As was concluded by the research done by Smith et al. (2014), high levels of maternal warmth and positive remarks were significantly related to decreased expression of problem behaviors, repetitive behaviors, and restricted interests in adolescents and adults with ASD, indicative of a strong influence in the direction of family environment on the expression of child problem behaviors.

Given the increasing number of individuals diagnosed with autism entering adulthood and the paucity of supports and services for this population, the need for familial supports and interventions are great. The current research being conducted using the Working Together multi-family psychoeducational intervention program seeks to address this need with the hypothesis that the intervention will decrease familial stress and increase quality of life and community involvement for young adults with autism.
Bibliography


