

## Vulnerable children in Ukraine : impact of institutional care and HIV on the development of preschoolers

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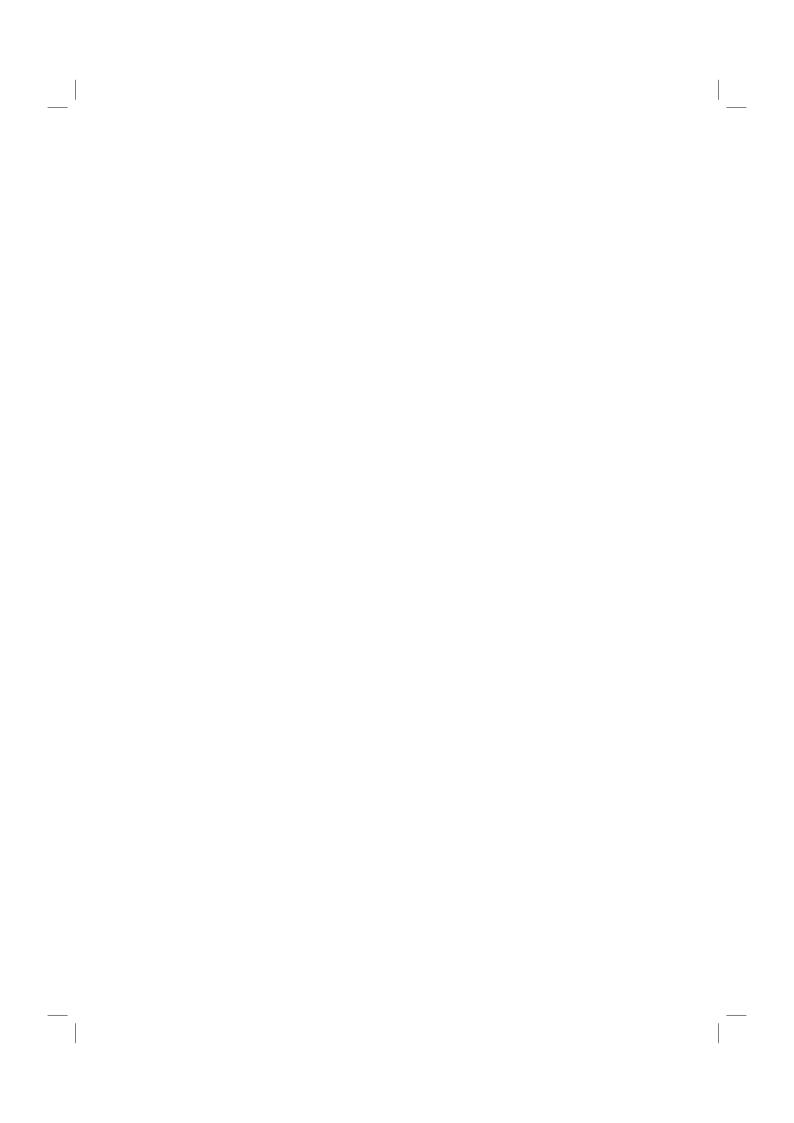
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# Chapter 5

### **Discussion and Conclusion**

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#### Discussion

In this study the impact of institutional care and perinatal HIV infection on different developmental domains of preschool children was examined. We examined the contribution of various child characteristics and different aspects of the rearing environment to the developmental outcomes of children in search for possible risk and protective factors. Our ultimate goal was to gain more insight into potential intervention targets in childcare institutions. In this study the following research questions were addressed:

- (1) What impact do institutional care and HIV infection have on different developmental domains of children?
- (2) How do HIV-infected children reared in disadvantaged families compare to HIV-infected children reared in institutions in various developmental domains?
- (3) Which individual characteristics and which aspects of the rearing environment buffer or exacerbate the impact of institutional rearing?

The development of four ethnically homogeneous groups was compared: children with and without perinatal HIV infection reared in their biological families and childcare institutions. We assessed children who were put into care at one month after birth on average. These children permanently resided in institutions with a similar organization and quality of care. Institutions involved in our study provided adequate nutrition and health care, but lacked stimulation and stability in child-caregiver relationships. As far as family-reared children are concerned, both uninfected and HIV-infected children were raised in families with low to middle incomes. HIV-impacted families had lower monthly incomes and were more likely to experience multiple adversities than families without HIV. HIV-infected children in families and institutions had about the same level of immune control over HIV as was reflected by their CD4 T-lymphocyte count.

In this chapter the findings of our study are summarized and discussed and we also discuss the implications of our findings for policy and practice and for future (intervention) research.

## The impact of institutional care and HIV on the development of children

The findings of our study contribute to a body of research demonstrating that structural institutional neglect impedes the normal development of children. We found that institutional care was associated with less favorable outcomes in all developmental domains that we examined. We also found that presence of HIV infection led to less favorable developmental outcomes, however, negative impact of institutional care was greater than presence of HIV in several domains as separately discussed below.

#### Physical Growth

Our findings around physical growth contribute to the wealth of data demonstrating significant suppression of physical growth among children reared in institutions. The suppression of physical growth among institution-reared children usually results from a complex interplay of different factors, such as nutritional insufficiency, child health condition, and structural neglect (see Johnson, Gunnar & Palacios, 2009, Van IJzendoorn et al., 2007 for reviews). The growth failure of HIV-infected children is usually caused by HIV replication, or HIV-related diseases, and/or treatment toxicity (Bailey et al., 1999; The European Collaborative Study, 2003).

In our study institution-reared children regardless of their HIV status demonstrated substantial delays in physical growth despite relatively adequate nutrition and health provision and even after controlling for possible impact of the child's morbidity. This finding suggests that structural neglect may be the main cause of physical growth delays among institution-reared children in our sample (see chapter 2). Presence of HIV infection was also associated with less favorable growth dynamics both among family- and institution-reared children. We demonstrated that in our sample institutional care had a greater negative impact on children's physical development than HIV infection (see chapter 3).

#### Regulation of Stress

Our study provided a unique opportunity to contribute to the rather scarce data on stress regulation of currently institutionalized children. Institution- and family-reared children in our sample, on average, showed similar patterns of diurnal cortisol production with decreases in the course of the day. However, we found elevated total diurnal cortisol production in uninfected institution-reared children and no difference among the other three groups (uninfected and HIV-infected family-reared children and HIV-infected institution-reared children). Elevation of the cortisol production among uninfected institution-reared children, as we discussed in chapter 2, may be caused by a stressful institutional environment and limited or absent comforting interactions with a caregiver (Gunnar, 2000; Gunnar & Vazquez, 2001). The lack of difference in total daily cortisol production found among the remaining groups may most likely be caused by the medical treatment that the majority of children with HIV infection underwent. The medical treatment may have inhibited the production of cortisol, thus masking the dysregulation of stress (see chapter 3).

#### Cognitive Performance

The negative impact of structural institutional neglect on cognitive development of children has been demonstrated in a substantial body of research. A meta-analysis of 75 studies on the cognitive development of children in orphanages throughout the world demonstrated that an absolute difference in IQ between institutionalized and family-reared children amounted to 20 IQ points (Van IJzendoorn, Luijk, & Juffer, 2008). Studies on cognitive sequelae of HIV in infancy and early childhood also report on cognitive deficits observed in HIV-infected children (e.g., Blanchette et al., 2002; Jeremy et al., 2005; Wachsler-Felder & Golden, 2002).

We found that, on average, institution-reared children were more than 22 IQ points behind family-reared children. The difference in cognitive performance between HIV-infected and uninfected children was about 12 IQ points. We demonstrated that rearing adversities, and institutional care in particular, were associated with greater delays in cognitive development than presence of HIV infection (see chapter 3)

#### Theory of Mind (ToM)

The average expectable environment and especially its caregiving component, i.e., sensitivity, fine tuning and mind-mindedness facilitates earlier acquisition of ToM which refers to the ability to see self and others in terms of mental states. Compromised rearing circumstances may decrease the quality of caregiving and lead to delayed false belief understanding.

In our study, more than a half of the uninfected family-reared children whose rearing circumstances were most favorable among the four groups passed the ToM task. The remaining three groups of children performed almost twice worse and did not substantially differ from each other. Both structural institutional neglect and multiple family adversities could have delayed development of ToM. The fact that there was no substantial difference between infected and uninfected institution-reared children suggests that presence of HIV did not pose an additional risk to the development of ToM among institution-reared children (see chapter 3).

#### Attachment

While institutional care has a negative impact on virtually every developmental domain, research demonstrates that the development of attachment relationships is most at risk in institutional care (Zeanah et al., 2006). Presence of a chronic pediatric condition can also be potentially disruptive to the attachment formation process of children due to the associated medication regimens, recurrent hospitalizations, and frequent separations from caregivers and peers (e.g., Barlow & Ellard, 2006; Odegard, 2005).

We found that only a quarter of children reared in institutions developed clear attachment patterns, as opposed to 97% of children reared in families. Institutional care but not the presence of HIV was associated with less attachment security. Because most children in our study were asymptomatic, HIV infection may not have interfered with attachment formation (see chapter 4).

#### Indiscriminate Friendliness

Deviations of the rearing environment from the average expectable norm may lead to deviant social behaviors such as indiscriminate friendliness. Indiscriminate friendliness is defined as a failure to exhibit reticence around unfamiliar adults, impersonal and superficial contacts with strangers, and lack of checking back with a caregiver in anxiety-provoking situations (e.g., Rutter, Kreppner, & Sonuga-Barke, 2009; Zeanah & Smyke, 2008). It has been described as one of the most persistent behavioral abnormalities associated with institutional background and foster care (e.g., Chisholm, 1998; Zeanah, Smyke, Dumitrescu, 2002). Indiscriminate friendliness has also been observed among maltreated children reared in families (e.g., Zeanah et al., 2004).

In this study we found that, on average, the level of indiscriminate friendliness among institution-reared children was more than twice higher than among family-reared children. As expected, we did not find any association between presence of HIV and indiscriminate friendliness. We found that indiscriminate friendliness was associated with lower attachment security among family-reared children, and with more positive caregiving among institution-reared children. This finding as well as previous research allowed us to suggest that the etiology of indiscriminate friendliness may differ for family- and institution-reared children. In chapter 4 we also argue that indiscriminate friendliness observed among institution-reared children may not be adaptive, as some scholars suggest. We argue that it may result from the lack of expected experience, i.e. consistent interactions with a stable caregiver, during a sensitive period. This sensitive period is likely to be in the first year of life when the transition from indiscriminate response towards strangers to stranger anxiety takes place.

The findings of our study demonstrate that structural institutional neglect impedes the development of children in all examined domains. Presence of HIV infection was also found to be associated with less favorable outcomes in physical growth and cognitive development, however, negative impact of institutional care was greater than presence of HIV.

#### HIV-infected children in families and children in institutions

One of the questions of our study was whether the presence of a primary caregiver, and family care, even of compromised quality, as was the case for HIV-impacted families involved in this research, continues to facilitate the development of HIV-infected children better than institutional care. Or do institutions that provided fairly clean environment and good medical care, such as those where the present study was conducted, offer a more optimal rearing environment for HIV-infected children?

We found that in three out of six developmental outcomes that we examined, HIV-infected children reared in disadvantaged families demonstrated better results than HIV-infected children reared in institutions. Thus, physical growth delays of HIV-infected children reared in families were less substantial. They showed better cognitive performance than HIV-infected institution-reared children, who lagged with more than 15 IQ points behind. 96% of the HIV-infected children reared in families managed to develop clearly discernable attachment relationships as opposed to only 46% of the HIV-infected children in institutional care. We also found that HIV-infected family-reared children were more often secure and less often disorganized than HIV-infected children in institutions. Moreover, HIV-infected children reared in families tended to show more favorable developmental outcomes even in comparison to uninfected and relatively healthy children reared in institutions.

When we compared the quality of the rearing environment of HIV-infected children in families and institutions with the help of the HOME inventory, we did not find any significant differences on the HOME Total Score between these groups. Examination of the individual HOME scales revealed that institutional care offered better physical environment, whereas families secured better quality of child-caregiver interactions. Finally, families provided a more consistent rearing environment with limited stable caregivers, which was not possible in institutions because of their structure and functioning. We may conclude that due to the consistency, stability and better quality of child-caregiver relationships, even compromised family care promoted more optimal development of HIV-infected children compared to institutions that provided better physical environments.

Compared to the institutions, HIV-impacted families facilitated better outcomes in several domains. However, HIV-impacted families failed to facilitate early ToM development. Besides, the elevated levels of disorganized attachment and indiscriminate friendliness in comparison to uninfected family-reared children, and lack of difference in these domains with HIV-infected institution-reared children indicate that the rearing environment in HIV-impacted families was not optimal for the normal development of children.

On the basis of our findings we may conclude that the structural neglect of childcare institutions appeared to be more damaging for children's physical growth, cognitive development, and attachment formation than the presence of HIV in multiple-problem families.

#### Risk and protective factors

Although, on average, institutional care was associated with less favorable outcomes in all developmental domains that we have studied, there was a certain individual variation in the responses of institution-reared children to apparently similar adverse experiences. In some cases the outcomes in different domains were even close to normal. For instance, in almost 30% of children height-forage scores were within one standard deviation from population norms at the time of the assessment; 7% of children in our sample demonstrated cognitive performance within the normal range; 21% of children succeeded in the Theory of Mind task. Finally, 28% of children managed to form secure, clearly developed attachment relationships with their favorite caregiver, and about 37% of children exhibited no or little signs of indiscriminate friendliness. These findings point to the presence of certain factors which may buffer or exacerbate the influence of structural institutional neglect on the development of the child.

Variation in the developmental outcomes may be related to variations in the genetic background, child-related characteristics, variations in the rearing circumstances, as well as complex interrelation between different environmental and child-related factors. We were not able to examine the relation between genetic background and developmental outcomes. Also, because of the modest sample size, limited information on perinatal development and logistical constraints, exploration of the interrelation and mutual influence of child characteristic and environmental factors was limited. Nevertheless, on the basis of our study as well as previous findings we were able to identify several protective factors, risks, and potential intervention targets.

As to the child-related characteristics, we did not find any association between gender, age, or duration of institutionalization. Because there was little variation in the age of admission and the majority of children was admitted to institutional care at the age of one month on average, we did not find any association between the age of admission and subsequent developmental outcomes. Neither did the examination of the impact of individual history of institutionalization, such as transference within and between institutions, presence of siblings in the same institution, and contacts with parents or relatives yield significant results.

We found that perinatal adversities and less optimal physical and health condition of the child at birth were significantly associated with less favorable physical development. An important, although indirect finding was related to a subgroup of children with the so called perinatal hypoxic conditions. Children who were diagnosed with these conditions demonstrated persistent severe growth delays. Despite some improvement in the course of their development, at the time of the assessment these children remained severely delayed. Their cortisol production also clearly deviated from other uninfected institution-reared children. Obviously, children with perinatal complications may be at increased risk for developmental delays in institutional care and require special attention.

As to the environmental factors, we found that better quality of the rearing environment and especially better quality of caregiving was significantly associated with better physical growth and with better cognitive performance of HIVinfected institution-reared children. As we discussed earlier, the overall quality of rearing environment within the institutions was fairly adequate. Moreover, for a number of its physical characteristics, e.g., safety, quantity and variety of toys, and even structured learning activities it appeared to be better than in HIVimpacted families. Nevertheless, fairly adequate physical aspects of the rearing environment of the childcare institutions appeared to be insufficient to facilitate normative physical and cognitive development of HIV-infected children. Better quality of caregiving was also associated with more attachment security even after controlling for the possible impact of the physical and cognitive domains, type of care (family vs. institution), and HIV status. Thus, we can conclude that good quality of caregiving may facilitate better development of institution-reared children and act as a buffer against environmental and health-related adversities. Therefore, the quality of caregiving represents an important intervention target.

#### Quality of Caregiving as an Intervention Target

Various intervention studies demonstrate that the quality of the rearing environment in the childcare institutions can be improved in different ways. Thus, for instance, a 15 minutes auditory, tactile and visual stimulation program twice a day, 5 days a week during a month, resulted in significant gains in height, weight and head circumference in the experimental group of newborn children reared in a Korean orphanage (Kim, Shin, & White-Traut, 2003). Indirect findings of The St. Petersburg-USA Orphanage Research Team (2008) pointed to the importance of the nutritional component in the improvement of physical growth of institution-reared children. A meta-analysis of 14 intervention studies enhancing cognitive development of institutionalized children reported that all interventions in this meta-analysis showed positive but varying results (Bakermans-Kranenburg, Van IJzendoorn, & Juffer, 2008). As to the development of attachment relationships, which we discussed in chapter 4, more favorable child-to-caregiver ratios may better facilitate the attachment formation between caregivers and children in institutional care. Smyke and colleagues (2002) report in their study that even

when the child-to-caregiver ratio remained unchanged but only the number of caregivers attending to a given child was reduced, children appeared to show fewer signs of disordered attachment. These and other studies point to the children's plasticity and the variety of means than can be used to stimulate the development of institution-reared children.

Ideally, to decrease the gap between the institutional care and family rearing comprehensive measures are required. These measures should include optimization of the physical environment, reduction of the child-to-caregiver ratio, facilitation of consistency and continuity of child-caregiver relationships, and enhancement of the quality of caregiving. An excellent example of such a comprehensive program is an intervention study in one of the Russian orphanages that involved training of the caregivers to promote responsive caregiving, and structural alterations aimed to increase the consistency of caregivers. Children involved in this intervention program showed improvements in physical growth, cognition, language, motor development, personal-social adjustment and affect (Groark, Muhamedrahimov, Palmov, Nikiforova, & McCall et al., 2005; Muhamedrahimov, 2007; The St. Petersburg – USA Orphanage Research Team, 2008). However, in Ukraine, in view of the already high costs associated with institutional care that are more than twice higher than in foster care (Carter, 2005), the feasibility and cost-efficiency of such intervention programs are a matter of concern.

The findings of our study indicate that it is primarily the stability and quality of child-caregiver relationships and not so much the presence of HIV-infection and the quality of the physical environment that contribute substantially to the delays in the development of children. Therefore, the effectiveness of less extensive, interaction-focused interventions in childcare institutions should be tested. One of such intervention programs that may be potentially effective in the childcare institutions is a Video-feedback Intervention to promote Positive Parenting (VIPP; Juffer, Bakermans-Kranenburg, & Van IJzendoorn, 2008).

Finally, an important issue in the discussion of possible intervention measures in the context of institutional care is their timing. The first year of life is crucial for different developmental domains. Thus, as far as the physical growth is concerned, the younger the child is, the greater the risk for growth retardation. The growth velocities during the first year of life are the highest. At the same time, this is the period when children are totally dependent on others for their care and, therefore, most vulnerable to poor caregiving (Johnson, 2000; Johnson et al., 2009; Van IJzendoorn et al., 2007). Our study also demonstrates that in the first years of their lives children in institutional care were most severely delayed in their physical growth.

We were not able to examine the development of the stress regulation system and cognitive development during the first year of life. However, a body of research indicates that the first year of life is also crucial for the development of the stress regulation system. If an infant is distressed, the caregiver's comforting behavior reduces the levels of cortisol and related stress hormones. By helping an infant to regulate his or her affective state during the postnatal period, the caregiver helps to buffer or protect the developing brain from the potential deleterious effects of elevated glucocorticoids which may otherwise hamper subsequent emotional and physical development of the child (Gunnar 2000; Gunnar & Cheatham, 2003; Nelson et al., 2009). As to the cognitive development, the meta-analysis of interventions improving cognitive development of institution-reared children reports that interventions with children younger than 12 months were more effective than interventions starting at a later age (Bakermans-Kranenburg et al. 2008).

For the formation of the attachment relationships, according to Bowlby (1988), a sensitive period appears to start from about six weeks of age, and during the first year of life attachment behavior develops most readily (Bowlby, 1969/1997). Our findings on indiscriminate friendliness among institution-reared children also illustrate how the lack of consistent and sensitive caregiving during the first year of life may impede the formation of stranger anxiety and the development of preference for familiar caregivers. Adoption research as well as intervention studies in childcare institutions demonstrate that the earlier (sometimes as early as 6 months) the adoption or intervention takes place, the more effective it is in fostering security and diminishing indiscriminate friendliness (e.g., Rutter et al., 2007; Smyke et al., in press; Van den Dries, Juffer, Van IJzendoorn, Bakermans-Kranenburg, 2009). Therefore, to provide children with necessary conditions for their normative development, interventions should ideally be introduced at the earliest stages of life.

#### Limitations and future directions

The major limitations of the current study are a modest sample size and its quasi-experimental design that did not allow for random assignment of children to different rearing conditions. Besides, children are not admitted to institutional care at random and often suffer from various disadvantageous conditions including poor perinatal condition and physical health. In our sample we identified a subgroup of children with a perinatal hypoxic condition that clearly deviated in their development from the rest. Perinatal hypoxic conditions were not unique to our sample and appear to be widely spread among international adoptees and institution-reared children (Albers et al., 1997, Landgren et al., 2006, Pomerleau et al., 2005; Miller, 2005; Miller et al., 2007). Thus, for instance, Miller (2005) reports that nearly 50% of children adopted from Eastern Europe had been diagnosed with perinatal encephalopathy. However, as Miller and colleagues further point

out (2005, 2007), this and other similar diagnoses related to perinatal hypoxic conditions do not correspond to the International Classification of Disease - 10 (World Health Organization, 2004). In childcare institutions perinatal hypoxic conditions are frequently treated with medications including 'nootrops' and 'brain microcirculation enhancers' meant to improve cognitive function (Miller et al., 2007). Because these conditions are widely spread among Eastern-European children with an institutional background and associated treatment involves the use of medicine that may have lasting effect on the developing brain and nervous system, further exploration of their meaning as well as the (long-term) impact of the treatment on the development of children is required.

We also need to extend our understanding of the contribution of the individual child characteristics to their developmental outcomes and their interplay with different aspects of the rearing environment. Furthermore, it was difficult to disentangle the impact of HIV from other family adversities. For that reason, conclusions regarding the effects of HIV should remain preliminary until a direct comparison with a group of uninfected children reared by HIV-infected primary caregivers is made.

In this study we used a traditional dyadic approach in the examination of attachment relationships of institution-reared children and studied attachment relationships with only one, favorite, caregiver. However, in the multiple-caregiver environment multiple attachment relationships may be developed, forming an attachment network that appears to have more predictive power and therefore should be addressed in future research (Tavecchio & Van IJzendoorn, 1987; Van IJzendoorn, 2005; Van IJzendoorn & Sagi-Swartz, 2008).

Finally, children appear to be differentially susceptible to (adverse) rearing experiences and genetic differences may play an important role (e.g., Bakermans-Kranenburg & Van IJzendoorn, 2006, 2007; Belsky, Hsieh, & Crnic, 1998; Caspi et al., 2002). Therefore, further research examining the influence of gene-environment interactions may shed more light on how inheritance influences both the dynamics and the outcome of the development of institution-reared children. This will contribute to the further exploration of possible risk and protective factors, which is indispensable for the development of targeted and effective intervention programs.

#### Conclusion

Almost sixty years ago Bowlby reported to the World Health Organization that even in troubled homes children thrive better than in good institutions. We may now add that children infected by HIV appear to thrive better in their troubled families than healthy children in relatively good institutions. Bowlby explained that "...the infant and young child should experience a warm, intimate, and continuous relationship with his mother (or permanent mother-substitute)" (p. 11), because "...mother-love in infancy and childhood is as important for mental health as are vitamins and proteins for physical health" (p. 158). We may now also confirm that for vulnerable children deprived of parental care and/or infected by HIV mother's or caregiver's continuous presence and sensitive care is crucial and may ameliorate environmental and child-related adversities.

Therefore, efforts should be made to prevent child abandonment and to support HIV-impacted families in their parenting role. For those children who nevertheless end up in an institution the rearing environment must be optimized. Given that adequate physical and medical care is provided, it can be achieved by ensuring stability and improving the quality of caregiving. The timing of such interventions is of great importance. Because (structural) neglect and traumatic experiences during the first year of life may have long-term or even permanent detrimental impact on children, interventions should be introduced at the earliest possible stages of life.

