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Mass Screening for Severe Problem Behavior among Infants and Toddlers In Peru

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Abstract

Introduction—Severe behavior problems among people with intellectual and developmental disabilities (IDD) are a major barrier to integration in the community. Recent research suggests that these behaviors often begin very early in life and might be prevented by early identification and intervention (Rojahn, Schroeder, & Hoch, 2008). The current paper presents a method of mass screening for early signs of severe behavior problems among infants and toddlers in Peru.

Methods—A Parental Concerns Questionnaire (PCQ) which asks 15 questions, each related to a risk factor for severe behavior problems, based on past research on IDD, was used by veteran parents to interview 341 new parents who had been solicited by TV, radio, and public service announcements across the country. Of these, 262 were recruited and enrolled in a longitudinal study in which they will be followed for 12 months, to see if at-risk children actually will develop severe behavior problems. An extensive initial interdisciplinary evaluation was given to each child. Consumer satisfaction questionnaires were given to the parents as to their attitude toward the screening method.

Results—Data from the Interdisciplinary Evaluations of the sample suggest a very high hit rate (96%) by the screening instrument (PCQ). Consumer satisfaction was 98%, suggesting that the method was tolerated well by parents.

Discussion—The PCQ is a brief and efficient method to screen infants and toddlers at risk for severe behavior problems. The data also suggest that parents suspect these problems at a very early age. Early intervention thus seems a feasible strategy to intervene before these problems become deeply ingrained as children develop.

Keywords

severe aggression; self-injurious behavior; stereotyped behavior; behavior problems; intellectual disabilities; infants and toddlers; early prevention

Recent reviews of research on the incidence of psychopathology in intellectual and developmental disorders (IDD) have found that many of these behaviors begin at a very early age and persist into later childhood and adulthood (Rojahn, Schroeder, & Hoch, 2008).

This may also be true of severe behavior problems like aggression, self-injury, and stereotyped behavior among infants and toddlers (see reviews by Richman, 2008; Symons, Sperry, Dropik, & Bodfish, 2005). Most of these studies among children with disabilities were cross-sectional studies of self-injurious behavior (SIB), often using retrospective chart review methods.

One of the first longitudinal developmental studies of the incidence of stereotyped behavior and SIB was by Berkson and colleagues in the 1990s (Berkson, Tupa, & Sherman, 2001). In this study they followed 457 infants and toddlers in Birth-Three (P.L. 99–457, Part C) Programs in five Chicago school districts, showing that stereotyped movements and self-injury began as early as 12 months in some infants and increased over the next year.

More recent studies of early development of severe problem behaviors in (Kurtz, et al., this issue; Matson, Fodstad, & Dempsey, 2009; Matson, Dempsey & Fodstad, 2009; Matson, Fodstad, Mahan, & Rojahn, 2010; Matson, Hess, & Bosjoli, 2010) support Berkson's findings, but they also suggest increased comorbidity with age, not only with aggression and stereotyped behavior, but also with other more traditional psychopathology (Matson, Mahan, Sipes, & Kozlowski, 2010).

This preliminary report focuses on a culturally sensitive and cost effective method of mass screening for early signs of aggression, SIB, and stereotyped behavior in a developing country and the initial interdisciplinary evaluations necessary to enroll over 200 children in a longitudinal study at the Centro Ann Sullivan del Peru (CASP) in Lima, Peru. Unlike Berkson's early identification method which capitalized on a convenience sample in a specific geographical area of Chicago, we used a mass screening technique of the general population of Peru on weekends. This method fit the needs of the Peruvian culture and the busy work schedules of families and of professionals participating in the study and most of whom were not in a structured early intervention program.

Method

Recruitment Screening and Participant Ascertainment

Parents were solicited by newspaper, radio, and TV public service ads in Lima and later throughout the country of Peru. Approximately 1000 concerned parents called in to CASP, and 341 were given an appointment to be interviewed by one of the 10 veteran parents of CASP students, who had been trained to administer the Parental Concerns Questionnaire (PCQ) (see Table 3). This questionnaire was devised for the present study based upon risk factors in Table 1 gleaned from the literature (Rojahn, et al., 2008; Schroeder, Oster-Granite, & Thompson, 2002; Schroeder, Loupe, & Tessel, 2008).

Recruitment screening lasted for two months. Of the 341 parents interviewed, 262 met the criteria for enrollment in the study and were invited by the veteran parent interviewers to participate in an extensive interdisciplinary evaluation on two weekends in September and October, 2010 if their child showed or was suspected to have any of the risk factors shown in Table 1. Parents also received an explanation of informed consent and signed a consent form approved by the Human Subjects Committees of CASP and of the University of Kansas.

An additional 19 parents were interviewed and 35 were placed on a waiting list without interview as replacements, in case of drop-out. The screening was very successful. Only 23 families have dropped out so far for a variety of reasons, e.g. loss of cell phone contact, moving, hospitalization, illness, or they refused to comply with the protocol of the study.

Eleven children (4%) did not meet inclusion criteria (see Table 1) after interdisciplinary evaluation, and they were excluded from the study.

Description of Primary Dependent Variables

The primary dependent variables were the Behavior Problem Inventory (BPI-01) (Rojahn, Matson, Lott, Esbensen, & Smalls, 2001), the Aberrant Behavior Checklist (ABC) (Aman, Stewart, and Field, 1985), and the Repetitive Behavior Scale-Revised (RBS-R) (Bodfish, Symons, Parker, & Lewis, 2000). These measures overlap somewhat, but they have rarely been used among infants and /toddlers. The present study offered an opportunity to cross-validate them in this very young population in Peru. The secondary measures of potential covariate and/or confounding variables are listed in Table 2.

Behavior Problem Inventory(BPI-01)—The BPI-01 is the main dependent measure in the assessment battery. It is a 49-item behavior-rating instrument with 14 specific self-injurious behavior, 24 stereotypic behavior, and 11 aggressive/destructive behavior items (Rojahn, et al., 2001) Each of the three problem behavior groups is preceded by a generic definition that applies to all items within the group. Items are scored on a five-point frequency scale (0 = never, 1 = monthly, 2 = weekly, 3 = daily, 4 = hourly) and a four-point degree-of-the-problem or severity scale (0 = no problem, 1 = a slight problem, 2 = a moderate problem, 3 = a severe problem). Only behaviors that have occurred at least once during the past two months are scored. For clinically significant behaviors that are not captured by of the 49 items, "other" categories are provided for each of the three behavior groups. The BPI has been used predominately in groups of adult individuals in the severe to profound range of intellectual disabilities. However, the BPI-01 was also found to be sensitive to drug effects in studies with community-based children with sub-average cognitive functioning. The instrument has also proved useful for longitudinal assessments for people who are at risk for behavior problems, as it permits monitoring changes in the frequency or intensity of existing behavior problems, the emergence of new behaviors, and the remission of others.

Aberrant Behavior Checklist (ABC)—The ABC is one of the most widely used and psychometrically sound assessment instruments in research and clinical practice in developmental disabilities. It is an informant-oriented problem behavior rating scale that was empirically derived by factor analysis based on a large sample in New Zealand (Aman, Singh, Stewart & Field, 1985). It consists of 58 items, each scored on a four-point scale (0 = not a problem, through 3 = problem is severe in degree). The items are divided into five subscales: (1) *Irritability/ Agitation/ Crying*, (2) *Lethargy/ Social Withdrawal*, (3) *Stereotypic Behavior*, (4) *Hyperactivity/Non-Compliance*, and (5) *Inappropriate Speech*. Norms are available for adults and for children and adolescents (Aman & Singh, 1994; Aman et al., 1985; Marshburn & Aman, 1992).

Repetitive Behavior Scale-Revised (RBS-R)—The RBS-R is an empirically derived behavior rating instrument that was designed for the assessment of the presence and severity of abnormal, repetitive behaviors in persons with a variety of conditions, including intellectual disabilities, psychiatric, neurological, and behavioral disorders (Bodfish, Symons & Lewis, 1999; Bodfish, Symons, Parker & Lewis, 2000). The scale was developed by compiling items from several existing behavior-rating scales that measured repetitive behaviors. The selected 43 items were assigned by clinical staff to one of six dimensions or subscales of repetitive behavior: (1) *Stereotyped behavior* (six items), (2) *self-injurious behavior* (eight items), (3) *Compulsive behavior* (eight items), (4) *Ritualistic behavior* (six items), (5) *Sameness behavior* (11 items), and (6) *Restricted behavior* (four items). Items are evaluated on a four-point Likert scale (from 0 = behavior does not occur, to 3 = behavior

occurs and is a severe problem.) The scale has been used to measure repetitive behavior in people with intellectual disabilities and autism spectrum disorders.

U.S. Consultant Training

U.S. Consultant Training occurred in the summer of 2010. Each of eight consultants from the U.S. spent a week or more training CASP staff teams (40 staff) in general and on their specific assessment instruments. They used a lecture, demonstration, and practice model (using infants and toddlers of CASP staff mothers as teaching models), so that each trainee was competent and experienced at the end of training. In addition, they gave seven lectures in their specialty to the entire CASP staff, as well as to CASP parents in the evening at the CASP School of Families.

CASP staff members were trained using a train-the-trainer model: One CASP Director and a specialist in the Early Education Program of CASP were trained on the Cognitive Subscale of the Bayley Scales of Infant Development (Third Ed., Bayley, 2006) who in turn trained and supervised 8 CASP staff (five teams), who administered the test. Similarly, one CASP Director was trained in Wetherby's Communication and Symbolic Behavior Scale (Wetherby & Prizant, 2002), who in turn trained and supervised 8 CASP staff (9 teams) to administer it. One CASP Director was trained on the Behavior Problems Inventory-01 (Rojahn, et al., 2001), the Aberrant Behavior Checklist (Aman, et al., 1985), and the Repetitive Behavior Scale-Revised (Bodfish, et al., 2000), who in turn trained and supervised 11 CASP staff interviewers to administer these scales. Two CASP specialists were trained in Functional Analysis (Richman & Lindauer, 2005), videotaping behaviors in different conditions, observing behavior, defining behavior, and calculating observer reliability, who in turn trained and supervised 8 staff to administer the test. Two Developmental and Behavioral Pediatricians from the U.S. trained five Peruvian pediatricians and three medical students to do the Developmental Pediatric examinations. One Fogarty physician, a Pediatrician, and three Fogarty Medical Student Fellows from the U.S. also assisted in the Pediatric examinations. Three Pediatric Ophthalmologists (one U.S., two Peruvian) plus the three Fogarty Pediatric Fellows also conducted vision screening of all children on Evaluation Days. A Peruvian Dentist and his 6 Dental residents who specialized in working with people who have IDD also did dental screening of all children. A Clinical Geneticist lectured the staff on the principles of genetics and answered questions. He examined several students enrolled at CASP for genetic conditions causing developmental delay and/or autism.

Interdisciplinary Evaluations Days

Interdisciplinary Evaluations Days occurred from 8:00 a.m.–4:00 p.m. using the following interdisciplinary protocol in Table 2. All 65 of the CASP staff, all of the above trained professionals and students, plus two Peruvian Pediatric Neurologists and one Peruvian Geneticist were available for consultation if referred by the 11 pediatricians on Evaluation Days. A total of 23 Peruvian nurses and medical students collected basic demographic information and developmental history (e.g. height, weight, head circumference, etc). CASP staff, over 80 student volunteers from a local university, and 19 CASP volunteer mothers assisted the families in moving from one evaluation station to the next on Evaluation Days. Three professional translators and 5 student translators from a local university were available to assist in translation where needed. CASP Security Guards and Maintenance staff assisted in the logistics in using all 22 classrooms of the Center. Three clowns entertained the children and their families during long waits in lines. It is estimated that a total of over 1300 professional hours were required to complete the evaluations. A total of 220 professionals participated in the screening evaluation.

In some cases, not all of the evaluations could be completed on Evaluation Days, due to time constraints. Those parents were invited to return to complete their evaluations later by appointment. When all evaluations were finished, parents were given a brief review of what was completed. They were invited to return to CASP on a monthly basis for introductory workshops in which they reviewed the purpose of the grant and what to expect, the basics of autism, behavior management, etc. They were also given Internet information about developmental disabilities and a home diary to keep, were scheduled for follow-up home visits and additional evaluations for those who needed them, e.g. extended evaluation for autism at CASP, genetic consultations and testing, neurological consultations by appointment in the physicians' offices, nutritionist consultation, etc. Finally, parents were reimbursed for their travel to the Evaluation and were given a Consumer Satisfaction Questionnaire to rate on a three point Likert scale the quality, thoroughness, and courtesy of services they received in the evaluation process.

Results

All initial evaluations, except for Functional Analyses, were completed, and telephone follow-up and home visits are now being done. All raw data, except for the ophthalmological and dental exams, have been cleaned, scanned, and sent via the Internet to the Life Span Institute at the University of Kansas for analysis. Complete data are available on 228 cases. Some of the 262 cases (34) withdrew from the study for various reasons or could not be located upon follow-up. For example, one parent's neurologist had told her that her child's self-injurious behavior (SIB) was a part of normal development and he would outgrow it.

Initial Review of the Data

After a preliminary examination of 228 cases, the data suggest the following:

1. There was a good distribution of scores on the Behavior Problems Inventory (BPI) Total Frequency Score (the main dependent variable). Range was 1–99, and the mean was 29. BPI Subscale scores, i.e., SIB, Stereotyped Behavior, and Aggression, all were elevated and intercorrelated ($r > 0.413$, $P < .01$). There were a few children with very high BPI scores, and they were entered into an early intervention program immediately. Most scores, though elevated, were relatively low, and we expect them to increase upon the six-monthly follow-up (see Figure 1).
2. Almost 65% of the children were suspected of autism by the parents on the Parental Concerns Questionnaire (PCQ), and they received further evaluation by CASP staff, e.g. Child Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1988)), observations, etc. Indeed CARS cut-off scores of 30+ were elevated for 63% of the children suspected of autism on the PCQ, and many more had lower but elevated CARS scores (see Figure 2).
3. There was a wide range of Bayley Scores. Ninety-two per cent of the children exhibited cognitive delays. The distribution appeared to be bimodal, i.e. a mild-to-moderate group and a severe-to-profound group. Bayley standard scores did not correlate with the BPI total frequency scores ($r = 0.059$, n.s.), perhaps because of the age of the children. In adults, for instance, there is usually a robust inverse relationship of IQ and SIB frequency (Rojahn, et al., 2008)(see Figure 3). It will be interesting to see whether this relationship changes with age.
4. There was also a wide range of language/communication scores on the Wetherby CSBS. The mean standard score was 78, range, 65–127. CSBS scores correlated .514 with Bayley Scores. CSBS subscale (social. speech, symbolic) scores showed a

high degree of correlation with one another (Pearson correlation, $r > 0.63$). CSBS scores also correlated with CARS scores ($r = 0.568$, $P < .01$) (see Figure 4).

5. There were relatively few genetic referrals (42), neurological referrals (43), or psychiatric (1) referrals, perhaps because the children are so young. Such problems may appear later as the children grow older.
6. Mean age of the sample at entry to the study was 27 months, range 4–48 months. Approximately 80% of the children were 18 months or older, but that still leaves 40+ children in the younger group (4–17mos.).
7. There was a significant number (58) of children with Down Syndrome, and suspected of autism (89 with $CARS > 30$) but few had other recognized genetic syndromes in the risk algorithm associated with aggression, self-injury, and stereotyped behavior listed in Table 1. So there were likely two main genetic cohorts, i.e. Down Syndrome and Autism. Children suspected of autism will be followed and observed closely by the CASP Interdisciplinary team to confirm their diagnosis when they are older.
8. Of the parents' responses on the Parental Concerns Questionnaire (PCQ), 96% had at least one of the risk factors in Table 1 as reliably reflected in the results of the subsequent interdisciplinary evaluations. Table 3 shows the percentage of parents' response to each question on the PCQ. As can be seen, they correspond well with the results on the BPI, Bayley, CSBS, and CARS. It appears that the PCQ was a valid screening questionnaire for the purposes we intended.
9. Parents rated the services they received on the Consumer Satisfaction Questionnaire with an average score of 98%. They were very satisfied with the services.

Discussion

Not much research is available on mass screening methods among children with disabilities, although this technique has been very common among charitable organizations delivering health care to the needy in the U.S. Most of the few screening studies of aberrant behaviors among infants and toddlers with disabilities, e.g. Berkson, Tupa, and Sherman (2001), Matson, Fodstad, Mahan, and Rojahn (2009) and with older children over three years of age, e.g. Emerson and Einfeld, (2010); MacLean, Tervo, Hoch, Tervo, and Symons (2010); MacLean and Dornbush (this issue); and Murphy, Hall, Oliver, and Kissi-Bebra (1999), suggest that the sampling methods are an important determinant of the prevalence of these behaviors. The mass screening method with the Parental Concerns Questionnaire we used in Peru was very effective in identifying infants and toddlers at risk for aggression, self-injury, and stereotyped behavior. Clearly parents could identify some of these problems very early. We will know more precisely how early they can do so accurately after we analyze the follow-up data in one year. They will be followed at six-month intervals for a year, as Berkson, et al. did, to verify which of them increases these behaviors and which drop out without intervention. For those for whom the behaviors persist, we will recruit them into an early intervention program based upon language and functional communication training.

The overlap of SIB, aggression, and stereotyped behavior on the BPI with scores on the CARS supports the previous research on the infant and toddler IDD population in Peru and gives cross-cultural support to the findings of Matson, et. al. (2009, 2010) in the U.S. Birth-Three, Part C population in Louisiana.

Another innovative feature of our screening was the use of veteran mothers as interviewers on the PCQ. These were highly trained and experienced mothers of CASP students who had

immediate credibility with new concerned parents. They could also empathize with them and give them hope for the future of their child. We feel that this was a major factor in the success of the mass screening, and we are also looking to use veteran parents more in our plans for intervention in the future.

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Figure 1.
Distribution of BPI-01 Total Frequency Scores

Figure 2.
Distribution of CARS Total Scores

Figure 3.
Distribution of Bayley Cognitive Standard Scores

Figure 4.
Distribution of CSBS Standard Total Scores

Table 1**Risk Factors for Early Development of in Neurobehavioral Disorders***Genetic Factors*

Lesch-Nyhan syndrome, Down syndrome, Smith-Magenis syndrome, Prader-Willi syndrome, Rett syndrome, Riley-Day syndrome, Prader-Willi syndrome, Tourette's syndrome, FragileX syndrome, Neurofibromatosis, Fetal Alcohol syndrome,

*Family History of Autism and Other Brain Disorders**Related Medical Conditions as Overlapping Risk Factors*

Congenital Rubella, Tuberous Sclerosis, neuroacanthocytosis, brain trauma, stroke,

*Pre-and Perinatal Disorders Resulting in Severe and Profound Mental Retardation**Neurological and /Neuropathological Factors*

Infantile Spasms, Seizures, Neuroanatomical Abnormalities in Hippocampal Complex, Entorhinal Cortex, Amygdala, Mammillary Body, Medial Septal Nucleus, Anterior Cingulate Gyrus, Cerebellum, Inferior Olivary Nucleus, Limbic System, Basal Ganglia System, Cerebellar Circuit System.

Psychiatric Factors

Family history of autism, mood disorders, compulsive disorders, anxiety disorders borderline personality disorder.

Neurochemical Metabolic Factors

Hyperserotonemia, dopamine depletion in the nigrostriatal pathways of the basal ganglia, dysfunctional opioid peptide system, elevated ammonia or lactic acid levels, organic aciduria, fatty acid disorder, aminoacidopathy, mitochondrial disorder.

Neuropsychological Factors

Orientation to social stimuli, joint attention, motor coordination, position, and/or stereotypy, motor imitation, severity of mental retardation.

Communication Deficits

Receptive communication, expressive communication.

Note: It should be noted that many of these risk factors are infrequent and relatively non-specific to aberrant behavior; but, when taken cumulatively, they increase the probability of a diagnosis of aberrant behavior (Bodfish & Lewis, 2002; Dawson, 1996; Dunlap, Strain, Fox, Carta, Conroy, et al., 2006).

Table 2**Standard Protocol for Age-Appropriate Assessment Instruments to be used at the CASP Clinic***Initial Screening*

Scripted Telephone Interview by Veteran Parents using the Parental Concerns

Questionnaire

*Participant Interdisciplinary Evaluation Visit**Parent Interview*

1. Behavior Problem Inventory-01 (BPI-01)
2. Aberrant Behavior Checklist (ABC)
3. Repetitive Behavior Scale-Revised (RBS-R)
4. Child Autism Rating Scale (CARS)
5. Behavioral History and Profile, Parent Diary

Child Testing

1. Functional Analysis (Taped Direct Scripted Behavior Observation Session)
2. Cognitive Measure-Bayley Scales of Infant Development III, Cognitive Scale
3. Wetherby Communication, Symbolic, Behavior Scale (CSBS)
4. Home visit-Home Observation for Measurement of the Environment (HOME)
5. Developmental Pediatric Examination and History
6. Other Specialty Exams as indicated (Pediatric Neurology, Genetics, Nutrition, Ophthalmology, Dentistry),

Table 3

<i>Parents' Affirmative Answers to the Parental Concerns Questionnaire</i>		<i>%</i>
1.	Is your child usually happy?	65
2.	Are you concerned about your child's motor development?	53
3.	Does your child have a genetic syndrome?	31
4.	Does your child have a neurological syndrome?	54
5.	Has your child ever had a seizure?	12
6.	Are you concerned about your child's learning abilities?	58
7.	Does your child have problems with attending to others?	52
	with communicating to others?	58
	with unusual repetitive behaviors?	49
8.	Are you concerned about your child's language development?	82
9.	Are you concerned about your child's repeatedly hitting others?	68
10.	Are you concerned about your child's repeatedly destroying objects?	35
11.	Does your child purposely and repeatedly injure himself, e.g. head-bang, bite-self, scratch-self, pull his/her hair?	61
12.	Does your child make funny movements, e.g. body rocking, hand waving, head-weaving?	60
13.	Are you concerned that your child may have autism?	53
14.	Does your child have a sibling with autism?	63
15.	Do you have any other concerns about your child's development?	74