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Brief report: Service implementation and maternal distress surrounding evaluation recommendations for young children diagnosed with autism

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Abstract

There is limited evidence surrounding the ability of families of children with autism spectrum disorders to access and implement recommended interventions following diagnosis. The distress a family may encounter with regard to inability to access recommended services is also poorly understood. In this study, we present preliminary data regarding implementation of clinical recommendations following autism spectrum disorder diagnosis as well as associations of implementation with maternal functioning. In total, 75 mothers of young children diagnosed with autism spectrum disorder through a university-based preschool autism clinic returned surveys regarding access to recommended services as well as maternal mental health and distress. Results indicate that while families were able to implement numerous recommendations, specific categories of intervention were less likely to be received. Challenges implementing recommended services were not related to increased maternal distress. These results suggest that despite potential barriers toward accessing some specific recommended services following diagnosis of autism spectrum disorder, many families may be quite successful in implementing many other core recommended services and that failure to access such services may not necessarily negatively impact maternal mental health and distress.

Keywords

adherence; autism spectrum disorders; caregiver distress; diagnosis; service implementation

Introduction

With an estimated prevalence of 1 in 88, effective early identification and treatment of autism spectrum disorder (ASD) represent pressing public health and clinical care issues (Center for Disease Control and Prevention, 2012). While numerous professional groups have endorsed methodologies for early screening and identification (see Johnson and Myers, 2007), and there are extensive public awareness campaigns attempting to educate individuals about the earliest “red flags” of ASD (see Center for Disease Control and Prevention, 2010), the process of accurately screening for concerns, obtaining appropriate clinical diagnostic assessment subsequent to screening, and translating a diagnosis into potent, appropriate, and meaningful intervention is complex and stressful for families of children with ASD and their pediatric providers (Bailey, 2008). Many barriers exist within this process, including screening and evaluation tools with substantial limits, cumbersome care system bureaucracies, lengthy waits for specialized evaluation and treatment services, limited and expensive intervention services and resources, as well as fundamental limitations in our knowledge base about the specific impact of interventions for young children with ASD (Al-Qabandi et al., 2011; Warren et al., 2011). Given this complex context, there have been recent criticisms of early identification and universal screening procedures based on the assumptions that we have very limited information on whether families can access appropriate services subsequent to diagnosis in a manner that promotes optimum functioning, rather than contributing to substantial distress (Al-Qabandi et al., 2011).

Caregivers of children with ASD often report elevated levels of depression and distress compared to caregivers of individuals with other developmental and behavioral disorders (Dumas et al., 1991; Estes et al., 2009; Gallagher and Bristol, 1989; Montes and Halterman, 2007). While it is clear that parents of school-aged children with ASD report experiencing elevated distress (Hastings, 2003; Lecavalier et al., 2006; Lounds et al., 2007; Tomanik et al., 2004), far less is known about caregivers of younger, recently diagnosed children (Carter et al., 2009). These caregivers are often placed in the difficult roles of expert advocates, resource specialists, and interventionists (Hutton and Caron, 2005; Warren and Stone, 2011). Therefore, caregiver distress following an ASD diagnosis may be especially deleterious, as it holds the unfortunate potential for not only adversely impacting day-to-day life of the caregiver and family, but also potentially impeding service access and delivery during what is thought to be a critical window of neurobehavioral plasticity (Dawson, 2008; Osborne et al., 2008).

The current study represents a brief empirical evaluation of the ability of caregivers of young children to implement recommended interventions following an ASD diagnosis (see Taylor and Warren, 2012). We examined not only the specific types of interventions accessed and implemented, but also the association of implementation, or failure to implement, with parenting distress. We hypothesized that most families would report ready access to certain categories of service (e.g., publicly mandated/funded educational services), but report more difficulties accessing intensive autism-specific interventions (e.g., Applied Behavior Analysis (ABA) based intensive intervention). Finally, we hypothesized that families struggling to access a large number of recommended services would more likely endorse significant symptoms of distress than families capable of accessing and implementing such services.

Methods

Participants and design

This sample was drawn from a systematic approach of all families ($n = 201$) receiving an ASD diagnosis from a university-based autism diagnostic center for young children over a 3-year interval. All families were invited to complete a mail survey designed to assess caregivers' experiences of initial disclosure of ASD diagnosis, subsequent service access, caregiver depression and well-being, child behavior, as well as other areas of child and family functioning. This survey took approximately 2 h to complete and was administered at one single point in time, which was an average of 1.38 years ($SD = 0.75$) after the child had received an ASD diagnosis.

Eighty-two caregivers, primarily mothers (91%), completed and returned the survey, yielding a response rate of 41%. Clinical data from each child's initial diagnostic evaluation were extracted from the medical record, including demographic information, measures of cognitive ability, adaptive behavior, autism symptoms, as well as recommendations offered within the clinical report provided to families (see Taylor and Warren, 2012).

There were no significant differences between respondents ($n = 82$) and nonrespondents ($n = 119$) at the time of evaluation regarding family income, child cognitive abilities, adaptive behavior, child age, or Autism Diagnostic Observation Schedule severity scores (Gotham et al., 2009). Given limited paternal participation, all subsequent data analyses were restricted to maternal data ($n = 75$). The sample was primarily Caucasian (91%), married (89%), and had boys with ASD (88%). The median household income was between US\$50,000 and US\$60,000, with 25% of the sample having incomes less than US\$30,000 and 25% having incomes greater than US\$90,000. Nearly 39% of mothers had a high school education or less, and 53% of the sample completed at least a bachelor's degree. Children in the sample averaged 3.61 ($SD = 1.44$) years of age at the time of diagnosis with some 76% of the sample representing children under 36 months of age. The majority of families (76%) reported having concerns about their child's development on or before 24 months of age, and 73% of families reported waiting for more than 6 months (with 41% reporting a waiting time of more than a year) to receive their child's diagnosis. The children in this sample attended 65 different schools in 39 counties across Tennessee and neighboring states.

Measures

As part of a larger survey, caregivers completed measures assessing (a) implementation of recommended intervention services as well as (b) parenting and psychological distress.

Implementation—Caregivers were presented with a list of common clinic interventions (see Table 1) and asked whether the specific recommendations were implemented. Original recommendations made by the clinical psychologist conducting the evaluation were extracted from the evaluation by two research assistants blinded to participant identifiers, survey responses, and other clinical evaluation data. Raters completed the same checklist about recommendations (i.e. coded whether common list of services were recommended) that parents completed within the survey based on reading the psychological evaluation report recommendations. Ambiguous codes and discrepancies (e.g. whether wording of a specific recommendation indicated a specific code) were discussed and adjudicated via research team discussion and consensus rating. As the scope, number, and type of recommendations varied by child and family, an overall nonweighted percentage of recommendations implemented variable was calculated. This was accomplished by dividing (a) the number of recommendations implemented by the caregiver by (b) the number of recommendations extracted from the original clinical assessment report for the specific

family/child (i.e. implemented recommendations/all recommendations). Importantly, this was a simple tally of endorsed and/or coded recommendations, respectively, with no specific measure of intensity or relative clinical import of the content of the recommendations.

Maternal distress—In terms of indexing psychological and parenting distress, mothers were asked to complete the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977), a 20-item self-report questionnaire indexing depressive symptoms over a 1-week period; the Beck Anxiety Inventory (BAI; Beck et al., 1988), a self-report questionnaire of 21 symptoms of anxiety experienced in the past week; and the Parenting Stress Index–Short Form (PSI; Abidin, 1995), a 36-item self-report which comprises three scales: Parental Distress, Difficult Child Characteristics, and Dysfunctional Parent–Child Interaction. Total scores from each of these indices were used as primary measures in analyses.

Analytic plan—Given presumed non-normal distribution of the percentage of recommendations implemented variable, nonparametric correlations were conducted to determine bivariate relations between percentage of services implemented and measures of parental anxiety, depression, and parenting stress.

Results

There was substantial variability in terms of successful implementation of services (see Table 1). While a majority of mothers reported considerable success in terms of implementing educational and/or early intervention services (Individualized Educational Program (IEP), 85.7%; Individualized Family Service Plan (IFSP), 95.5%; and conducting specific readings, 94.5%), some mothers reported more moderate success regarding implementation of autism clinic followup visits (74%), speech/language intervention (74.2%), occupational therapy (OT) (67.7%), and medication consultation (66.7%). Only a minority of families reported the ability to implement recommendations regarding ABA-based intensive intervention (42.1%), sleep evaluations (30.8%), and genetic testing (29.6%).

Examination of the overall nonweighted percentage of recommendations implemented variable revealed the following: 54 (72%) mothers implementing greater than 75% of recommendations, 11 (14.6%) implementing between 50% and 75%, 7 (9.3%) implementing between 25% and 50%, and 3 (4%) implementing less than 25% of recommendations. In order to evaluate the potential impact of difficulties implementing recommendations on maternal mental health and parenting stress, nonparametric correlations were examined between the percentage of recommendations implemented and BAI, PSI, and CES-D scores. No significant relations were found (see Table 2). Based on the fact that families frequently reported challenges implementing ABA-based intensive intervention, independent samples *t*-tests were utilized to examine potential differences for families implementing or failing to implement this specific recommendation. No statistically significant differences regarding implementation of this service with BAI ($t = -0.45$, $p = 0.65$), PSI ($t = 0.20$, $p = 0.85$), CES-D ($t = -0.15$, $p = 0.88$) were present. Differences in terms of implementing ABA-based intensive intervention were also not directly related to family income level.

Discussion

The current study represents a brief, preliminary investigation of the ability of a small but geographically and socioeconomically diverse clinical sample of mothers of young children with ASD to access and implement common recommendations following diagnosis. Results indicate that a substantial majority of mothers (72%) reported that they were able to

successfully implement most interventions (i.e. >75% of offered recommendations). Furthermore, challenges implementing recommendations within this sample were not significantly associated with differences in terms of maternal depression, anxiety, or parenting stress. This was somewhat surprising as we had hypothesized that such difficulties might be present; however, this suggests that the interplay of service access and parental distress may likely be a complex and dynamic process involving a number of factors. One specific possibility is that perceived global efficacy may not necessarily be tied to single categories of intervention or services that may be difficult for many, if not most, to access. Given that some 29.3% of mothers in the current sample met the CES-D clinical risk cutoffs for depression, and 78.7% had retrospectively reported exceeding a similar cutoff regarding the week following diagnosis (see Taylor and Warren, 2011), the limited evidence of negative association on maternal functioning takes on more meaning.

It is important to highlight several methodological limitations of the current investigation. Our findings are purely correlational, and we relied entirely on self-report. The sample was neither ethnically nor culturally diverse, with single parents, particularly, underrepresented. In addition, while no significant differential response patterns were noted regarding initial characteristics of children/families completing the survey and those not doing so, there could in fact be powerful differential response patterns related to key study outcomes. It is entirely plausible that families struggling to implement recommendations, as well as families experiencing more potent distress, were far less likely to respond to this lengthy survey. Furthermore, our findings do not take into account many factors that could affect service access and implementation (e.g. previous involvement with intervention services prior to evaluation, disagreement/agreement with specified recommendations, etc.). Given these limitations, as well as the complex biopsychosocial interactions known to be related to depression, anxiety, and stress, we must be cautious about interpreting and generalizing current findings. Specifically, knowing that parents of children with ASD consistently report high levels of parenting and psychological distress as their children develop, the absence of a relation at one point should not be interpreted as evidence of a lack of complex contribution and role over time. Future research addressing such questions from a prospective framework could help clarify such relations.

It is also important to note that implementation of service recommendations represents only a portion of the multifaceted construct of “adherence” with psychological evaluation recommendations. Adherence as a construct concerns numerous child, parent, family, and system factors beyond the scope of the current review (Geffken et al., 2006). Furthermore, adherence as applied to recommendations following ASD diagnosis become all the more complex in that implementation of certain categories of intervention often primarily depends on many external factors that may not be within the control of certain families (Warren and Stone, 2011).

Despite significant methodological limits, current results suggest that (a) in the face of numerous potential barriers toward accessing recommended services, many families with young children with ASD may be quite successful in implementing core recommended services subsequent to diagnosis and (b) failure to implement services may not be powerfully related to maternal distress for many families in the aftermath of a diagnosis of a young child. Therefore, it does not appear to be universally the case that families of recently diagnosed young children with ASD will experience deleterious distress as a result of challenges in implementing recommendations. We must be cautious in generalizing to the entirety of screening populations based on this sample that was able to successfully pursue ASD diagnosis at an early age. At the same time, specific broad criticisms of early universal screening programs may warrant significant revision, if certain families can in fact implement many recommended services.

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Table 1

Chart documentation and maternal report of implementation of recommendations.

Recommendation	Chart documented	Implemented
ABA services	57	24 (42.1%)
Accessing specific books/websites	73	69 (94.5%)
Clinic follow-up	50	37 (74%)
IEP	63	54 (85.7%)
IFSP	22	21 (95.5%)
Genetic testing	71	21 (29.6%)
Parent workshops	39	27 (69.2%)
Psychopharmacology	9	6 (66.7%)
OT	65	44 (67.7%)
Sleep evaluations	26	8 (30.8%)
Speech/language	62	46 (74.2%)

ABA: Intensive Applied Behavior Analysis Intervention; IEP: Individualized Educational Program; IFSP: Individualized Family Service Plan; OT: occupational therapy.

Table 2

Correlations between implementation percentage and clinical scales.

Clinical scale	<i>r</i>	<i>p</i>
BAI	0.129	0.271
PSI	−0.007	0.954
CES-D	0.107	0.361

BAI: Beck Anxiety Inventory—total score; PSI: Parenting Stress Inventory—total score; CES-D: Center for Epidemiological Studies Depression Scale—total score.