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Stereotypies in children with a history of early institutional care

Karen J. Bos, Charles H. Zeanah Jr, M.D., Anna T. Smyke, Ph.D., Nathan A. Fox, Ph.D., and Charles A. Nelson, Ph.D.

Laboratories of Cognitive Neuroscience, Children's Hospital Boston, Harvard Medical School, Boston, Massachusetts (Ms Bos and Dr Nelson); Department of Human Development, University of Maryland, College Park (Dr Fox); and Department of Psychiatry and Behavioral Sciences, Tulane University, New Orleans, Louisiana (Drs Zeanah and Smyke)

Abstract

Objectives—To investigate the prevalence of stereotypies in children with a history of early institutional care, to evaluate the efficacy of a foster care intervention compared with institutional care on the course of stereotypies, and to describe correlates in language, cognition, and anxiety for children who exhibit stereotypies.

Design—Randomized controlled trial.

Setting—Institutions in Bucharest, Romania.

Participants—136 children with a history of early institutional care.

Intervention—Comparison of a foster care intervention with continued care as usual in an institution.

Outcome Measures—The presence of stereotypies as well as outcomes in language, cognition, and anxiety.

Results—At the baseline assessment prior to placement in foster care (average age of 22 months), over 60% of children in institutional care exhibited stereotypies. Follow-up assessments at 30 months, 42 months, and 54 months indicate that being placed in families significantly reduces stereotypies, and with earlier and longer placements, reductions become larger. For children in the foster care group, but not in the care as usual group, stereotypies were significantly associated with lower outcomes on measures of language and cognition.

Conclusions—Stereotypies are prevalent in children with a history of institutional care. A foster care intervention appears to have a beneficial/moderating role on reducing stereotypies, underscoring the need for early placement in home-based care for abandoned children. Children who continue to exhibit stereotypies after foster care placement are significantly more impaired on outcomes of language and cognition than children without stereotypies, and thus may be a target for further assessments or interventions.

Correspondence: Charles A. Nelson III, Ph.D., Laboratories of Cognitive Neuroscience, Children's Hospital Boston, 1 Autumn Street, Office AU621, Mailbox #713, Boston, MA 02115-5365, charles.nelson@childrens.harvard.edu.

Introduction

Stereotypies are defined as repetitive, invariant movements with no obvious goal or function.¹ Stereotypies may occasionally be seen in typically developing children but are more commonly associated with a number of different medical conditions, including autism and mental retardation.² In addition, stereotypies are known to develop in association with atypical and especially restricted sensory environments or deprivation.¹ The association of stereotypies with disorders of the central nervous system suggests a neurological basis, but the underlying cause, pathophysiology, and possible approaches for treatment all require further investigation.³

In this paper, we focus on stereotypies associated with early psychosocial deprivation. Most of our understanding of stereotypies associated with sensory restricted environments comes from animal models. Stereotypies are the most common form of abnormal behavior found in caged animals, and animal models of deprivation-induced stereotypies have been found across many species.^{4–6} In these animal models, stereotypies have been linked to alterations in the cortical-basal ganglia circuitry.⁷

Human models of severe psychosocial deprivation in early childhood are understandably more limited. However, there are case reports of previously healthy children who developed stereotypies after exposure to prolonged extreme deprivation. In one case, a typically developing, healthy three year old girl in Thailand exhibited a number of motor stereotypies after being isolated in a cage for six years. Four years after her reintegration into the community, she showed considerable improvement including the elimination of stereotypies, but she continued to have many developmental difficulties, particularly with speech.⁸

Children raised in institutions provide another unfortunate but important group in which to study the effects of extreme early psychosocial deprivation, including the presence of stereotypies. Institutionalized children are known to exhibit deficits across numerous domains of functioning, including physical, psychiatric, and cognitive outcomes.^{9–11} There are a few reports in the literature suggesting an increased incidence and severity of motor stereotypies in this population, believed to be caused by the restricted sensory environment limiting typical input.^{12–14} Hypotheses for the functional significance of stereotypies in this environment include attempts at self-stimulating, coping mechanisms for self-soothing, or expressions of frustration or anxiety, particularly in children who lack adequate verbal communication skills.^{13–14}

An important issue that has not been addressed to date is a systematic study of the reduction or elimination of deprivation induced stereotypies by restitution of enhanced caregiving environments. One report in the literature suggests a reduction in stereotypies after adoption and calls for additional research in this area. In this study of 46 children adopted from Romanian orphanages by families in British Columbia, 84% of caregivers reported the presence of stereotypies at the time of placement. The average age of the children at adoption was 18.5 months, and the mean time spent in institutions prior to adoption was 17.5 months. By the time the interview for the study was conducted (a median of 11 months

after placement with the adopted family), 98% of stereotyped behavior problems were reported by caregivers to have shown some improvement or to be completely resolved.¹³ However, since children in this study were not randomly assigned to foster care placement, the application of these results to all children with a history of early institutional care is limited by selection bias. In addition, the study reports findings from only one assessment after placement, and therefore does not provide data on stereotypies at later ages.

In the current study, we draw on data from the Bucharest Early Intervention Project (BEIP), a study of current and formerly institutionalized children in Romania. The BEIP is unique in its ability to evaluate directly the effects of early family placement rather than institutional care for young children because the participants were institutionalized children randomly assigned either to continued care as usual in the institution or to a foster care intervention. The BEIP is the first such randomized clinical trial to evaluate foster care as an alternative to institutional care for abandoned children.¹⁵ Because the children enrolled in this study were closely followed longitudinally, this study also provides the unusual opportunity within the population of institutionalized children to investigate the course of stereotypies in children exposed to extreme deprivation and the presence of sensitive periods for the development or remediation of stereotypies.

The questions addressed in this study are the following: 1) How many young children being raised in institutions exhibit stereotypies? 2) For children with a history of early institutionalization, does placement in a foster care intervention reduce or eliminate stereotypies? If so, is there an effect of timing of placement? 3) To characterize those children who continue to exhibit stereotypies compared to those whose stereotypies resolve, are there any correlates of stereotypies that we can identify in this population, particularly focusing on outcomes in language, cognition, and anxiety?

Methods

Participants

Participants for this study were children with a history of early institutional care enrolled in the Bucharest Early Intervention Project (BEIP). Children under the age of 31 months living in six institutions in Bucharest underwent screening for enrollment in this study. These children were originally placed in an institution at or close to the time of birth. Of 187 children who were screened, 51 were excluded for medical reasons, including genetic syndromes, fetal alcohol syndrome, and microcephaly.⁹ Of the remaining 136 children, 68 were randomly assigned to foster care placement (referred to as the foster care group, or FCG) and 68 were assigned to continued care as usual in the institution (the care as usual group, or CAUG). The foster care intervention was created through collaboration between study investigators and Romanian authorities, and the characteristics of the foster care system are discussed at length elsewhere.¹⁵ A thorough discussion of the ethical issues inherent to this study has been covered in previous publications.^{9,16–17}

The average age at foster care placement was 22.9 months with a range of 6–33 months. After a baseline evaluation prior to foster care placement, all children were reassessed at ages 30, 42, and 54 months. The flow of participants and causes of attrition by the last

assessment point at 54 months are described in Figure 1. All analyses were done following an intent-to-treat model, with children considered within their original group assignment even though many of the CAUG children were later placed in foster care.

Instruments

Trained and reliable Romanian staff administered all assessments. For the instruments that rely on caregiver report, for children living with foster parents, the foster mother served as the reporter. For children living in institutions, an institutional caregiver reported on the child's behavior. If the child was identified by staff as having a favorite caregiver, this person was selected. If no favorite was identified, a staff member who knew the child well was chosen.

Stereotypies—The Disturbances of Attachment Interview (DAI), a semi-structured interview administered by a trained clinician to the child's primary caregiver, was used to assess stereotypies. Based on probes detailing the child's behavior, caregivers' responses were coded by interviewers as "0" = "none," "1" = "somewhat or sometimes," and "2" = "many or often." The DAI was administered to all children in the study at baseline, 30 months, 42 months, and 54 months.

Language—The Reynell Developmental Language Scales (RDLS) were used to assess verbal comprehension (receptive language skills) and expressive language skills. The RDLS is designed to measure language skills in young or developmentally delayed children and is intended for use with children between 18 months and 7 years of age. This measure was administered to all children in the study at the assessments at 30 months and 42 months.

Cognition—Cognitive development was assessed at baseline, 30 months, and 42 months using the Bayley Scales of Infant Development (BSID-II), and at 54 months with the Wechsler Preschool Primary Scales of Intelligence (WPPSI-R). The BSID-II, intended for infants from 1–42 months of age, assesses a child's development in three domains: cognitive, motor, and behavioral. The child's score is reported as the developmental quotient (DQ). The WPPSI-R measures intellectual functioning in verbal and performance domains and also provides a measure of the child's general intellectual ability (full-scale IQ).

Anxiety—The Preschool Age Psychiatric Assessment (PAPA), a structured psychiatric interview, was administered to the child's primary caregiver at the 54 month assessment. If the caregiver reported symptoms, the interviewer collected information about frequency, duration, and dates of onset. This information was used to determine whether the symptoms met DSM diagnostic criteria for various disorders. This assessment, intended for children ages 3–6 years old, has been found to have test-retest reliability comparable to that of well-established measures for older children and adults.¹⁸ In this analysis, the outcome measure used from the PAPA was the presence of any anxiety diagnosis.

Statistical analysis

To examine the prevalence of stereotypies the Wilcoxon-Mann-Whitney test was used. This test was chosen because the dependent variable, stereotypy score, is ordinally scaled. Timing

of placement analyses were done using Fisher's exact test. Other analyses were done using independent sample *t* tests for continuous variables and $\chi 2$ tests or Fisher's exact test for categorical variables. A *P* value lower than .05 was considered significant.

Results

No significant relationship was found between stereotypies and gender, ethnicity, or birthweight at the baseline assessment or any of the follow-up assessments.

Prevalence of stereotypies

The prevalence of caregiver-reported stereotypies is summarized for the CAUG in Figure 2 and for the FCG in Figure 3. As expected, there was no statistically significant difference in the underlying distributions of stereotypies in the CAUG and the FCG at the baseline evaluation, prior to placement in foster care (z = -.20, P = .839). At each follow-up assessment, the results indicate that there is a statistically significant difference between the distribution of stereotypies in the CAUG and in the FCG, with children in the FCG exhibiting fewer stereotypies (30 months, z = -2.99, P = .003; 42 months, z = -3.36, P = .001; 54 months, z = -2.06, P = .040).

As a comparison, the same assessments were administered to a group of children raised with their biological families in the greater Bucharest area. At the initial baseline evaluation, 1/61 (1.64%) of the children in this never-institutionalized group had many stereotypies, 12/61 (19.7%) had some stereotypies, and 48/61 (78.7%) had no reported stereotypies. At 30 months, no children in this group had many stereotypies, 1/52 (1.9%) had some stereotypies, and 51/52 (98.1%) had no stereotypies. At 42 months and 54 months, no children in this group were reported to exhibit stereotypies.

Timing of placement in foster care intervention

Next we looked within the foster care group to see if there is a relation between timing of placement into foster care and subsequent stereotypies. Children in the FCG were divided into three groups based on age of placement into foster care: younger than 12 months, between 12–24 months, and greater than 24 months. At each follow-up assessment, the percentage of children who exhibited any stereotypies was lowest for the children placed youngest and highest for the children placed oldest (see Table 1). The difference between the three age of placement groups was significant at the 30 month (P = 0.006) and 54 month assessments (P = 0.025). The 42 month data shows the expected ordering, but the difference is not significant (P = 0.337).

Correlates of stereotypies

For each of the following assessments conducted after the baseline evaluation, analyses were performed with subjects stratified by group assignment (CAUG or FCG). Within each of these groups, we compared outcomes for children with and without stereotypies.

Language—At all assessments, children with stereotypies had lower mean scores for verbal comprehension and for expressive language than children without stereotypies, but

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these differences were significant only in the FCG and not in the CAUG. In the CAUG at 30 months, the mean comprehension score was 17.1 for children with stereotypies and 19.7 for children without stereotypies (P = .185). The mean expressive language score was 5.30 for children with stereotypies and 6.31 for children without stereotypies (P = .532). At 42 months in the CAUG, the mean comprehension score was 32.0 for children with stereotypies and 33.1 for children without stereotypies (P = .516). The mean expressive language score was 17.4 for children with stereotypies and 19.1 for children without stereotypies (P = .392).

In the FCG at 30 months, the mean comprehension score was 17.9 for children with stereotypies and 25.4 for children without stereotypies (P = .003). The mean expressive language score was 5.4 for children with stereotypies and 10.8 for children without stereotypies (P = .009). At 42 months in the FCG, the mean comprehension score was 34.2 for children with stereotypies and 38.5 for children without stereotypies (P = .081). The mean expressive language score was 17.8 for children with stereotypies and 24.6 for children without stereotypies (P = .001).

Cognition—At all assessments, children with stereotypies had lower mean scores for cognitive outcomes than children without stereotypies, but this difference only achieved significance within the FCG. In the group of all ever-institutionalized children (both the CAUG and FCG) at baseline, the difference on DQ between children with and without stereotypies was not statistically significant (71.08 vs. 75.75, P = .073). Within the CAUG, differences on DQ or full scale IQ between children with and without stereotypies were not statistically significant at 30 months (74.74 vs. 78.75, P = .214), 42 months (72.46 vs. 78.72, P = .092), or 54 months (70.91 vs. 75.21, P = .248). At 54 months, in addition to full scale IQ, scores were also obtained for performance IQ and verbal IQ. Neither performance IQ (71.00 vs. 76.25, P = .138) or verbal IQ (76.22 vs. 78.86, P = .486) was significantly different for children with and without stereotypies in this group.

In the FCG, differences on DQ or full-scale IQ between children with and without stereotypies were statistically significant at 30 months (77.46 vs. 84.92, P = .021), 42 months (75.12 vs. 87.53, P = .004) and 54 months (72.18 vs. 84.55, P = .019). In the FCG, the difference between the mean score for children with and without stereotypies was statistically significant for verbal IQ (74.24 vs. 88.26, P = .007), but not performance IQ (75.71 vs. 84.48, P = .079).

Anxiety—In the CAUG, 12/24 (50%) of the children with stereotypies had an anxiety diagnosis, and 9/28 (32%) of the children without stereotypies had an anxiety diagnosis, a difference that was not statistically significant (P = 0.191, Pearson chi-square test).

In the FCG, 5/17 (29%) of the children with stereotypies had an anxiety diagnosis, and 5/42 (12%) of the children without stereotypies had an anxiety diagnosis, a difference that was not statistically significant (P = 0.133, Fisher's exact test).

Discussion

This study is the first randomized trial of foster care as an alternative to institutional care and therefore the first clinical trial to determine if family care can remediate stereotypies in children being raised in conditions of social deprivation. We believe that this study has several important findings. First, a striking number of children who have a history of institutional care exhibit stereotypies, with the majority of children in institutional care at our baseline evaluation showing such behaviors. At follow-up evaluations, we described a general course of declining prevalence of stereotypies over time in both the CAUG and FCG. The stereotypy scores in the FCG, however, were significantly lower than in the CAUG, suggesting a beneficial/moderating role of the foster care intervention. This pattern of resolution of stereotypies with time contrasts with the literature on the longitudinal course for deprivation-induced stereotypies.¹⁹ This is consistent with a previous report in the literature on the resolution of stereotypies in children adopted out of institutions.¹³

To investigate further the foster care intervention, we next considered timing of placement into foster care. Results indicate that being placed in families significantly reduces stereotypies, and with earlier and longer placements, reductions become larger. These results underscore the need for early placement in home-based care for abandoned children.

Finally, we investigated possible correlates in language, cognition, and anxiety among children in order to characterize children who exhibit stereotypies compared with those who do not. The results indicated a pattern of significant differences on language and cognition measures within the FCG, but not within the CAUG, for children with and without stereotypies.

These data suggest that for children with a history of early severe deprivation who are subsequently exposed to a family environment, two subgroups emerge. Most children experience remediation of stereotypical behavior, suggesting that recovery is possible. However, a significant subset of this population continues to exhibit stereotypies. These children are also significantly more impaired on outcomes of language and cognition than the children who do not exhibit stereotypies. Since stereotypies are an easily observable measure (more so than extensive cognitive or language assessments, for example), this may point to a potential strategy for identifying young children with a prior history of early deprivation who may be most at risk for poor outcomes in language and cognition and who may benefit from further assessments. Further research is needed to clarify what might be different about these two groups.

Though stereotypies may serve as a marker of poor outcomes in these domains, we do not believe it is appropriate to suggest from these data that stereotypies are a *cause* of lower cognitive outcomes. It remains unclear what precisely the presence of stereotypies may indicate in respect to brain damage or development in this population. Previous research has identified a variety of ways in which early institutionalization of young children affects brain development, including alterations in metabolic, physiological, and neurochemical activity, changes in the size of certain areas of the brain, and diminished white matter

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connectivity.^{21–24} However, the relation between these identified neurobiological changes and the development of deprivation-induced stereotypies requires additional research.

There are several limitations of this study that should be noted. First, the data on stereotypies used in these analyses were gathered through caregiver report, not direct observation by study staff. This approach was chosen because the caregiver had observed the child in multiple settings on numerous occasions, and thus we felt was able to provide a more accurate assessment than could be obtained through a brief observed session. Previous reports on stereotypies in typically developing children have suggested that children are most likely to exhibit this behavior when alone in a crib or when irritable or upset,²⁰ and we believe that these situations are more likely to be observed by a caregiver than during a time in which the child is actively engaged in a study assessment. However, relying on data from caregivers introduces the possibility of reporter bias. For example, foster parents may be more likely to report stereotypies than institutional caregivers if they spend more time observing the child or if they are more likely to believe that foster parents may be beneficial to the child. Conversely, it is also possible that foster parents may minimize this type of behavior if they believe it will reflect poorly on the care they are providing or that it will mark their child as abnormal.

Additional limitations include that motor stereotypies were grouped together in these analyses and the impact of a particular type of stereotypy (for example, rocking back and forth as compared to a more elaborate stereotypy) was not considered separately. To address this, further analyses could consider the quality and nature of stereotypies in more detail. In addition, the data reported in this study extend only through 54 months. Future work should be done to investigate if the results found here persist into adolescence and adulthood.

In summary, these findings contribute to our understanding of the prevalence of deprivationinduced stereotypies and to associated deficits in language and cognition in children who exhibit this behavior. The results also provide evidence that young children with a history of early institutional care who are placed into foster care may experience significant recovery from stereotypies. These findings have implications beyond the unique population of children in orphanages, as the extreme example of institutional care can help us to better understand the impact of deprivation on children in many settings.

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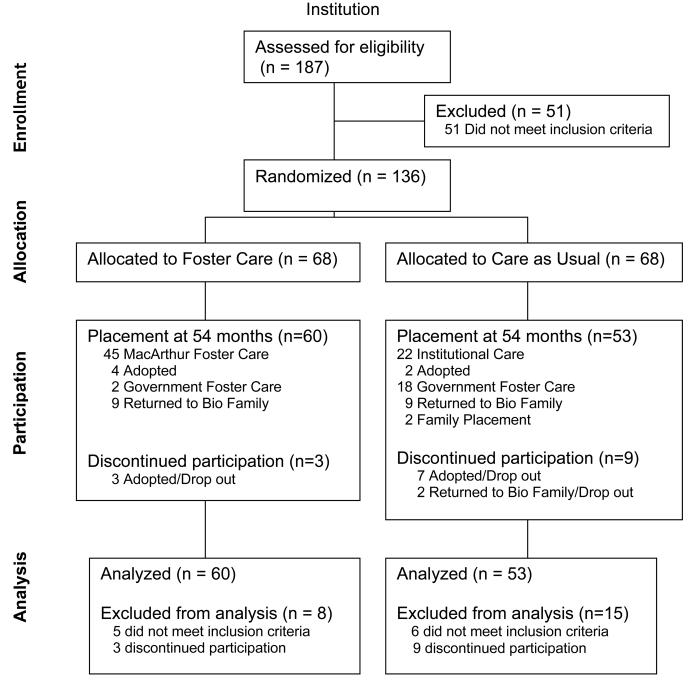


Figure 1.

Flowchart of participants randomized to a foster care intervention or care as usual in the institution. Information is presented for the final assessment point of 54 months.

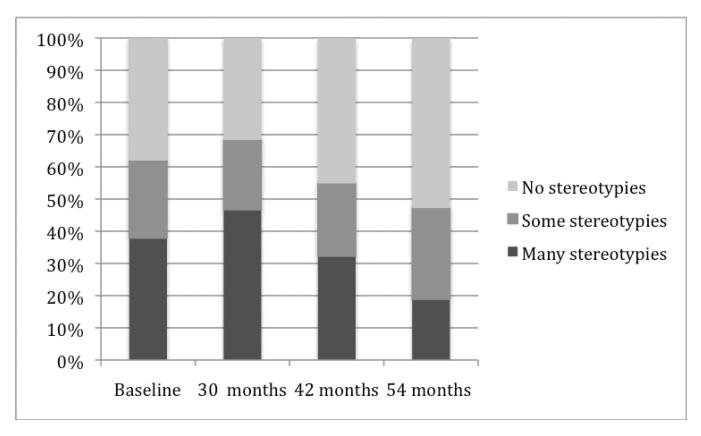


Figure 2.

Percentage of children exhibiting none, some, or many stereotypies in the CAUG at baseline and at follow-up assessments at 30 months, 42 months, and 54 months.

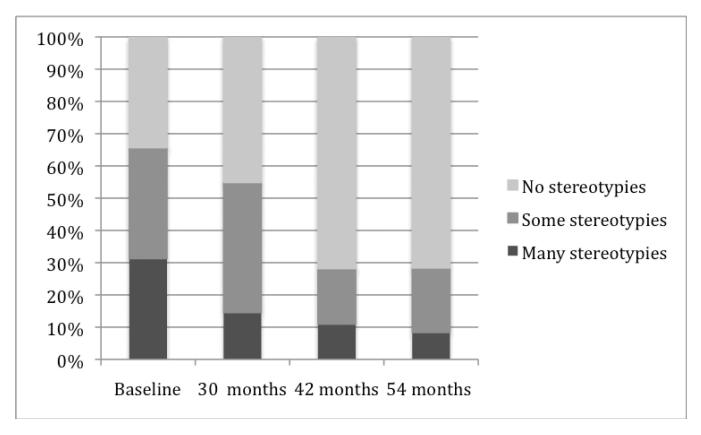


Figure 3.

Percentage of children exhibiting none, some, or many stereotypies in the FCG at baseline and at follow-up assessments at 30 months, 42 months, and 54 months.

Table 1

Percentage of children in the FCG exhibiting stereotypies by age group of entry into foster care.

Age at placement		30 months		42 months		54 months
	N	% with stereotypies	2	% with stereotypies	Ν	% with stereotypies
0–12 months	×	25%	٢	14%	٢	0
12–24 months	23	39%	25	20%	23	17%
24+ months	31	74%	32	38%	30	43%

Note: N values differ because results were not available for some children at all evaluations. For a summary of the flow of participants and causes of attrition by the last assessment point at 54 months, see Figure 1.