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Institutionalized Children and the Risk of Fetal Alcohol Spectrum Disorder (FASD); A Primer for Clinicians, Adoption Staff and Parents

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Abstract

Objectives: Our objective was to estimate the likelihood of abnormal development among institutionalized children, addressing either the risk in general, or the risk for fetal alcohol spectrum disorder (FASD).

Methods: Narrative review of studies measuring developmental effects of these populations. We identified all systematic reviews and meta analyses dealing with the associations between institutionalization of children and their neurodevelopment in general, or between institunalization of children and their likelihood of suffering from FASD.

Results: a) In a published meta-analysis the mean IQ/DQ was 84 among institutionalized children, as compared to 104 among children raised in families. Favorable caregiver-child ratios appeared to have a protective effect, whereas longer stays in institutions had a detrimental effect on IQ/DQ.

b) A further meta- analysis has shown a positive impact of adoption on children's cognitive development with adopted children's displaying remarkably normal cognitive competence as compared to their non-adopted peers.

c) The overall pooled prevalence was 6% (60 per 1,000, 95% CI 38-85) for full blown fetal alcohol syndrome (FAS), and 16.9% (95% CI 109-238 per 1,000) for the whole range of FASD.

d) The estimated prevalence of FASD was 10-40 fold higher than the 7.7 per 1000 in the general population.

Conclusions: A large proportion of adopted institutionalized children may not follow a normal developmental trajectory. If not afflicted by FASD, there is a positive impact of adoption on children's cognitive development and in general they are comparable to their non- adopted peers.

Keywords

Institutionalization, fetal alcohol spectrum disorder, FASD, neglect, adoption, foster homes

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Introduction

Between 1999-2014 about a quarter of a million children were adopted in the United States with the origin of the adopted children in China (74,000), Russia (46,000), Guatemala (30,000) and South Korea (20,000) leading in numbers.[1]

Many of these children, and especially from the former Soviet Union, had been institutionalized at the time of adoption. There is ample evidence that institutional care is associated with "structural neglect" characterized by suboptimal physical resources, minimal staffing, extreme neglect and lack of adequate caregiver-child interactions.[2] Consistent evidence suggests that these may adversely affect the physical, hormonal, cognitive, behavioral and emotional wellbeing of many of these children. While there is still a debate whether there is a distinctive "post-institutional syndrome", many of these youngsters sustain neuro-behavioral and emotional impairments.[2]

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Summarized by Bledsoe and Johnston,[3] the chances of a child to follow a normal trajectory at the time of adoption are limited. Destitute, single mothers with poor prenatal care and inadequate diet, are common associations surrounding children given for adoption.

In addition to the multifaceted insult caused to the child by being institutionalized, a large percentage of the single mothers that bring these children to typical "children's homes" consume alcohol and drugs of abuse, rendering the fetus vulnerable to the detrimental effects of illicit drugs, especially fetal alcohol spectrum disorder (FASD).[3]

Recognizing FASD is therefore critical in any attempt to evaluate medically adopted children from "children's homes".

Fetal Alcohol Spectrum Disorder (FASD)

Fetal Alcohol Spectrum Disorder (FASD) describes a range of adverse physical, behavioural and cognitive effects following ethyl alcohol (herein named alcohol) exposure during embryonic and fetal life. The 'spectrum' term allows a wide range of severity of neurodevelopmental effects.[4,5] The full blown fetal alcohol syndrome [FAS] is characterized by a triad of pathognomonic features that include; distinctive craniofacial dysmorphology (reduced palpebral fissure length, smooth filtrum, thin upper lip), intrauterine growth retardation, and central nervous system (CNS) developmental abnormalities.[6] Early diagnosis of FASD and developmental disabilities is best achieved at an early age.[7] Identification of alcohol abuse during pregnancy is heavily stigmatized with rare prenatal screening attention in routine care.[8]

Presently, the lower limit of safety of maternal alcohol consumption during pregnancy on fetal development has not been determined,[9] and virtually all medical organizations call for abstaining from any alcohol consumption during pregnancy (e.g. American College of Obstetrics and Gynecology and American Pediatric Society). Binge consumption has been associated with the greatest FASD risk, and second and third trimester alcohol consumption increases FASD risk five-fold over first trimester consumption.[9,10]

Individuals with more subtle impairments tend to have poorer quality of life outcomes due to lack of recognition of their neurological deficits.[10,11] Secondary disabilities associated with FASD, such as dependent living, incarceration, early death, addictions, and early school drop-out, may be preventable with early diagnosis and medical/social/educational interventions.[10-13] It is critical to note that not all chronically exposed infants will exhibit alcohol-related neurotoxicity. Rather, an estimated 40% of chronically exposed fetuses will exhibit diagnosable FASD.[14]

The majority of children with FASD display attention-deficit hyperactivity disorder, oppositional defiance disorder, depression, and conduct disorders.[15-17] Lack of widespread recognition of FASD by medical, law enforcement and judicial authorities has led to very large numbers of affected individuals experiencing substantial difficulties without consideration of their cognitive and behavioral limitations.[18]

Chasnoff et al.[19] have shown evidence that in the United States up to 80% of children with FASD in the general population, or referred for foster care or adoption are undiagnosed, and 7% are misdiagnosed. It is very likely that similar figures would prevail in other parts of the world.

Objective

The objective of the present review was to define the developmental trajectory among institutionalized children, and to address either their risk in general, or the risk for FASD.

Methods

We conducted a narrative review of PubMed, Embase and Cochrane databases from inception to April 15, 2019 for all human studies reporting a systematic review and meta- analysis on child development among institutionalized children. We included any systematic review and meta analysis that reported on neurodevelopment of institutionalized children using the terms "institutionalized children"/"children's home"/ "abandoned children"/ "child development"/ "cognition"/ "IQ"/ FASD/ alcohol in pregnancy/ AND "systematic review" and "meta analysis". The analysis looked at either neurodevelopment in general, and also for studies where the assessment was focused on FASD.

Because in both cases of risk estimates (i.e. in general and specifically for FASD) comprehensive meta- analyses have been published, we did not attempt to reproduce them, but rather to apply some of their statistics for calculating overall risks.

Results

Out of 5,872 articles dealing with FASD or instititutionalized children, we identified 4 systematic reviews and meta analyses addressing the two issues aimed: development of institutionalized children,[20,21] and FASD among institutionalized children.[22,23]

Cognitive development among institutionalised children:

Numerous papers have been published as early as in the 1930's, invariably showing low IQ and language delays among institutionalized children (2). For the sake of the present review, we focused on the meta-analysis published by van IJzendoorn et al.[20] in 2008, combining 75 studies with more than 3,800 children in 19 countries. Mean IQ/DQ was 84+/- 16.8 among institutionalized children, as compared to 104+/- 13 among children raised in families. The mean effect size was an IQ/DQ reduction of 0.75 standard deviation, which is considered a large Cohen's D effect size. The mean difference of 20 points IQ was highly significant and it practically meant that many more children were in the range of " mental retardation" as defined at that time. Favorable caregiver-child ratios appeared to have a protective effect, whereas longer stays in institutions had a detrimental effect on IQ/DQ. One or more years of family life prior to institutionalization provided a partial protective effect.[20] Children placed in orphanages before 12 months of age did poorer than children reared at home for at least 12 months before being placed in orphanages.

The very unique randomized, controlled Romanian study where institutionalized children were randomized to continue in children's homes, or joining foster care, has provided further important insight into the potential effects of institutionalization. In general, toddlers reared in children's homes had serious intellectual delays, with a mean intelligence at the "borderline- mental retardation" range .The children randomized to foster care exhibited significant intellectual gains. Importantly, and consistent with the meta- analysis, the younger the age of joining foster care, the better was the cognitive outcome at 54 months of age.[24] However, according to van IJzendoorn et al.,[20] based on the available data the full extent of the benefits of adoption are still unclear, because adopting parents may tend to choose to adopt better developed children.

In further research, van IJzendroorn et al.[21] addressed more closely the question whether the cognitive development of adopted children is different from that of children who have remained in institutional care or in their birth families, or from their current (environmental) non adopted siblings or peers. In a meta-analysis of 62 studies including 17,767 adopted children, spanning from the 1930s till 2008, the team compared their current non- adopted environmental peers or siblings. Adopted children showed similar IQ scores but still, despite adoption, their school performance and language abilities lagged somewhat behind.[21] Importantly, there was a twofold increase in special-education referrals among adopted children compared to their non-adopted peers. These results indicate a positive impact of adoption on children's cognitive development with adopted children showing remarkably normal cognitive competence but somewhat delayed school performance.

Prevalence of FASD among institutionalized children

It has been estimated that over 600,000 children reside in children's homes in Russia. Miller et al.[25] reported, in a phenotypic survey, on the rate of FASD among children residing in Russian orphanages. They screened 234 toddlers at a mean age of 21months (SD 12.6), including facial dysmorphology, other physical signs and growth rate. The medical charts of 64% of the cases were also reviewed. Thirteen percent of children had facial dysmorphology highly compatible with FASD, and 45% had intermediate dysmorphology. The facial dysmorphology correlated with reduced physical growth and developmental delay. More than 70% of children with high pre- defined FASD phenotypic scores exhibited moderate to severe developmental delay.

Lange et al. conducted a meta-analysis of the prevalence of FASD among institutionalized children with studies published between 1989 and 2014. The overall pooled prevalence was 6% (60 per 1,000, 95% CI 38-85) for full blown FAS, and 16.9% (95% CI 109-238 per 1,000) for the whole range of FASD.[22]

The same group completed an additional meta- analysis on the prevalence of FASD among "children in care".[23] Overall, 69 studies included 6,177 individuals diagnosed with FASD from 17 countries between 1989-2014. The estimated prevalence of FASD was 10-40 fold higher than the 7.7 per 1000 in the general population. The top prevalence was in Russia, with a pooled prevalence of 95. 5 per 1,000 (95% CI 85.3-105.4). Prevalence was lower in other countries, but still very high in comparison to the general population.[23] However, these estimates, stemming from a meta-analysis using mostly poor and passive methodologies of case ascertainment over 40 years, represent gross underestimates. In a recent study in 4 American communities, based on active case ascertainment studies, the prevalence of FASD ranged between 1.1-5 %.[26]

Integrating the existing data into medical knowledge and counseling

The objectives of the present article were to estimate what is the likelihood of institutionalized children not fulfilling normal developmental trajectory, as well as their risk of being afflicted by FASD.

According to the thorough meta -analysis by van IJzendoorn et al.,[24] the typical institutionalized child loose about 20 IQ points. This can be the result of multiple causes, starting from the genetics of the parents, the suboptimal family and institutional physical resources, minimal staffing, extreme neglect, lack of adequate caregiver-child interactions and sometimes malnutrition or nutritional imbalance. In the vast majority of cases there is insufficient information on the medical and psychiatric status of the biological parents. Numerous studies have shown that some of these insults can be reversed by transferring the child to foster or adoptive homes, and comparison of these adopted children to their non-adopted peers reveals an encouraging positive impact of adoption on children's cognitive development.[20,21,24] In the case of FASD, the prevalence is up to 40 fold higher than in the general population, and the range is up to 45% of all institutionalized children.

In parallel to addressing the information needs of the medical community and parents, these findings should be balanced by more research focusing on potential interventions in affected cases; how institutions should strive to prevent "structural neglect"; and how institutions should deal with children with FASD.

One cannot over emphasize the importance of diagnosis of FASD which can help foster and adopting parents to adequately support the child. Not knowing that the child is affected by FASD would implicate that the child might not receive the attention and support needed. Therefore adequate methods for diagnosis are necessary.

The examining physician dealing with institutionalized children should carefully assess the gestational age at delivery and birth weight, look for any dysmorphic features or aberration of postnatal growth, and above all, should carefully assess the developmental and behavioral milestones, evaluating their adequacy for the child's chronological age. The examiner should keep in mind that often institutionalized children tend to be behind in their developmental milestones and that developmental milestones can normalize if the child is raised in a favorable environment.[27,28] If one suspects FASD or genetic diseases which may be in the differential diagnosis of FASD,[29,30] a complete genetic evaluation can be carried out including chromosome studies, chromosomal microanalysis (CMA), exome sequencing or complete DNA sequencing. It is as yet impossible to diagnose all neurodevelopmental problems but the many that can be diagnosed should be explored.

Limitations of the current scientific understanding need to be acknowledged. In the United States up to 80% of children with FASD in the general population, or referred for foster care or adoption are undiagnosed, and 7% are misdiagnosed.[19] It is very likely that similar figures would prevail in other parts of the world. Importantly, the estimates of prevalence of FASD among institutionalized children stem from meta-analyses which, because of poor and passive methodologies of case ascertainment used for 40 years by most prevalence studies, represent gross underestimates.[26]

Conclusions

A large proportion of adopted institutionalized children may not follow a normal developmental trajectory. The likelihood for FASD is 10-40 higher than in the general population and the institutional environment negatively affects the child's development. There is a positive impact of adoption on children's cognitive development and in general, if not inflicted by FASD, they are comparable to their non- adopted peers.

Authors' Note

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Author Contributions

Both authors discussed the content of the manuscript.
GK wrote the first draft which AO read and added his own thoughts.
Then the authors agreed about the entire content of the manuscript.

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