Addressing the Needs of Children Without a Family: The Medical Response as of 2006

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Outcomes for Abandoned, Homeless & Adopted Children?

CAVEATS:

• We have limited information about the health and developmental outcomes of children who remain outside of child welfare systems
• My comments will primarily discuss our current knowledge with respect to outcomes for children with a history of international adoption & role of medical providers
Outline of this talk

• Review changing epidemiology of international adoption in the U.S.
• Emergence of adoption medicine
  – Clinics; literature; professional groups
• Highlight evidence from literature about international adoptees
  – Medical outcomes
  – Developmental and behavioral outcomes

*Important for discussing expected child/family outcomes with families*

- Trend towards Asia & E Europe
  - Health, developmental expectations?
- Older children at adoption
- More countries with children primarily in orphanages
  - ~20% in 1992 vs. 75% in 2000
International Adoption Statistics (children adopted to US)
Emergence of ‘adoption medicine’

1980s
• Case series/peer reviewed articles
• Clinics focusing on ‘international adoption’
  (Minnesota, Michigan, New York, Boston)

1990s
• American Academy of Pediatrics
  – Red Book includes ‘international adoption’
  – Section on Adoption & Foster Care
International Adoptees: Themes from Literature Review

Infectious concerns
- Tuberculosis
- Parasites
- Hepatitis B/C, HIV, syphilis

Noninfectious concerns
- Growth & development delayed at adoption
- Risk of prenatal alcohol exposure & abuse
- Attention, attachment & behavioral concerns
Health Care Providers & Internationally Adoption Children

• Pre-adoptive consultation
  – medical record, video review, more data?
  – option for further data gathering?

• Immediate post-adoptive concerns
  – medical and behavioral screening

• Long-term post-adoptive concerns
  – chronic medical, developmental issues
  – behavioral, emotional, learning considerations
Some immediate post-adoptive considerations for child/family

- Treatable infections (acute & chronic)
- Growth & developmental assessment
- Routine health screening (AAP Red Book)
- Country specific: iodine, toxic exposures
- Behavioral concerns?
- Age assessment?
- Parental support, empowerment & attachment
Resources for Providers
International Adoptee Screening:

- CBC with diff
- Lead
- VDRL or RPR (syphilis exposure)
- Hep B profile (HBsAg, HBsAb, HBcAb)
- HIV (age dependent test)
- Stool for O &P
- Mantoux for TB (REGARDLESS OF BCG !)
- Hearing and vision screens
- CONSIDER: newborn screen; thyroid; LFTs; hepatitis A/C/D; H. Pylori; giardia ag/stool cxns
Elevated lead levels:

• Assessed by blood tests
  – Not valid if assessed urine, other fluids
• Environmental sources of lead
  – Paint, industrial, air (gasoline), lead, water
• Dose response relationship
  – Higher level, increased risk of later developmental difficulties
• Note: Over the past 20 years in the U.S. – ‘normal’ lead levels have moved from <25 mcg/dl to <10 mcg/dl
Syphilis Exposure:

• Assessed by RPR or VDRL tests
• If newborn is found to be positive
  – May be maternal antibodies
  – Child may be infected in multiple areas
    • Blood
    • Spinal fluid
• Bacterial (spirochete) infection
  – Very responsive to antibiotics
Hepatitis B infection:

- Infection of liver
  - May be acute and then resolved
  - May be chronic and have long-term implications
  - Ultimately may lead to liver failure, liver cancer
- Spread via blood products, and mother/infant
- Assessment of immunity/infection:
  - Assess hepatitis B S AB, S AG, C AB
  - Immune: hepatitis B ANTIBODY positive
  - Infected: hepatitis B ANTIGENs
  - Maternal infection: hepatitis B ANTIBODY positive
HIV infection:

- Spread via blood/body fluids, mother/infant
- If **mother** is positive for infection (antibody +)
  - Expect infant antibody positive
  - Untreated mothers → ~30% infants positive
- Infant may be later infected if:
  - Antibody positive
  - Viral studies (PCR) positive
- Diagnosis complicated in first 6 months
International Adoptee Immunizations (AAP Red Book):

Several options:

• Definitely re-immunize if:
  – schedule is not per AAP/WHO standards

• Options (AAP Red Book, 2005)
  – re-immunize
  – check titers (tetanus, polio, hep B, MMR)
  – accept from Guatemala, Korea (?)
    • Private MD visits, records, foster care
PPD and BCG:

• PPD interpretation post-BCG isn’t clear cut
  – Even with a BCG, >10mm is significant
  – BCG theoretically prevents overwhelming disease
    – but NOT infection with mycobacterium
• Children receive BCG because of risk
• International adoption increasing in tuberculosis endemic areas (ie E Europe; SE Asia; China)
• *If BCG scar is fresh* - wait 6-12 mos to test (?)
Case #1: Pre-adoptive consult

Mr. Jones contacts my office and requests a pre-adoptive appointment to discuss an adoption referral of a 1 yr old girl from China.

- He would like my opinion about her health
- He will fax the information this afternoon and would like to meet tomorrow morning in order to discuss her health and development as well as possible ‘avian flu,’ ‘attachment problems,’ ‘developmental delays,’ or other concerns.
Pre-adoptive considerations?

• Parental expectations?
  – Which country and why?
  – Long-term expectations?
• Why is this child available for adoption?
• How old is the child now?
• Where has he or she previously lived? How long? (home, foster care, orphanage)
• Medical issues, growth
Pre-adoptive Record Review Caveats

• Finding family for child vs. child for family!

• Quality of medical information variable
  • Abstracted DIAGNOSES, not current status
  • Loss of meaning because of abstraction, translation, unfamiliar terms

• Growth curves (CDC, WHO, birth country?)

• More information may NOT be helpful
What should pediatric health care providers know if they will be providing consultations prior to international adoption of a child?
Before providing a ‘preadoption consultation’ – know the scene

- Are you familiar with general health of that population (country demographics, institutional care)?
- What can you really tell a family from information provided?
- Consider prenatal alcohol exposure
- With older children – attachment, transition, second language issues/assessment
**If you provide ‘preadoption consultations’ **

- Read Pedi Clinics N Am (Oct 2005 volume)
- Join the AAP Section on Adoption & Foster Care and attend NCE CME meetings
- Consider taking a trip with preadoptive families
- Know your limitations
- Know the political scene
  - Agencies, country specific
- Know what families are saying after adoption
  - FRUA, FCC. PNPIC
‘Developmental Delays’

Delays in developmental milestones result from:

• Institutionalization
• Malnutrition
• Neglect/abuse
• Different cultural expectations

BUT….

• ‘Delay’ doesn’t always mean ‘catch-up’
• Consider Early Intervention & non-verbal assessment
Attachment, Internationally Adopted Children and New Family

• Started as a theory (Bowlby, Spitz)
• Lack of secure infant attachment related to later impairments in social relationships, attachments, trust, intimacy
  – Attachment is a 2 way street
  – No easy ‘assessment’ pre-adoption!!!
  – Previous attachment bodes well for future
  – Increased risk of ‘attachment difficulties’ with increased age & more pre-adoptive placements
• MANY variables including temperament, parents, positive preadoptive factors
What does research tell us about child development after international adoption?
Developmental Outcomes: Where do we get our data?

- Sources include:
  - Historical data
  - Case series – specialty clinic populations
  - Longitudinal studies
    - Rutter, O'Connor, et al – UK
    - Ames, LeMare, et al - Canada
  - National data sets (eg Scandinavia)

- Sentinel events:
  - Adoption disruptions
  - Parent support groups
  - Media reports
U.S. International Adoption Research

- Primarily focused on infections, case series
- Only since the late 1980s
- Data gathering complicated by:
  - Variable pre-adoptive data
  - No central data gathering re: US adoption stats
  - Adoptions from >60 countries
  - Handled separately in 50 states
Where do we get our data?
Worldwide Data Re: Development of International Adoptees

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Caretaker to child ratio!

- The lower the caretaker to child ratio, the better the children fare
  - Foster care vs. orphanage
  - Variation between countries
Research summary: Orphanages & Child Development - I

Historical review of institutionalized children
• Adequate medical care, nutrition
• No social or cognitive stimulation
• No consistent caretaker

Over time, children demonstrate:
• Progressive motor & cognitive delays
• Become emotionally unresponsive
  – minimal crying, cooing, babbling or moving

(Provence & Lipton, 1962; Ames, 1997; Rutter & ERA, 1998)
Research Summary: Orphanages & Child Development - II

Considering Romania in the early 1990s

• Worst case scenario:
  – severe malnutrition, deprivation
  – untreated chronic illness

• Post-adoption:
  ➢ Most children improved with respect to development remarkably upon adoption
  ➢ Significant minority with severe neurocognitive disabilities

Orphanage children w/ adequate nutrition, medical care & devel stimulation – but NOT stable caretakers

• Fewer delays in motor & cognitive growth
• Suggests that stable relationships are NOT required for physical, sensorimotor, cognitive & language development

➢ At risk: regulatory aspects of thinking
    (attention maintenance/shifting, inhibitory control)

Orphanages to Foster Care

Orphanage children joining foster families in Romania (2001-current) demonstrate:

• Improved growth (ht; wt; ? HC)
• Improved general cognitive measures (IQ)
• Improved internalizing symptoms (eg anxiety)

➢ At risk for compromised language skills and externalizing behaviors

After Adoption from Orphanages

Orphanage children joining stable families with adequate resources demonstrate:

• Improved growth & developmental milestones
• Improved general cognitive measures (eg IQ)

- Developmental delays at time of adoption
- At risk for compromised social and emotional development, language/learning disorders

What does clinical experience suggest after international adoption?
Families’ Concerns Post-Adoption
Clinical experience - Adoption Program

• Delays in development and learning
• Regulatory difficulties
  – Impacts behavior, mood, learning
• Social difficulties
  – ? Attachment difficulties with parents
  – ? Difficulties with peers
• Was this because of pre-adoptive life or was it genetic?
  – Fetal Alcohol Syndrome
  – Malnutrition, Micronutrients
  – Underlying neurological/psychiatric difficulty
Prenatal Alcohol Exposure?

Diagnosis of ‘Fetal Alcohol Syndrome’: 
1. Growth delays 
2. Neurodevelopmental findings 
3. Typical facial features 

Note: Many institutional children may have #1 and #2; #3 must be judged compared to ethnicity specific facial features
Prenatal Alcohol Exposure?

For international adoptees:

- Consider the demographics of the country
- FAS is only ‘tip of the iceberg’
- May have relatively small impact overall
- Diagnosis of FAS/FASD useful for:
  - Obtaining services for child
  - Preventing secondary disabilities
Language Considerations after Adoption of an Older Child

• Loss of first language while gaining second
• Rate of acquiring new language related to competency in previous language
  – Poor quality of ‘orphanage language’
  – Difficult to assess post-adoptively
  – Functional first, then higher order language
• May need language REMEDIATION, not just enrichment or ‘English as Second Language’
Caveats for ALL adoptees

• All kids are different
• Multiple transitional issues will impact any child’s functioning
  – Grief & Loss
  – Transitional Issues
    • Feeding
    • Sleeping
    • Difficulty managing boundaries, new settings
  – Address acute medical problems
In the End....

- Can’t erase previous experience, but can strengthen the child/family system to respond to future experiences

- Most children do exceptionally well in the face of incredible stressors