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Social Support and Adherence to Recommendations Following ASD Diagnosis

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Acknowledgements

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Abstract

This experiment aimed to look at how social supports effected adherence to recommendations following a diagnosis of autism spectrum disorder. We hypothesized that families with higher levels of structural social support, as defined as more adults living in the home, help with child care, presence of a co-parent, and day care utilization, would also report higher levels of adherence to intervention recommendations. The participants (n=8) were caregivers of children diagnosed with ASD at either the University of Connecticut or Drexel University. These children were screened for ASD during a well-visit to their pediatrician, and upon failing the M-CHAT-R, were eligible for a diagnostic evaluation. If ASD was confirmed, the caregivers were contacted three months following the evaluation to complete a phone interview. Chi square tests and independent t tests were used to determine that the data was non-significant, because the respondents had all either initiated or began intervention. Exploratory analyses showed a significant difference between those who responded and those who did not when it came to diagnosis. All responders had an ASD diagnosis (n=8), while less than half of non-responders had an ASD diagnosis (n=4). Future studies may look at diagnosis as a factor in response and adherence.
Introduction

Autism spectrum disorder (ASD) is a developmental disability characterized by social and communication difficulties and stereotypic repetitive behaviors (The National Institute of Mental Health, 2018; Estes et al., 2009). Approximately one percent of the world population is currently diagnosed with ASD, and ASD was diagnosed in one in sixty-eight children in the United States in 2014 (Christensen et al., 2016). Many more are expected to be diagnosed with the fastest growing developmental disability (Christensen et al., 2016). A diagnosis of ASD has a life-long impact for the individual, regardless of the severity, and it can be both challenging and stressful for parents to maintain care (Johnson, Frenn, Feetham, & Simpson, 2011). One of the areas impacted by barriers to care is early intervention. Children who receive early intervention have been shown to attain more successful developmental outcomes than those without early intervention (Corsello 2005; Estes et al., 2009; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011).

There is a consensus in the literature that early intervention is critical to improving developmental outcomes for children with ASD. Early intervention takes advantage of a developmental period when the brain is most able to change and absorb new information (Center on the Developing Child, 2007). A diagnosis of ASD is generally considered a chronic or life-time diagnosis; thus, services may be recommended to build social, communication, or behavioral skills as early as possible. Importantly, effective intervention is in part determined by good adherence by families to recommended treatment, because positive outcomes are measured as a combination of consistent treatment delivered by clinicians and parents alike (Allen & Warzak, 2000). Despite the clear importance of early intervention, many parents face barriers to fully engaging with services. Economic obstacles such as transportation and work status are
better understood as barriers to engagement with intervention, but there is less research that explores the role of interpersonal factors such as social support in treatment adherence for families of children with ASD (Kazdin, Holland, and Crowley, 1997).

There are many types of social support, including structural and functional subtypes. Structural support relates to the number of social connections, while functional support refers to the strengths or weaknesses of the connections. Functional social support is defined in literature as family cohesiveness and conflict, while structural social support is defined as marital status and living arrangement (Dimatteo, 2004). In other words, structural support refers to the numbers of connections and level of integration in a social network (Barrera, 1986). This is exemplified in a family network through number of adults living in the home, the presence of a co-parent, or number of adults assisting with childcare.

It is clear that structural social supports have an impact on health behaviors, treatment effectivity, and mental health. Structural supports such as marriage and the presence of another adult in the home are linked with facilitating positive health behaviors in adults, including following through with recommended medical treatments (Umberson, 1987; Dimatteo, 2004; Moore & Symons, 2009). Likewise, insufficient social support (defined as few supportive friendships, uninvolved relatives, and an unavailable partner) is linked to constrained treatment effectiveness and maternal psychological distress (Allen & Warzak, 2000; Bromley, Hare, Davison, & Emerson, 2004). Greater structural social support appears to be related to greater adherence to intervention, which maximizes the potential effectiveness of intervention.

Several studies have examined the relationship between social support and stress within families with a child with ASD. One study found that fifty-nine percent of mothers raising children with ASD screened positive for psychological distress, which was correlated with lower
familial support, a form of structural social support (Bromley, Hare, Davison, & Emerson, 2004). Single mothers raising a child with ASD also reported lower familial social supports than mothers living with a partner (Bromley, Hare, Davison, & Emerson, 2004). These findings indicate the importance of social support in caring for a child with ASD. Similarly, social support in the form of a partner, other family members, and friends were each correlated with lower levels of depression and parent stress for mothers of children with ASD (Ekas, Lickenbrock, and Whitman, 2010). Overall, stronger social supports appear to be linked with less parenting stress. Elevated parenting stress is related to worse adherence to intervention in children with chronic medical conditions such as diabetes and may play a similar role in intervention adherence for other chronic childhood diagnoses (Streisand, Swift, Wickmar, Chen, & Holmes, 2005).

There is currently little research regarding the relationship between structural social supports and parental adherence to recommended interventions following an ASD diagnosis. A potential barrier to adherence is a lack of structural social support, likely because the absence of a co-parent or other adult assisting with childcare means there are fewer resources available to promote follow-through with treatment (Allen & Warzak, 2000). For instance, a second adult assisting with childcare may be able to assist with driving to appointments, help with implementing in-home therapy, or may be a source of financial support. Additionally, if there are more structural social supports in place in the family, like a partner or family member, it is easier to continue intervention in the home setting as well (Estes et al., 2009). In one study of children with a diagnosis of ASD below age 18, it was found that the interaction between the diagnosis severity and marital status predicted adherence to medical treatment (Moore & Symons, 2009). If the parents were married and the child received a diagnosis considered more severe on the
autism spectrum under DSM-IV diagnostic criteria, they were more likely to adhere to medical treatment. In this study, medical treatment was defined as office visits with a psychologist, psychiatrist, or other medical doctor. From these studies, it seems that caregivers with more structural supports in place may be better able to adhere to intervention recommendations. As stated above, adherence to intervention is critical to optimal developmental outcomes for children with ASD, so it is equally critical to understand what prevents adherence.

Much of the research on the relationship between structural social support and treatment adherence is focused on disorders such as developmental delay and intellectual disabilities, and those that do include ASD may center on medical recommendations rather than behavioral intervention recommendations. When studies include both an ASD sample and social supports they tend to exclude intervention adherence, especially in a clinical setting. Compared to the great number of studies on treatment effectiveness, treatment adherence research is scant (Allen & Warzak 2000). Definitions of structural social support vary across the current research as well, causing discrepancy among studies when it comes to variable measurement and coding. This makes it challenging to gain a sense of what, if any, relationship exists between structural social supports and treatment adherence for children with ASD and their families.

The current study aims to determine whether the level of structural social support, specifically relating to child care assistance, is related to adherence to recommendations for intervention following an ASD diagnosis. In this study, structural support is operationally defined as the presence (or lack of) adult help with childcare, a co-parent or other adult(s) living in the home, and daycare utilization. Adherence is measured as parents’ self-report of engagement with early intervention services, defined as either initiating or beginning recommended services. We hypothesized that parents with low structural support (e.g. lack of
another adult in the home, second parent not present, or no other individuals participating in care) will have a low adherence to recommendations, and parents with high structural supports will have a high or moderate adherence to recommendations.

The current study will expand upon the literature regarding adherence to behavioral intervention recommendations for ASD, as well as contribute to the understanding of the role of structural social support to adherence. In addition, the impact of this study will contribute to understanding good clinical practices for facilitating parent engagement with intervention. By furthering knowledge about the relationship between structural social support and adherence, clinicians will be better able to evaluate families for social support resources. Second, individually tailored recommendations will increase effective communication of feedback to caregivers following an evaluation by taking structural social support into account. It is critical that clinicians make recommendations for intervention that are feasible for caregivers, and better understanding the available structural social support for families will guide clinicians towards improved communication. Increased understanding of adherence in the context of structural social support for children with ASD will allow clinicians and other service providers to develop techniques to increase parental commitment to early intervention.

Methods

Participants

The participants in this study were parents of children participating in the Early Detection Project, a population-based study intended to evaluate the performance of three ASD screeners in children aged 12-24 months at the University of Connecticut, Drexel University, and Georgia State University. The screeners included the M-CHAT-Revised/Follow-up (M-CHAT-R/F; Robins et al., 2014), the First Year Inventory (FYI; Turner-Brown, Baranek, Watson, Crais, &
Reznick, 2001), and the Infant Toddler Checklist (ITC; Wetherby, Brosnan-Maddox, Peace, & Newton, 2008). Due to a low number of recruited individuals (n=1) from GSU, the current sample included only participants recruited from the University of Connecticut and Drexel University.

At the University of Connecticut, pediatricians at participating offices in the community invited caregivers to participate in screening at the child’s well-visit, if the child was in an eligible age range. Screening required the caregiver to complete the M-CHAT-R, which was then scored by the Early Detection Laboratory. If the child screened positive, the caregiver was contacted via telephone to confirm the failed items. Once a screen positive was confirmed, the family was invited to participate in a free diagnostic evaluation. If the child did not fail the screening measure but pediatrician concerns were noted, they were also invited to participate in a diagnostic evaluation. If transportation or distance are barriers to a family participating in the evaluation, the evaluation was conducted at the family’s pediatrician’s office.

At Drexel University, caregivers were also invited to participate in screening by pediatricians at a well-child visit. Children are also entered the study through day care centers, and in that case they were referred by the day care teacher. Caregivers completed the screening electronically or on paper, both of which consist of the M-CHAT-R. The electronic screening was immediately scored, and follow-up questions were completed following scoring. Paper screenings were scored by researchers, and then the caregivers were contacted to complete follow-up questions. Children who were determined to be at risk for autism spectrum disorder via the initial screening by either method were invited via telephone to participate in a diagnostic evaluation. If the child did not fail the screening measure but pediatrician concerns were noted, they are also invited to participate in a diagnostic evaluation.
After the evaluation at both recruitment sites, caregivers were provided with recommendations and resources appropriate to any diagnosis received. A comprehensive written report was mailed to the family after the evaluation, and families were informed they may be contacted for long-term follow-up studies as well. Consent to follow-up studies was included in the initial consent. Children with incomplete screening measures, those with a prior diagnosis of ASD or a medical diagnosis (e.g., epilepsy), and those who were lost to contact following the phone interview are excluded from this study.

Only English-speaking families were eligible for participation in the follow-up interview procedure due to limited availability of Spanish-speaking staff.

Procedures

Across sites, a licensed clinical psychologist or developmental pediatrician and a graduate student in clinical psychology conducted the evaluations; each evaluation consisted of parent interviews and child testing to assess the child’s cognitive, adaptive, and language skills as well as ASD-specific measures. Diagnoses were made based on the clinical judgment of experienced clinicians following DSM 5 criteria (American Psychiatric Association, 2013). Diagnoses included language disorder, global developmental delay (GDD), and autism spectrum disorder (ASD). All families with a diagnosis received a comprehensive report detailing recommendations for intervention approximately six weeks after the evaluation. Families who were lost to contact following the evaluation were excluded from this phase of the study.

Approximately three months after the family received a diagnosis, they were contacted by a graduate or research assistant by phone to complete the Evaluation Follow-Up Interview. Each phone interview was recorded. The caregiver was asked to answer a series of questions
pertaining to their experiences during and after the evaluation, adherence to recommendations, and reasons for or against adherence.

Interviews generated the outcome variable of interest: parent reported engagement with early intervention services, defined as either initiating or beginning recommended services. Family history forms generated independent variables related to structural social support, namely the presence of adult help with childcare, a co-parent or other adult(s) living in the home, or daycare utilization. Generally, the help with care and daycare variables were coded as (1) no, or (2) yes, while number of adults in the home was a continuous variable.

**Measures**

The *History Form* was used to gather information about the children and families. Caregivers provided data such as demographic information (age, gender, race/ethnicity, years of maternal education, yearly income), marital status, use of daycare, and reported whether other adults engaged in the care of the child.

The *Evaluation Satisfaction Interview* required roughly twenty minutes to complete and was given over the phone. It included questions to assess parents’ satisfaction with evaluation and the feedback process, as well as specific questions regarding whether parents began services and what services they initiated.

**Results**

*Overall Sample Characteristics*

The participants in this study from UConn (n=9) were predominantly non-white (78%, n=5), had services in place prior to the study (78%, n=7), and the children were on average 21 (SD=3) months old at follow-up. The average maternal education level of the sample was 14 years, or two years of education beyond high school, and the average annual income was
$60,001-$72,000. The participants from UConn had four diagnoses of autism spectrum disorder, four of global developmental delay, and one of language disorder.

The participants in this study from Drexel (n=10) were predominantly white (70%, n=7), had services prior to the study (70%, n=7), and the children on average were 23 (SD=7) months old at follow-up. The average maternal education level was 16 years, or four years of education beyond high school, and the average annual income was $60,001-$72,000. There were eight autism spectrum diagnoses and two global developmental delay diagnoses among the participants from Drexel.

There was no statistically significant difference between the participants from Drexel and from UConn on the basis of race, age at follow-up, level of services prior to evaluation, maternal education level, or income level. There was a trend-level difference between the ages of contact at the two sites, driven by an outlier in Drexel’s group, but we determined it was of low clinical significance [Table 1].

Next, the participants who responded to the follow-up interview (n=8) were analyzed as a group. Every participant had a diagnosis of ASD (n=8), and most had prior services in place (75%, n=6). All of the respondents had contacted services, and those who had not begun services were on a waitlist (n=2).

Structural Social Support Variables

The variables of interest were participation in daycare, number of adults in the home, and adult help with care. Across the whole sample (n=19), the majority of participants indicated no daycare use (80%, n=15), but indicated help with childcare (47%, n=9). We did not obtain
information for four participants regarding the help with childcare variable. There was an average of two adults in the home across all 19 participants.

Among the group that responded (n=8), the majority of participants indicated the presence of help with childcare (63%, n=5) and no daycare use (88%, n=7). In this group, we did not obtain childcare data for one participant. There was an average of two and a half adults living in the home with six participants (75%) indicating they were married. Because this group was also homogenous in the variables of interest, and all reported increasing, beginning, or attempting to begin services, we turned to exploratory analyses to examine differences between the participants who participated in the follow-up interview and those who did not.

**Exploratory Analyses**

Age in months at evaluation, race and ethnicity, services prior to study, maternal education levels, income levels, and diagnosis were analyzed using between the group of responders and the group of non-responders. Among the responders (n=8), there was an average child age of 23 months at evaluation, the group was predominantly white (75%, n=6), and the majority of responders had services in place prior to the evaluation (75%, n=6). The average maternal education level was 16 years, or four years of education following high school. The average yearly income was $72,001 - $84,000. All participants were diagnosed with autism spectrum disorder (n=8). The average total number of hours of intervention for the group of responders was 12, which is 55% of the average recommended level for this group. Adherence was calculated by diving the number of hours of intervention each individual receives by the recommended level, depending on evaluation location, and the resulting percentages were averaged. UConn recommends 15-20 hours of intervention each week, while Drexel recommends 25 hours a week.
Among the group of non-responders (n=11), the average child age at evaluation was 22 months, the group was predominantly non-white (55%, n=6), and the majority had services in place prior to the evaluation (73%, n=8). The average maternal education level was 15 years, or three years of education following high school. The average yearly income was $48,001-$60,000. Most participants were diagnosed with a global developmental delay (55%, n=6), with four participants diagnosed with autism spectrum disorder and one diagnosed with a language delay.

There was no significant difference between the groups in age, race/ethnicity, services prior to study, maternal education levels, or income levels. There was a significant difference by diagnosis, such that participants who completed the follow-up interview were more likely to have a diagnosis of autism spectrum disorder (p<.05). [Table 2].

Discussion

The initial purpose of the study was to determine whether variables such as having other adults in the home, day care, or help with childcare increased the parental adherence to recommendations following a diagnosis of autism spectrum disorder. However, following analysis of the variables, we discovered that the group of participants who responded to the follow-up interview was homogenous in terms of their adherence, as defined in this study. All had initiated services, and those who had not yet started them were on a waitlist to do so. Based on the small sample size of respondents (n=8), we are unable to comment on the impact of structural social support on follow-through because everyone in the sample followed through. Because of this, we instead turned to examine at the difference between the group who responded to the follow-up interview and those who did not.
Although we cannot draw many conclusions from the small sample, it is interesting to note that parents appeared more likely to respond if their child received a diagnosis of autism spectrum disorder, rather than global developmental delay or a language delay. Families with an ASD diagnosis may be more motivated to participate in follow-up because the diagnosis is perceived as more severe than GDD or LD. For a diagnosis such as ASD, more hours and more types of intervention are typically recommended. Similarly, if parents have already been utilizing state sponsored early intervention services such as Birth to Three and their child receives a diagnosis of GDD, they may not be eligible for an increase in services. This, of course, would preclude parents from making any change to their level of service interaction and may have deterred parents from participating in an interview about intervention engagement.

The group of responders also only shows us a specific economic upper-middle sample of people. Of the eight participants that responded, three indicated that they make over $96,000 a year, four indicated that they make between $60,001 and $72,000 a year, and one indicated making between $48,001 and $60,000 a year. Although the average income of this group was not statistically different from the average of the non-responders, five non-responders indicated making under $36,001 a year and five indicated making over $96,000 a year, with one making between $48,001 and $60,000. Because of this divide in non-responders and responders, we miss people with fewer resources and an abundance of resources in the responder group. Individuals with fewer resources available due to lower income may have less time or ability to complete the follow-up interview, while individual with more financial resources may have found that they were capable of completing the interventions and did not believe the follow-up interview was worthwhile.
This study is one of few studies that examines adherence to recommendations following a diagnosis of ASD in very young children, and it adds to the body of literature by inquiring into the role of structural social supports in adherence. This study is limited because we rely on self-report, so there is no way to ensure that the data we are provided with is entirely factual. The sample is also somewhat self-selecting due to a high average for education and income levels, so we are only characterizing a well-resourced section of the demographic. This self-selection bias leads to exclusion of very low and very high-resourced families, which in turn denies us a clear understanding of the full scope of engagement across a diverse socio-economic spectrum. A small sample size also makes it difficult for us to draw conclusions about the initial variables of interest.

As we learned, albeit from a small sample size, social support did not appear to be related to participant interaction with services following recommendations. Clinicians especially may benefit from this knowledge in order to keep their own potential biases in mind and refrain from assuming that someone with less social supports is less likely to follow through on recommendations. Clinicians working with a family with low structural support may work less hard to get parents to “buy in” to recommendations because they believe they will not follow through anyway. In this research, that assumption is not supported by data. This study provided very limited evidence that things we may traditionally assume to interrupt intervention are actually barriers, such as race, ethnicity, maternal education, and social support levels. However, this information can only be applied to economically upper-middle class families based on the data of the present study, so people on each end of the income spectrum may need different supports.
Future directions for research may include further examination of these variables, in addition to structural support variables, to understand adherence in families of children with ASD. Functional support variables may also be analyzed in future studies to understand whether quality of social support has a greater impact on adherence than quantity does. In order to gather a larger sample size, incentives may be offered to reach people from a wider demographic range and therefore increase generalizability of findings.
**Table 1**

*Sample Characteristics by Site*

<table>
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<th>Drexel (n=10)</th>
<th>t or $X^2$</th>
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<tr>
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References


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