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Parent-Nominated Symptoms as an Outcome Measure in Autism Intervention Research

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Abstract

The purpose of this study was to examine the feasibility of collecting quantitative measures from parents or other caregivers about the symptoms present in their children with autism spectrum disorders that are of most concern to them and may be ameliorated through intervention. These symptoms were measured by asking questions about frequency, duration, and interference with daily function and family life. The most common symptoms identified by parents were problems with communication/speech and socialization impairments. Parents and caregivers were able to provide quantitative information, and their responses appeared to describe things that would be sensitive to change. The Parent-Nominated Symptoms Questionnaire seems to be a reliable measure when creating interventions and provides variability of symptoms.

Introduction

Autism spectrum disorders (ASD) comprise a set of developmental disorders that are characterized by impairments in social and communication skills as well as the presence of restrictive, repetitive, and stereotypic behaviors (American Psychiatric Association, 1994). A characteristic of the disorder is the heterogeneity of its presentation. A challenge raised by this heterogeneity is that it is difficult to measure symptoms and changes in symptoms over time for a group of children with ASD using a single measure (Levy et al., 2009). This is particularly a problem in treatment studies. A second challenge in measuring outcomes for children with psychiatric and developmental disabilities in general is the measures’ ecological validity—that is, the extent to which they measure constructs that relate to
functioning in real-world settings. To address both challenges, researchers have sometimes turned to “parent-nominated symptoms” to assess outcomes in treatment trials.

Parent-nominated symptoms are the target symptoms that parents and caregivers identify in their children that are of most concern to them. They are measured by frequency, duration, and interference with daily function or family life. Parents are asked to provide detail about the symptoms their children exhibit that cause them the most concern. It is likely that standardized scales, though very helpful and reliable, can overlook certain domains as well as the exact items that are most important to the child and to parents and caregivers (Arnold et al., 2003). Parents and caregivers may be an important source of information regarding symptoms that their children exhibit that are of most concern to them and their family and may represent intervention targets.

The strategy of collecting information on parent-nominated symptoms has been used in pharmacological studies of children with ASD. For example, an individualized target symptom assessment originally described by Arnold et al. (1972) and used in later studies in attention-deficit/hyperactivity disorder (Arnold et al. 1976, 1978) was used in the Research Units on Pediatric Psychopharmacology (RUPP) Autism Network 8-week double-blind trial of risperidone versus placebo (Arnold et al. 2003). Clinicians interviewed parents at baseline and asked them to identify target symptoms that were assessed again at the end of the study. The target symptoms assessment was used as an outcome measure and was highly correlated with other standardized measures used.

The current study sought information from parents which clinicians may rate in order to track the changes in parent-nominated symptoms. This was done to take a qualitative measure and turn it into a quantitative measure. The study also tested the feasibility of refining and replicating this strategy in a behavioral study while shedding light on key symptoms that were relevant to parents and caregivers and could be important targets for intervention and measuring intervention effects. The drug trial sampled families that were of a higher socio-economic status (SES) and that had higher rates of literacy competency. The participants in the present behavioral study, on the other hand, were of lower SES, and many had literacy issues. Replicating the strategy from the drug trial was important in order to gain information from this underrepresented population.

Methods

Data were collected from the parents and caregivers of children that were enrolled in an ongoing randomized trial of a behavioral intervention, the Autism Instructional Methods Study (AIMS), taking place in the School District of Philadelphia. The sample included only those children still in the study
who have been floorin, or scoring the lowest possible score, on the standardized instruments being used as outcome measures in AIMS. Children in the lower-functioning autism population that are unable to complete standardized instruments are often not represented in autism studies, so it was important to focus mainly on them in this study.

Eighteen families were contacted for semi-structured phone interviews. They were asked questions about the domains of communicative and social impairments as well as maladaptive behaviors. This was done to ensure that the key characteristics that warrant a diagnosis of ASD were addressed. A phone script (see Appendix) was created for use when conducting phone interviews with parents and caregivers as well as a verbal consent form that was read to interviewees before questions about parent-nominated symptoms were asked.

Parents and caregivers were asked questions about the symptoms they are most concerned with. These questions asked about frequency and duration of the symptoms and how they interfere with daily life of the parents/caregivers and the family. The information was elicited by specific questions if necessary (“How often? How long each time? How many hours a day? How does it interfere with daily activities?”).

Results

Parents and caregivers made 36 reports (each parent reported 2 symptoms). The symptoms that they identified included problems with communication/speech (10), socialization/social interaction (7), hyperactivity/overactiveness (5), tantrums/aggressiveness (4), other behaviors (4), meltdowns (2), strange hand gestures (2), and following directions/comprehension (2). The breakdown of symptoms is shown in the figure below:
The reports parents and caregivers made provided quantifying information about their children’s symptoms that included the number of times they occur a day and how long they last. Their quantifications may lend themselves to measuring change in future studies. There were similarities and differences between the drug and behavioral trials. Parents and caregivers reported issues of tantrums and other aberrant behaviors in both. The drug trial focused on aberrant behavior, however, while issues of communication and social interaction arose mainly in the behavioral trial.

**Limitations**

There were a few limitations to the study. First, there were only 18 families included in the study and this small sample size may not accurately reflect what is going on in the larger population of children with ASD. In addition, the Arnold et al. (2003) study included a group of clinicians that rated the symptoms identified by parents and caregivers at baseline and again at the end of the trial, with the same symptoms being rated at both intervals. This study did not have ratings from a group of clinicians, and therefore there was no measure of change in the symptoms over time and no way to ensure that the results are statistically significant. This is the next step in behavioral studies that collect information of parent-nominated symptoms. Finally, the parent-identified symptoms were not validated against any other measure.

**Implications**

The addition of a Parent-Nominated Symptoms Questionnaire seems to provide invaluable information and insight to studies involving children with ASD. Often, the problems the families are talking about involve the absence of something rather than the presence of something. This is why it is important to speak with people who interact with these children on a regular basis and can speak on all of their issues that standardized measures cannot detect—in this case, the parents and caregivers. The parent-nominated symptoms measurement can be correlated with the information collected from the standardized scales and may provide an ecologically valid, statistically reliable outcome measure for behavioral intervention trials. Universal interventions for children with autism that are focused on learning need to change how parent-nominated symptoms are elicited. If we can rely on these measures, we can reduce bias associated with SES.
Appendix: Parent-Nominated Symptoms Phone Script

Hello, my name is Vanessa Dabel and I am part of the Philly AIMS Team (the study taking place with the University of Pennsylvania that your child, *Child’s name,* is participating in). I wanted to conduct a phone interview with you about (child’s name)’s symptoms that you think are the most concerning. First, thank you for completing the surveys we sent. I’m calling because we want to make sure that we learn about symptoms (child’s name) has that are most important to you. This interview should take about 5 minutes. Do you have a few minutes to talk? (If no: Is there another time that would be best for you? Is [ _time] ok? Home or cell #?) Before we start, the University of Pennsylvania requires that I read a brief statement to make sure you understand the study and make sure that you are willing to participate.

Consent Form portion
The purpose of the study is to learn more about the symptoms in children with autism that parents identify as the most concerning. You will be asked to complete a phone interview now.

There are no benefits to participating in this research study. Participation in this study is voluntary and all information that you provide will be kept strictly confidential. You are not obligated to participate in this study and it will not affect your participation in the AIMS project. If you decide after agreeing to participate in the study that you would not like to be involved anymore, you can stop at anytime.

If you have questions, concerns or complaints regarding your participation in this research study or if you have any questions about your rights as a research subject, you can contact the Principal Investigator (PI), David Mandell, at xxx-xxx-xxxx or you can contact me, Vanessa Dabel, at xxx-xxx-xxxx.

If you have any questions or if there is something you do not understand, please ask.

Are you still willing to participate in this study? (If they respond yes, go forth with the rest of the script. If they say no, reply “Thank you and have a great day.”)

What one or two symptoms are you most concerned about for [child’s name]? What thing does he do, what problem does he have that causes you the most concern or problems? How often do they occur? How long each time? How many hours a day? How does it interfere with daily activities?

Thank you for your time!