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Research Article

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A Transition Planning Program to Reduce Stress on a Parent Caring for an Adolescent with Autism Spectrum Disorder: A Pilot Study

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Abstract

Autism Spectrum Disorder affects approximately 3.5 million people in the United States [1]. The transition from childhood to adolescence poses an increase in parenting stress. A key component to the parenting stress is the feeling of unpreparedness for the next phase of life. Parents/caregivers need to be better prepared for these stressful years. Transition planning programs have proven to provide parents/caregivers with knowledge needed to face these years; however, there is minimal research examining the effect of a transition planning program on parenting stress. The sample for this pilot study consisted of parent/caregivers caring for an adolescent with Autism Spectrum Disorder who attended one of the two schools that were utilized in Northeast Ohio. The design consisted of a pre-test (Parent Stress Index-Short Form (PSI-SF), transition planning program, and a post-test Parent Stress Index-Short Form (PSI-SF). Data was analyzed using a paired t test. A Transition Planning Program provides information needed to prepare for the challenges that lie ahead therefore reducing the parenting stress.

Keywords: autism, adolescent, transition, parenting stress

Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder which affects 1 in 54 children [2] and approximately 3.5 million people in the United States [1]. Children with ASD exhibit symptoms that can continue and intensify as they grow older making the transition from childhood to adolescence increasingly difficult [3]. During this transition from childhood to adolescence, discussions about age-appropriate support services are limited [4] leaving the parent/caregiver feeling unprepared for the next phase of development [4]. The unpreparedness leads to an increase in parenting stress [5].

For this pilot study, the research question used was: What was the effect of a transition planning program on the stress level of parents caring for an adolescent (12-25 years developmentally) with Autism Spectrum Disorder.

Review of Literature

Numerous search engines: Google Scholar, PubMed, MESH, CINAHL, and Cochrane were used to gather qualitative, quantitative, and mixed method studies using keywords of: adolescent and autism and transition and parenting stress in the past five years. Two mixed method studies (one randomized controlled trial (RCT) design with randomly selected participants) [6] and one self-selected study [7] provided a better understanding of the problem of parenting stress when caring for an adolescent with ASD through the transition years. In another study, the authors [8] recommended better interdisciplinary collaboration (education, healthcare, and family) and adequate preparation for the transition from childhood to adolescence. Studies [6, 7, 9] were found examining the relationship of a transition program which resulted in 40% increase in new knowledge [9]. The relationship of transition planning program and knowledge had been minimally studied; however, there was a lack of research examining a transition planning program and its effect on parenting stress.

Theoretical Framework

The Family Resilience Theory, developed by McCubin in 1989, was the theoretical framework used to guide this pilot study. The theory guides interventions for the family to adapt, reduce stress, and dysfunction during a challenging event [10]. If no adaptation occurs, the family will remain in a state of dysfunction and stress levels remain present. The goal of the theory is for the family to adapt to the challenging event and regain a state of balance and healthy performance. Using a transition planning program will prepare the family caring for an adolescent with ASD for the challenges that lie ahead. Adequate preparation will allow the family time to adjust, reduce stress and regain a life of stability.

Methods

Setting/Sample

The pilot study was a pre/posttest design using a paired t-test for analysis. The two-week pilot study was conducted at two Northeast, Ohio schools: Potential Development (a nonpublic charter school) and The Rich Center for Autism (a nationally recognized facility for the study and treatment of autism). Both schools are dedicated to educating higher and lower functioning children and adolescents (ages 18 months to 25 years) diagnosed with ASD through educational and life skills training. A convenience sample of parents/caregivers was used from each school. The inclusion criteria were: parent/caregiver of an adolescent between the ages of 12-25 years (the age range is older due to developmental delays), diagnosed with ASD, and willingness to sign the informed consent document. Participants were excluded if inclusion criteria not met. Letters of support were obtained to utilize each school prior to the start of the pilot study.

Instruments

Instruments used included a demographic questionnaire and the Parenting Stress Index, short form. The demographic questionnaire was developed by the researcher and labeled with a random three-digit number for confidentiality. The end point was collecting nominal demographic data on the adolescent and the parent/caregiver. The Parenting Stress Index, short form (PSI-SF) was used to measure the dependent variable of parenting stress. The PSI-SF consists of 36 standardized questions, which was derived from the Parenting Stress Index, (PSI, full version of 101 questions). The PSI-SF has been used in a few studies [11, 12] with diverse populations and disabilities to measure parent stress with good reliability and internal consistency producing high Cronbach alpha [13, 14]. The PSI-SF was administered to parents with children 3 months to 10 years of age; however due to developmental delays this tool was appropriate for use in this pilot study. The PSI-SF was administered face to face with pencil and paper. The PSI-SF testing sheet was labeled with a random three-digit number (no personal identifiers were collected).

Intervention

Currently there are two programs, in the pilot study stage, but neither were ideal for this study due to time commitment and adolescent not parent focused. The first, The Volunteer Advocacy Program-Transition (VAP-T), a 12-week program [9], and second, Better Outcomes and Successful Transitions (BOOS-T), an online training geared for the adolescent with ASD [15]. Topics discussed in these programs included: Medicaid Waiver, Supplemental Security Income (SSI), education curriculum, and future living issues [9].

For this pilot study, a transition planning program (focusing on the above topics) was created by the researcher and presented to parent/caregiver participants face to face. The first component, transition and socialization challenges, covered areas of: challenges and socialization issues faced by the entire family and how to deal effectively. The financial, education and future living arrangement components were presented via prerecorded public webinar by an expert in each area. No permission was required due to public access availability. The second component was a public prerecorded webinar presented by Katy Bryan, PhD and Bryce Smetana, Skylight Financial Group (2018) titled, *Financial Strategies for Families with Special Needs: What's in Your Toolbox*. This webinar covered topics of financial position, life care planning, letter of intent, estate planning, and assistance programs in Ohio [16]. This presentation was made possible by a grant received in summer of 2017 by the Ohio State Bar Foundation and accessible through the Red Treehouse program of the Ronald McDonald House in Cleveland, Ohio. Components three and four, education reform (independent living skills) and residential living was addressed via public prerecorded video titled *First Steps to Independent Living* provided by the PACER Center in Minneapolis, Minnesota. The PACER Center (champions for children with disabilities) was established in 1977 and is a nonprofit parent training and information center funded through the United States Department of Education's Office of Special Education Programs [17]. The program focuses on "parents helping parents" by providing education, vocational trainings, parent workshops, and other resources for parents, families, and children and youth with disabilities across the nation (to date 2.2 million visits to the PACER website) [17]. Upon completion of the newly developed program, the participants were given an evaluation questionnaire. It consisted of 12 questions using a 5-point Likert scale where 5 was strongly agree to 1 strongly disagree.

Procedure

Institutional Review Board (IRB) approval was obtained prior to beginning the pilot study. If potential participants signed the consent form document, they were included in the study. On day one of the pilot study, the researcher handed the active participants a packet of all four questionnaires (pre-PSI-SF, demographic questionnaire, transition planning program evaluation, and post-PSI-SF) labeled with a random three-digit number. Instructions were verbally given for the PSI-SF and demographic questionnaire, to be completed by the active participants. Next, the transition planning program was presented by the researcher with a question and answer period in between each component. After the program, the transition planning program evaluation questionnaire was completed by each participant. To facilitate discussion around the

new information presented, lunch was provided to those participating in the study. After lunch, a post PSI-SF was completed by the participants. Two weeks post presentation, the researcher was available online to answer questions, offer support, and/or provide resources to the parent/caregivers. At completion of all components, the participants were given a stipend of a $10.00 gift card and a resource sheet which included web sites that can be utilized as a reference.

Results

Descriptive Characteristics

The sample consisted of active participants from both schools, Potential Development (n=10 or 58.8%) and The Rich Center for Autism (n=7 or 41.2%). The overall sample (N=17) was primarily female (88.2%) with an age range of 39 years to 72 years with a M=48.25 years. The primary ethnicity was Caucasian 88.2% and African American 11.8%. The majority (64.7%) of the sample was married, 17.6% single, and 17.6% divorced. The overall sample consisted of 17.6% attaining a high school diploma, 11.8% attended a trade school, 35.3% earned a college diploma, and 35.3% attended some college. The yearly household income range of the sample was <$40,000.00 to >$70,000.00 with 52.9% having a yearly income of <$40,000.00. The average number of members living in each active participant household was M=3.94. Of the overall sample, 13 out of 17 families had other siblings (M=1.82) and of those 13 families, seven had siblings who were diagnosed with ASD (M=.65) as reported by the parent/caregiver.

The adolescents with ASD ranged from 12 years to 18 years with a M=15.12 years. The average age when the adolescents were diagnosed with ASD was M=4.26 years. The majority were male (70.6%), Caucasian (88.2%), and verbal (76.5%). The adolescents within each school where placed in classrooms based on age and level of functionality. All the classrooms used technology (smartboards, IPADS, computers) with academic lessons and as assistive devices for nonverbal students. All the classrooms provided a dual focus of academics (math, science, language arts, and history) and life skills. Socialization was practiced in a variety of on and off school activities. For this pilot study, approximately 11.8% of adolescents were in the middle school room (ages 12-14 years), 35.3% in the intermediate room (ages 15-16 years), and 52.9% in the high school room (ages 17-18+years).

Pre/Post Parenting Stress Index-SF scores

Domain one, parental distress (PD), pre-PD (M=34.05, SD 9.70) falls in the typical stress percentile (score of 15-80). Domain two, parent-child dysfunctional interaction (P-CDI), pre-P-CDI (M=32.88, SD 11.26) falls in the typical stress percentile. The third domain, difficult child (DC), pre-DC (M=39.65, SD 10.31) falls in the typical stress percentile. Lastly, the total parenting stress score pre-score (M=106.59, SD 28.28) falls in the clinically significant stress percentile (score of 90-100+).

The post scores were, domain one, post-PD (M=32.12, SD 10.40) falls in the typical stress percentile. Domain two, post-P-CDI (M=32.71, SD 10.41) falls in the typical stress percentile. The third domain, post-DC (M=37.47, SD 11.04) falls in the typical stress percentile. The last domain the overall post-total parenting stress score (M=102.29, SD 29.88) falls in the clinically significant stress percentile. Pair 1 (pre-post PSI parental distress) showed statistical significance with a p value <.05 (paired t=3.801, df=16, p=.002). Pair 2 (pre-post parent-child dysfunctional interaction) was not statistically significant due to a p value >.05 (paired t=.185, df=16, p=.855). Pair 3 (pre-post PSI difficult child) was statistically significant with a p value <.05 (paired t=4.23, df=16, p=.039). Pair 4 (pre-post PSI total stress score) was statistically significant with a p value <.05 (paired t=7.78, df=16, p=.019).

Evaluation of Transition Planning Program Intervention

The newly created transition planning program was evaluated by the parent/caregivers at the end of the pilot study. Examining each component of the program, 94.1% of the active participants verbalized that they would use some portion of the information presented during the pilot study. Of these 94.1%, 35.3% expressed the information from the webinar presented by the Skylight Financial Group was most helpful.

Discussion

Parents/caregivers experience more parenting stress when caring for an adolescent with ASD than a typically developing adolescent [5]. When a child is diagnosed with ASD, many discussions occur during the early intervention phase, but as the child grows and transitions into adolescence, these conversations become less. This lack of conversation and age appropriate knowledge leaves the parents alone and unprepared to handle the transition from childhood into adolescence, leading to an increase in parenting stress [18]. Active participants in the pilot study were hoping to have conversations that would begin to cover some of the needed information focusing on this difficult time. The transition planning program was a way to begin the needed conversations for these parents/caregivers. Due to the lack of research focusing on parenting stress when caring for an adolescent with ASD, this pilot study was a stepping stone for future research. The program provided information on socialization issues and ways to promote socialization for the adolescents with ASD. It also focused on financial concerns, especially disability waiver and SSI, education reform and independent living. Even with the small sample size, positive results were identified. The decrease in parenting stress was measured comparing the total parent stress score via the pre/post PSI-SF. This pilot study concluded that providing a transition planning program to parents/caregivers of adolescents with ASD decreased parenting stress. The active participants expressed gratitude that these important areas were discussed.

Strength and Limitations

Strengths of this pilot study include, the use of two facilities to maximize the sample size of this vulnerable population. Parents/caregivers who participated in this pilot study were well educated having a minimum of a high school diploma and the majority

attended college and earned a degree. This pilot study focused on an area where little research has been conducted (transition from childhood to adolescence with ASD) which may lead to further research. The same trained researcher conducted this pilot study and used a valid and reliable standardized tool (PSI-SF) at both facilities. Providing a two week follow- up gave the parents/caregivers the opportunity to ask questions or clarification of a topic that was provided during the transition planning program intervention.

Limitations of the pilot study included a relatively small sample size that lacked diversity. The majority of parents/caregivers were females, primarily of Caucasian origin. Male input was lacking. Geographic region (residing county) data was not collected. Socioeconomic status within various counties could have played a factor in the level of parenting stress. Data collection was self-reported and from only one parent/caregiver per family of active participants. For more robust results, the post PSI-SF should have been done one-week post presentation of the transition planning program to allow parent/caregivers to process the new information. All data collected was hand scored by a trained member of the research team and categorized based on total score.

Finally, the transition planning program, a treatment protocol, was newly created for this pilot study so no integrity and fidelity were available. This sample of active participants with adolescent's age 12-20 years old had already begun much of their future planning. The majority of the content within the newly created transition planning program was review for this sample. Due to the content of the transition planning program, parents/caregivers of children age nine to fifteen years old would have benefitted most from this program.

Implications for Clinical Practice

The author acknowledges there is a lack of research in the area of transition planning programs with this population and in particular examining the effect on parent stress. A transition planning program can be used in a number of settings by different disciplines. The program will provide answers to many questions' parents/caregivers of an adolescence with ASD have in relation to the transition from childhood to adolescence. Educating others through the use of a transition planning program leads to more conversations about the needs of adolescents with ASD and their family which in turn will help prepare other parents. A transition planning program will aid in a more seamless and less stressful transition for the parent/caregiver, adolescent and the entire family.

This pilot study had a relatively small sample size and time frame however, produced positive results. The author acknowledges that the decrease in parenting stress after the transition planning program may have been influenced by situational variables; such as a relaxing setting away from the home environment, friendly conversation, and lunch. This pilot study was a stepping stone for future longitudinal research where these situational variables can be controlled to examine more closely the effect the program has on parenting stress. With no known cure, these individuals live with ASD throughout their lives. These parents/caregivers and adolescents with ASD deserve adequate and age appropriate preparation for the transition [4, 5, 19]. No matter where or when the transition planning program is used, the end result remains the same: efficient and consistent care.

Conclusion

The transition years from childhood to adolescence can be challenging and cause an increase in parenting stress. Much information is needed to prepare parents/caregivers of adolescents with ASD for this transition. Literature showed a key stressor was the lack of preparedness for the future. A transition planning program provides information to parents/caregivers necessary to help prepare for the transition from childhood to adolescence. The transition planning program showed a decrease in overall parenting stress of adolescents with ASD. Autism spectrum disorder is a lifelong disorder and if provided early on with the appropriate tools, parents/caregivers of adolescents with ASD can have positive outcomes.

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