

Diagnostic methods of autism and developmental

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ABSTRACT

The subject selection and diagnostic techniques documented in the Journal of Autism and Developmental Disorders are summarized in this review. The researchers looked at 142 empirical studies published between February 1993 and April 1997. Using a coding instrument created by the authors, reviewers separately evaluated publications. The majority of researchers used one or more standard

diagnostic criteria to categorize their individuals, according to the findings. However, several researches failed to mention the methodology used to quantify or apply the diagnostic criteria. In addition, the inclusion and exclusion criteria for concomitant conditions were not clearly defined. Making improvements to the documentation of Researchers and practitioners will benefit from diagnostic procedures in autism research.

INTRODUCTION

The diagnosis of Autistic Disorder is based on the application of behavioral descriptions of the disorder's distinguishing features. Despite our improving awareness of the disorder's behavioral aspects, many specialists dispute the disorder's basic symptoms (Klinger & Dawson, 1996) and boundaries (Rutter & Schopler, 1987). A range of problems to developing a coherent research basis have developed as our understanding of the behavioral description of the condition has evolved. As a result, it's crucial to figure out what diagnostic criteria and processes researchers utilize [1]. The definition of autism has evolved since Kanner (1943) published the first clinical description of the illness. In 1980, the Diagnostic and Statistical Manual of Mental Disorders included Infantile Autism as a diagnosis (DSM-III; American Psychiatric Association (APA), 1980). The disorder was classified as part of the Pervasive Developmental Disorders group and was characterized by symptoms that appeared in early childhood. The criteria were chastised for being overly stringent, failing to account for developmental changes, and underdiagnosing autism (Denckla, 1986) [1,2]. As a result, the DSM-III-R (APA, 1987) introduced some revisions to the autism diagnosis. The syndrome was given the label autistic disorder, and diagnostic criteria were widened to account for developmental abnormalities. Despite the improved description, researchers began to speculate about the possibility of autism overdiagnosis (Volkmar, Bregman, Cohen, & Cicchetti, 1988; Volkmar, Cicchetti, Bregman, & Cohen, 1992; Volkmar et al., 1994). The World Health Organization's (WHO) International Statistical Classification of Diseases and Related Health Problems, 10th

Revision (ICD-10; 1993) and the American Psychological Association's (APA) Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV; 1994) attempted to improve on the broad diagnostic criteria while keeping developmental considerations in mind [3]. Researchers have unique hurdles as a result of changes in standard criteria typically employed for the autism diagnosis. Researchers and therapists attempting to replicate and generalize findings using DSM-III-R criteria are likely to involve varied groups of subjects (Szatmari, 1992), which raises ambiguity. Similarly, it has been suggested that some researchers may use DSM diagnostic designations to characterize their subject samples, even when their participants may not meet all of the criteria for the disease (Cohen, Volkmar, & Paul, 1986). As a result, it's critical to consider how researchers characterize their work. Some diagnostic devices have been created to help researchers identify their samples more clearly. While such equipment can improve diagnostic accuracy in many situations, they do have some drawbacks. Most instruments, for example, have been claimed to target the most severely damaged individuals and hence may not capture the whole range of people affected by the condition (Rutter & Schopler, 1987) [4].

Between 1971 and 1982, Kistner and Robbins (1986) looked at how autism researchers described their subject samples in papers published in the Journal of Autism and Developmental Disorders (JADD). They discovered that while the majority of researchers said they used a formal diagnostic approach, only a few people supplied information on the methods used to choose the subjects. Furthermore, just a few studies mentioned using quantitative techniques to choose subjects. Given these restrictions, Kistner and

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Robbins believe that autism research's replicability and generalizability may be jeopardized. Charman (1994) found a trend toward growing more detailed subject descriptions in a study of descriptive information provided by autism researchers in JADD between 1982 and 1991. Subject selection and diagnostic techniques, on the other hand, were not specifically assessed [5].

The purpose of this study was to look into current trends in autism research subject selection and diagnosis processes. This study aimed to raise consumer awareness of behaviors that influence the determination of research samples by empirically examining selection and diagnostic methods. The importance of keeping track of these behaviors is especially significant when the diagnostic criteria are used subjectively. Consumers may make informed decisions about the confidence with which they can use research findings by knowing the various tools and techniques utilized to arrive at a research diagnosis. Subject demographics, subject selection criteria, and diagnostic methodologies reported in research published in the JADD between February 1993 and April 1997 were assessed to achieve these objectives [6].

Articles that satisfied the following criteria that were published in JADD between February 1993 and April 1997 were reviewed: (a) All articles were empirical—theoretical and review papers were excluded from this study; and (b) all articles included autistic subjects, including those with formal diagnoses (e.g., Infantile Autism, Autism, or Autistic Disorder) as well as those whose diagnostic status was mentioned in general terms (e.g., autistic children, or children with autism). Studies were disqualified if the researchers failed to characterize their samples in a way that suggested the individuals satisfied all diagnostic criteria (e.g., autistic-like or having autistic features).

Three clinical psychology Ph.D. students independently reviewed articles using a scoring system created by the authors. The coding instrument included information on the subject's demographics, selection criteria, and the diagnosis procedure. On 10 publications not included in this review, reviewers were instructed to achieve 93 percent interrater agreement. Each reviewer's ratings were compared to the criterion reviewer's ratings to determine agreement. The number of agreements was divided by the sum of agreements and disagreements to arrive at an agreement figure. The quotient that resulted was multiplied by 100. Interrater agreement was examined in 31% of the publications reviewed [7,8]. The observers' agreement ranged from 93 percent to 96 percent.

A total of 142 publications were reviewed, with 152 distinct experiments. When there was evidence that the subjects or subject selection criteria for each experiment within an article were different, the article was separated into independent experiments. Experiments that used the same or a subset of the same subjects were not considered separately.

Treatment or intervention studies accounted for 22% of the 152 total studies, while evaluation or descriptive studies accounted for 78%. A quarter of the sample consisted of brief reports. Eighty-four percent of the research featured many subjects, whereas just nine percent had just one. The number of subjects in 7% of the studies could not be determined.

The age of the subjects ranged from 6 months to 59 years, with a mean of 12.5 years (SD = 8.3 years). With a range of 1 to 199 subjects, the median number of subjects per study was 15. In 77 percent of the research, gender was mentioned. Seventy percent of

the studies that included gender information said that female subjects were included. The average number of males in each research was 12, whereas the average number of females was two [9]. Females accounted for 19% of the total individuals, resulting in a male to the female gender ratio of 4:1.

Researchers characterized their sample as autistic in 18% of the trials but included people who were not diagnosed with autism in their autistic sample. Sixty percent of the overall subjects in that series of research reportedly did not fulfill the complete autism criteria or were diagnosed with another disease. Some participants were not diagnosed with Autistic Disorder or Autism among a certain group of subjects assigned to the researchers' sample of youngsters diagnosed with autism. These children frequently failed to meet a sufficient number of DSM criteria or scored below the threshold on behavioral rating scales. Similarly, some "autistic" samples contained people who were given diagnostic names like "Pervasive Developmental Disorder (PDD)" without any further explanation. PDD could have been used to describe people who fulfilled the diagnostic criteria for PDD Not Otherwise Specified (PDDNOS), or it could have been used to describe people who met the diagnostic criteria for Autistic Disorder, which is a PDD. It was impossible to identify the actual meaning of this label based on the information provided. The exact number of nonautistic subjects could not be determined in 26% of the trials.

In 32% of the studies, autism was identified as a previous diagnosis, and in 51% of those studies, the diagnosis was confirmed by the researchers. In 10% of the studies, the researchers produced a new diagnosis of autism, and in 2% of the studies, a mix of the above methods was used. It was unclear where the diagnosis was established in 55% of the total trials.

Direct observation (65 percent of studies reporting diagnostic methods), structured interviews with the subjects' parents (29 percent), parent questionnaires (21 percent), teacher questionnaires (6 percent), structured interviews with the subjects' teachers (4 percent), and unstructured interviews with the subjects' parents (4 percent) were the most common techniques used to document autistic status (4 percent). In 18 percent of the studies, specific standardized measures (such as the Childhood Autism Rating Scale, Schopler, Reichler, and Renner, 1988; Autism Behavior Checklist, Krug, Arick, and Almond, 1980; Autism Diagnostic Interview, Le Couteur, et al., 1989; Autism Diagnostic Observation Schedule, Lord, et al., 1989) were used to determine diagnostic status for at least some of the subjects. Researchers did not indicate how the diagnosis was established in 68 percent of the trials.

In 67 percent of the investigations, one or more versions of the DSM were utilized to make a diagnosis. DSM-III-R (APA, 1987) was the most often referenced version, with 73 percent of studies reporting DSM-derived diagnoses citing it. In 9% of the studies, the ICD-10 (WHO, 1993) criteria were employed for diagnosis.

The inclusion of people with diagnoses other than Autistic Disorder (or similar) and nondiagnosed subjects in samples referred to as "autistic" adds to the ambiguity. This mislabeling of subject samples is not only misleading but also reduces the generalizability of results to the intended community of Autistic Disorder patients. It's unclear why researchers included these non-autistic persons in their samples or why they didn't specify how many of them there were [8,9]. It's possible that researchers omitted to give this information, or that it

was included in their original publications but removed owing to length limits in journals. It's also possible that the researchers were constrained by the lack of subjects that met all of the Autistic Disorder diagnosis criteria. Whatever the cause, including detailed explanations of subject selection techniques in the literature, will considerably minimize ambiguity and allow our research base to advance systematically.

It's challenging to make diagnostic practice recommendations. It would be foolish to establish a minimal diagnostic threshold because the evolution of a diagnostic category is dependent in part on researchers' ability to report on factors and interpretations they deem important. Clinical researchers, for example, come across borderline instances similar to those seen by practitioners. It would be inappropriate for researchers to disregard those situations on the edge. Rather, researchers should be transparent about the inclusion and exclusion criteria they utilized with the subjects they used. To improve the impact of future research on the topic, it is advised that the following minimal subject information be included. Age, gender, race, standardized test scores, and any other features unique to the sample should all be included in the subject's descriptive characteristics [10]. Diagnostic information should include how the diagnosis was made (i.e., diagnostic criteria used; assessment tools used and cutoff scores; specific techniques used, such as direct observation, interviews, chart reviews, or clinical judgment); when the diagnosis was made; and how the diagnosis was confirmed (when not made by the researchers). Finally, any inclusion or exclusion criteria used to form the samples should be specified (e.g., other diagnoses, standardized test scores, medical conditions, or background characteristics).

CONCLUSION

The necessity for a more thorough identification of subject features and diagnostic data remains a pressing concern. It is difficult to replicate and generalize research findings without this information. In circumstances when research diagnoses and clinical diagnoses differ, doctors may inadvertently try to apply research findings. As a result, the current research literature has a limited influence. To further the field of autism research, future studies must include subject and diagnostic descriptions.

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