Validation of the Phenomenon of Autistic Regression Using Home Videotapes

Emily Werner, PhD; Geraldine Dawson, PhD

Context: To date, there has been no objective validation of the phenomenon of autistic regression early in life.

Objective: To validate parental report of autistic regression using behavioral data coded from home videotapes of children with autism spectrum disorder (ASD) vs typical development taken at 12 and 24 months of age.

Design: Home videotapes of 56 children’s first and second birthday parties were collected from parents of young children with ASD with and without a reported history of regression and typically developing children. Child behaviors were coded by raters blind to child diagnosis and regression history. A parent interview that elicited information about parents’ recall of early symptoms from birth was also administered.

Setting: Participants were recruited from a multidisciplinary study of autism conducted at a major university.

Participants: Fifteen children with ASD with a history of regression, 21 children with ASD with early-onset autism, and 20 typically developing children and their parents participated.

Main Outcome Measures: Observations of children’s communicative, social, affective, repetitive behaviors, and toy play coded from videotapes of the toddlers’ first and second birthday parties.

Results: Analyses revealed that infants with ASD with regression show similar use of joint attention and more frequent use of words and babble compared with typical infants at 12 months of age. In contrast, infants with ASD with early onset of symptoms and no regression displayed fewer joint attention and communicative behaviors at 12 months of age. By 24 months of age, both groups of toddlers with ASD displayed fewer instances of word use, vocalizations, declarative pointing, social gaze, and orienting to name as compared with typically developing 24-month-olds. Parent interview data suggested that some children with regression displayed difficulties in regulatory behavior before the regression occurred.

Conclusion: This study validates the existence of early autistic regression.

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A growing body of research is aimed at detecting and understanding the earliest emerging symptoms of autism.1-9 Home videotape studies have validated what many parents report; namely, that although they didn’t necessarily recognize their child’s developmental difficulties until the toddler years, with hindsight they believed that behavioral difficulties were present in the first year of life. Using home videotape methods, symptoms have been observed at 8 to 12 months of age.1-10 Parent report data also suggest, however, that not all children with autism are symptomatic at such young ages. For a subgroup of children, parents report that their child had normal or near-normal development for their first 15 to 24 months and then experienced a regression in their communication skills and/or social skills. Estimates of the prevalence of this “regressive” pattern range from 20% to 47% among children with autism.11-17 Often, information about autistic regression has been gathered retrospectively from parents many years after the regression was reported to have occurred. Indeed most, if not all, published information on the phenomenon of autistic regression has been derived from retrospective parent report or, in a minority of studies, on a review of medical records. Medical records may be less subject to reporting bias; however, they are often brief and may not contain important details regarding early developmental course. To date, there has been no published study that has systematically examined the validity of autistic regression.

Author Affiliations: UW Autism Center and Departments of Psychology and Psychiatry and Behavioral Science, University of Washington, Seattle.
regression using a data source that is free from reporting bias. Studies of early home videotapes provide such an opportunity. An earlier such study examined separately the behavior of the group of children whose parents reported a loss of skills and found that the group with regression did not display social impairments at 12 months of age. These results were based on a regression sample of only 7 children, so they must be interpreted cautiously.

The goal of the present study was to better understand variations in the early developmental course of autism by studying detailed parent report data in combination with observations derived from home videotapes of children with autism taken both before and after the regression reportedly occurred. The aim was to empirically validate the phenomenon of regression using a data source that is not based entirely on parent recall.

**METHOD**

**PARTICIPANTS**

Participants consisted of 3 groups of children and their parents: 15 children with autism spectrum disorder (ASD) (12 children with autistic disorder, 3 children with pervasive developmental disorder, not otherwise specified) whose parents reported a regression in social and/or communication skills within the first 3 years of life on the Autism Diagnostic Interview–Revised (ADI-R) (“regressed”), 21 children with ASD (16 children with autistic disorder and 5 children with pervasive developmental disorder, not otherwise specified) whose parents reported that they had impairments before age 1 year and did not experience a regression based on the ADI-R (“early onset”), and 20 typically developing children. Children were younger than 7 years, and all but 3 were younger than 4 years (Table 1).

The study was approved by the University of Washington (Seattle) institutional review board, and informed consent for human investigation was obtained from parents. Participants were recruited from the University of Washington Autism Center, local parent advocacy groups, schools, clinics, and university child participant pools. Exclusionary criteria included presence of a neurological disorder of known genetic etiology (eg, fragile X syndrome), significant sensory or motor impairment, major physical abnormalities, and history of serious head injury and/or neurological disease. In addition, children with typical development were excluded if they exhibited unusually high or low cognitive ability as assessed by their composite score on the Mullen Scales of Early Learning. Participants were also excluded if they had obvious facial dysmorphology that might alert coders to diagnostic status or the parent did not have physical custody of the child for his or her entire first 2 years of life.

Diagnosis of ASD was based on the ADI-R and the Autism Diagnostic Observation Schedule–Generic. The Autism Diagnostic Observation Schedule–Generic was administered to typically developing children to confirm the absence of autism symptoms. Because the children were quite young, an experienced health care professional also made a clinical judgment of diagnosis based on the DSM-IV to confirm scores obtained on the ADI-R and Autism Diagnostic Observation Schedule–Generic. The regressed and nonregression groups did not differ in their nonverbal mental age (combined visual reasoning and fine motor scales) as assessed by the Mullen Scales of Early Learning.

**CLASSIFICATION OF REGRESSION**

Children were included in the regressed group if their parent reported a regression between the ages of 12 and 24 months.
during standard administration of the ADI-R. Regressed was defined as receiving a score of 2 (definite) on at least 1 of the following ADI-R items: loss of spontaneous meaningful communicative speech at some level (item 38), loss of words used spontaneously but without clear communicative intent (item 39), or loss of skills in areas other than language before age 5 years (item 95). The average age at which parents reported that main loss of skills was first apparent (ADI-R item 103) was 22 months with a range of 16 to 31 months.

HOME VIDEOTAPE CODING

Contextual Variables

Whenever possible, home videotapes of children’s first and second birthday parties were obtained; however, nonbirthday party footage was used in a small minority of cases, but this did not differ by group at either the 12-month ($\chi^2 = 3.96; P = .041$) or 24-month ($\chi^2 = 2.79; P = .60$) point. To further control for the possibility that differences in filming situations might confound results, the following contextual variables were coded: length of footage, percentage of time the child was on-screen with others, percentage of time the child was alone on-screen, number of opportunities to orient (name called), and percentage of time others talked to the child. No group differences were found in any of these variables except frequency of instances of not talking to the child in 24-month videotapes ($F_{2,52} = 7.48; P = .001$). Children with autism were disproportionately represented in instances when the child was not spoken to during the foot- age; however, there was no significant difference in the number of regressed vs early-onset children with ASD who were not spoken to during the 24-month footage.

Behavioral Variables

Behaviors coded from 12- and 24-month videotapes included language, joint attention, gaze, orienting, repetitive behavior, affect, and toy play, as described in Table 2. Discrete instances of behaviors, such as pointing, were coded in terms of frequency of occurrence (divided by total minutes of videotaped footage), while behaviors such as gaze were coded in terms of duration (percentage of total videotaped footage). Interrater reliability for each behavior (eg, gaze behaviors, repetitive motor behaviors) was assessed by double coding 20% of the videotapes. Intraclass correlation coefficients were computed for all frequency codes (range, 0.81–0.91 for 12-month videotapes and 0.76–0.87 for 24-months videotapes) and k coefficients were computed for all duration codes (range, 0.71–0.97 for 12-month videotapes and 0.69–0.90 for 24-month videotapes). Coders were blind to the child’s diagnostic status and regression history. The orienting variables took into account the number of opportunities to orient (ie, each orienting behavior was calculated as a percentage of the number of opportunities available to that subject). Word usage occurred very rarely in the 12-month videotapes so this variable was combined with complex babbling. At 24 months, both types of vocalizations occurred with sufficient frequency to treat as separate variables.

Table 2. Behavioral Variables Coded at 12 and 24 Months of Age

<table>
<thead>
<tr>
<th>Variable</th>
<th>12 Months of Age</th>
<th>24 Months of Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language</td>
<td>Frequency of simple babble</td>
<td>Frequency of complex babble</td>
</tr>
<tr>
<td></td>
<td>Frequency of complex babble</td>
<td>Frequency of single words</td>
</tr>
<tr>
<td>Joint attention</td>
<td>Frequency of words</td>
<td>Frequency of ≥2 words</td>
</tr>
<tr>
<td></td>
<td>Frequency of declarative pointing</td>
<td>Frequency of declarative pointing</td>
</tr>
<tr>
<td></td>
<td>Frequency of imperative pointing</td>
<td>Frequency of imperative pointing</td>
</tr>
<tr>
<td>Gaze</td>
<td>Looks at people</td>
<td>Looks at people</td>
</tr>
<tr>
<td></td>
<td>Looks at object held by another</td>
<td>Looks at object held by another</td>
</tr>
<tr>
<td></td>
<td>Nonsocial looking</td>
<td>Nonsocial looking</td>
</tr>
<tr>
<td>Orienting</td>
<td>Percentage of instances orients to name call</td>
<td>Percentage of instances orients to name call</td>
</tr>
<tr>
<td></td>
<td>Percentage of instances orients with difficulty</td>
<td>Percentage of instances orients with difficulty</td>
</tr>
<tr>
<td>Repetitive behavior</td>
<td>Percentage of time engages in repetitive behavior</td>
<td>Percentage of time engages in repetitive motor behavior</td>
</tr>
<tr>
<td>Affect</td>
<td>Smiles at people</td>
<td>Smiles at people</td>
</tr>
<tr>
<td></td>
<td>Distressed</td>
<td>Distressed</td>
</tr>
<tr>
<td>Toy play</td>
<td>NA</td>
<td>Percentage of appropriate play with toys</td>
</tr>
</tbody>
</table>

Abbreviation: NA, not applicable.

RESULTS

All analyses were first conducted using all participants who met criteria for either autism or pervasive developmental disorder not otherwise specified, classified as regressed or early onset according to the ADI-R. Analyses were repeated using only children who met diagnostic criteria for autism, excluding children with pervasive developmental disorder not otherwise specified. The stricter diagnostic criteria did not change the results of the analyses; therefore, the means, standard deviations, and statistical values reported are for the more inclusive ASD group. Multivariate analyses of variance (ANOVAs) were conducted for each category of behaviors, with the ex-
ception of joint attention, which was examined using the Fisher exact test. The Wilks λ test statistic is reported for all multivariate analyses. The Tukey honestly significant difference test was used for post hoc analyses, unless otherwise noted. The means, standard deviations, and results for all ANOVAs are presented in Table 3 (12 months) and Table 4 (24 months).

12-MONTH VIDEOTAPE DATA

Language

The 3 groups significantly differed in their use of pre-linguistic and meaningful verbal communication at age 12 months. Post hoc analyses showed that regressed infants used complex babbling and words significantly more frequently than early-onset infants, with typical infants falling in between the early-onset and regressed groups in terms of their use of complex babbling and words (Table 3). Regressed infants used complex babble or words nearly twice as frequently as typical infants. Examining the mean frequency of use of complex babble, 46% of the regressed infants had mean levels of complex babble that were at or higher than the mean level for typical infants (they had a distribution similar to that of typical infants), compared with only 6% of early-onset infants.

Joint Attention

Joint attention variables were dichotomized as either present or absent and examined using 2a priori pairwise Fisher exact tests. Results showed early-onset infants were significantly less likely to use declarative pointing than typical infants (Fisher exact probability, P<.05); however, regressed and typical infants did not significantly differ in their use of declarative pointing at age 12 months (Fisher exact probability, P=.20). There were no group differences in imperative pointing (typical vs early onset, P=.18; typical vs regressed, P=.12).

Gaze, Orienting, Repetitive Motor Behavior, and Affect

There were no group differences in gaze (F6,102=0.53; P=.78), orienting to name (F4,70=1.60; P=.18), repetitive motor behavior (F2,53=0.14; P=.87), or affect (F4,104=0.36; P=.84).

24-MONTH VIDEOTAPE DATA

Group differences in the same 6 categories of behavior were examined again at age 24 months, along with the additional category of toy play. Means, standard deviations, and results of statistical analyses based on ANOVAs are presented in Table 4.

Language

The groups significantly differed in the frequency of complex babble, single words, and phrases involving 2 or more words but not in the frequency of simple babble sounds. Post hoc analyses revealed that typical toddlers used significantly more words and wordlike vocalizations at age 24 months than the early-onset and regressed toddlers with ASD (Table 4). Recall that at 12 months of age, when use of complex babble was examined, about half of the regressed toddlers had mean levels of complex babble that were at or higher than the mean level for typical infants. By 24 months of age, the percentage of regressed toddlers who were using single words at or higher than the typical mean level was now 9%. None of the early-onset toddlers was at or higher than the mean level for typical toddlers.

Joint Attention

Results of Fisher exact test analyses showed that typical toddlers displayed declarative pointing more often than

Table 3. Videotape Observations at 12 Months of Age

<table>
<thead>
<tr>
<th>Variable</th>
<th>Infants With Early-Onset ASD, Mean (SD)</th>
<th>Infants With ASD With Regression, Mean (SD)</th>
<th>Typical Infants, Mean (SD)</th>
<th>F Test</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Simple babble*</td>
<td>0.61 (0.66)</td>
<td>0.47 (0.43)</td>
<td>0.80 (0.80)</td>
<td>2.66</td>
<td>.04</td>
</tr>
<tr>
<td>Complex babble or words*</td>
<td>0.01 (0.06)</td>
<td>0.20 (0.31)</td>
<td>0.11 (0.21)</td>
<td>0.98</td>
<td>.38</td>
</tr>
<tr>
<td>Gaze</td>
<td></td>
<td></td>
<td></td>
<td>3.77</td>
<td>.03</td>
</tr>
<tr>
<td>Looks at people†</td>
<td>23.4 (12.2)</td>
<td>26.8 (11.4)</td>
<td>21.4 (9.8)</td>
<td>0.53</td>
<td>.78</td>
</tr>
<tr>
<td>Looks at object held by person†</td>
<td>10.6 (11.2)</td>
<td>9.0 (9.4)</td>
<td>11.6 (9.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Orienting</td>
<td></td>
<td></td>
<td></td>
<td>1.60</td>
<td>.18</td>
</tr>
<tr>
<td>Orients to name*</td>
<td>21.0 (26.3)</td>
<td>28.7 (21.8)</td>
<td>36.8 (39.2)</td>
<td>0.14</td>
<td>.87</td>
</tr>
<tr>
<td>Orients with difficulty†</td>
<td>16.6 (21.9)</td>
<td>20.7 (24.2)</td>
<td>3.7 (7.2)</td>
<td>0.36</td>
<td>.84</td>
</tr>
<tr>
<td>Repetitive motor behavior†</td>
<td>3.1 (3.0)</td>
<td>3.5 (3.8)</td>
<td>2.9 (3.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affect</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smiles at people*</td>
<td>0.17 (0.25)</td>
<td>0.19 (0.25)</td>
<td>0.18 (0.23)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distressed†</td>
<td>0.5 (1.2)</td>
<td>0.2 (0.5)</td>
<td>0.6 (1.3)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Abbreviation: ASD, autism spectrum disorder.
*Variable coded for frequency of occurrence.
†Variable coded for duration of occurrence.
the early-onset (P = .02) and regressed (P = .055) toddlers with ASD. Similar to findings at 12 months, no significant group differences in the number of toddlers who displayed imperative pointing were found (P = 0.11 and 0.42).

**Gaze**

At age 24 months, the groups significantly differed in terms of the percentage of time spent looking at people. The typical toddlers looked at people a significantly greater percentage of the time as compared with the early-onset and regressed toddlers with ASD (Table 4).

**Orienting**

Significant group differences in frequency of orienting to name were found, with the typical toddlers showing more instances of orienting to name called compared with the regressed and early-onset toddlers with ASD (Table 4).

**Repetitive Motor Behavior, Affect, and Toy Play**

There were no significant group differences at age 24 months in terms of repetitive motor behavior, affect, or appropriate toy play.

**GROUP X TIME INTERACTION BASED ON HOME VIDEOTAPES**

To determine if children with regression failed to progress vs showed a decrease in skills over time compared with the other groups, a series of 3 (group) × 2 (time) ANOVAs were conducted on the variables social gaze and language use, measured at ages 12 and 24 months. For social gaze, there was a significant main effect for time (F1,52 = 27.41; P < .001) and a significant group × time interaction (F1,52 = 5.47; P = .007). Typical children directed their gaze to people about 20% of the time in both the 12-month and 24-month videotapes. Both early-onset and regressed infants with ASD showed a decrease in their use of social gaze across the 2 points, and the decrease was of approximately the same magnitude for each of the groups (16 percentage points for the regressed group and 13 percentage points for the early-onset group). In other words, social gaze worsened between the ages of 1 and 2 years for all of the infants with ASD, not just those with regression. A composite variable consisting of the rates of complex babbling and the rates of word usage across the 2 ages indicated that there was a highly significant main effect of group (F1,52 = 10.12; P < .001), time (F1,52 = 17.97; P < .001), and group × time interaction (F1,52 = 10.33; P < .001). The typical children increased their use of complex babble and words dramatically between the 12- and 24-month videotapes, while both the early-onset and regressed infants with ASD did not make significant gains.

**EARLY DEVELOPMENT INTERVIEW**

A 3 (group) × 4 (symptom area) multivariate ANOVA revealed a significant main effect of group for all 4 symptom areas at age 12 months (Table 5). Post hoc Tukey honestly significant difference tests revealed that early-onset infants displayed significantly more symptoms than typical infants in all domains (regulatory, P = .008; social, P = .002; communication, P = .04; repetitive, P = .04). The regressed infants did not differ in their social, communication, or repetitive behavior from typical infants, but they were reported to have more regulatory symptoms (P = .049).

Similar analyses at age 24 months revealed a significant main effect of group for all symptoms. Post hoc analy-
ses showed that both the early-onset and regressed toddlers with ASD exhibited significantly more symptoms than typical toddlers (Table 5).

**COMMENT**

This study validates the phenomenon of regression between the ages of 12 and 24 months in children with ASD based on behavioral observations coded from home videotapes by coders blind to diagnostic and regression status. Infants with ASD whose parents reported early onset displayed impairments in joint attention and communication behaviors at 12 months of age. These infants used complex babbling, words, and declarative pointing less frequently than typically developing infants. In contrast, the 12-month-old infants with regression used complex babbling or words more frequently than typically developing 12-month-old infants and did not differ in their use of joint attention. These same children observed at age 24 months, however, did display symptoms of autism, which were manifested as impairments in joint attention, communication behavior, social orienting, and eye contact. At age 24 months, both groups of toddlers with ASD—with and without a history of regression—showed fewer instances of word use, vocalizations, declarative pointing, social gaze, and orienting to name, as compared with the typically developing toddlers. When trends across time were examined, it was found that both groups of infants with ASD—those with and without regression—showed a significant decrease in their use of social gaze between ages 12 and 24 months. Furthermore, whereas the typically developing infants showed a dramatic increase in use of complex babble and words between ages 12 and 24 months, both of the regressed and early-onset toddlers with ASD failed to make significant gains. These results provide empirical support for regressive and nonregressive patterns of development in autism using home videotapes. They corroborate parent reports that, early on, some children with ASD use words and gestures and then lose these skills. These results also support research indicating that regression in language is often seen in combination with regression in at least 1 other area. 

While we cannot be certain from these data that children with autistic regression were developing entirely normally before the regression occurred, the results of the present study suggest that at least some children with autism do not display prototypical impairments in joint attention, such as a lack of declarative pointing, nor do they display obvious delays in their use of language at the end of their first year of life. Although these core autism symptoms were not observed at age 12 months in the present study, it is possible that the infants with regression did have other types of unusual behavior before the regression occurred. This was suggested by the Early Development Interview data. On this interview, parents of children with regression noted that their child had regulatory difficulties before the onset of autism symptoms. These findings raise the question of whether there were subtle differences in the early development of children who experienced regression. Regulatory behaviors included sleeping problems and oversensitivity to sensory stimulation, symptoms that are not part of DSM-IV criteria for autism but that might reflect subtle differences in neurological development. This is congruent with an earlier study, which found that some children with regression were reported by parents to have regulatory and temperament difficulties before age 12 months. Previous home video research also found that children with ASD displayed regulatory impairments at ages 9 to 12 months, such as social touch aversion, and other recent reports have documented the presence of subtle abnormalities prior to the onset of specific symptoms. Clearly, these kinds of regulatory or temperamental characteristics are not specific to ASD and are not considered highly atypical at 9 to 12 months of age, yet infants with both regressive and nonregressive forms of autism appear to display them more frequently than typical infants.

### Table 5. Early Development Interview (EDI) at 12 and 24 Months of Age

<table>
<thead>
<tr>
<th></th>
<th>12-mo EDI Scores</th>
<th></th>
<th>24-mo EDI Scores</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Regulatory</td>
<td>Social</td>
<td>Language</td>
<td>Repetitive</td>
</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>F Test</td>
<td>Mean (SD)</td>
<td>F Test</td>
</tr>
<tr>
<td>Toddlers with early-onset ASD</td>
<td>0.62 (0.61)</td>
<td>5.5*</td>
<td>0.79 (0.72)</td>
<td>6.5*</td>
</tr>
<tr>
<td>Toddlers with ASD with regression</td>
<td>0.53 (0.69)</td>
<td>4.9 (0.74)</td>
<td>0.77 (0.90)</td>
<td>3.8†</td>
</tr>
<tr>
<td>Typical toddlers</td>
<td>0.08 (0.25)</td>
<td>0.11 (0.17)</td>
<td>0.21 (0.38)</td>
<td>0</td>
</tr>
</tbody>
</table>

Abbreviation: ASD, autism spectrum disorder.

*P<.01.
†P<.05.
‡P<.001.
In summary, this study examined the validity of the phenomenon of regression using home videotape observations and provided support for parental report of regression in autism. These results represent an external validity check on parent report of regression on the ADI-R. This assurance is quite important, given the wide usage of the ADI-R to identify regression in autism research. The Early Development Interview provided additional validation for the phenomenon of autistic regression and supplied evidence of possible early regulatory abnormalities in children with regression, before the onset of autism-specific symptoms.

Regarding the potential clinical implications of early variations in the course of autism, in a larger sample that included the children who participated in this study, we found that there were no outcome differences at ages 3 and 4 years in children with a history of regression vs early-onset autism, in terms of severity of autism symptoms, IQ, adaptive behavior, or neuropsychological functioning. We are following up this group of children to determine whether differences in outcome emerge as children get older. Future research should focus on examining whether autistic regression in the first 2 years of life is distinct from later regression seen in cases of childhood disintegrative disorder and determining whether regressive forms of autism represent genetic subtypes and/or other distinct etiologies.

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Correspondence: Geraldine Dawson, PhD, UW Autism Center, Box 357920, Seattle, WA 98195 (dawson@uw .washington.edu).

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