Children of the Epidemic

The Psychological effects of maternal HIV disease on young South African children

Brian Forsyth
Objectives

- Illustrate the extent to which the AIDS epidemic has contributed to children becoming orphans
- Discuss the psychological effects of parental HIV disease on children
- Describe our own research
- Discuss the growing evidence that uninfected children born to HIV positive mothers are doing poorly
Estimates of number of children in sub-Saharan Africa orphaned by AIDS

UNAIDS & UNICEF, 2006
Proportion of children in sub-Saharan Africa orphaned by any cause

These maps do not reflect a position by the publishers on the legal status of any country or territory or the delimitation of any frontiers.

Contribution of AIDS to number of orphans in sub-Saharan countries

UNAIDS & UNICEF estimates, 2006
Age distribution of orphans in sub-Saharan Africa (2005)

**Orphans due to all causes**
- 0-5 years: 16%
- 6-11 years: 36%
- 12-17 years: 48%

**Double orphans due to all causes**
- 0-5 years: 8%
- 6-11 years: 29%
- 12-17 years: 63%
South Africa
2009

- HIV prevalence among adults: 17.8%
- Women living with HIV: 3,300,000
- Children orphaned by AIDS: 1,900,000
Adverse effects on AIDS orphans

- Diminished psychological wellbeing
  - Stigma, depression, bullying
- Increased poverty
  - Child-headed & “skipped generation” households
- Poor school performance and increased dropout rate
- Decreased access to health care and other services
- Increased risk for STDs and HIV
  - earlier sexual debut
The mental health of children orphaned by AIDS
Cluver L & Gardner F: J Child & Adol. Mental Health, 2009

- 24 studies worldwide (19 Africa, 5 USA)
  - All except two were cross-sectional
  - Wide variation in sample characteristics

Results
- Externalizing problems: 16/19 studies
- Internalizing problems: 5/10 studies

“More longitudinal studies or studies with a control group of children living with caregivers who are ill with AIDS are also necessary.”
Parental HIV/AIDS and psychosocial adjustment among rural Chinese children

All differences $P<0.05$

- Orphans ($N=755$)
- Vulnerable children ($N=466$)
- Comparison children ($N=404$)

Fang X et al: J Ped Psychol, 2009; 34(10):1053
Interventions for orphans and vulnerable children

- Center-based
- Community-based
  - Psychosocial support
  - Home-based care
  - Legal protection e.g. inheritance rights, rights of child-headed households to receive subsidies
  - Educational assistance
  - Economic incentives (Child Development Accounts)
Interventions: Are they effective?

- **Quality Assurance Project / USAID / UNICEF 2008**
  - 414 studies reviewed: 3 systematic reviews, 16 RCTs and 64 with control groups
  - “The evidence base on effectiveness and efficiency of interventions ... is almost non-existent”

- **Schenk et al. AIDS Care 2009; 21(7) 918**
  - 21 studies involving community interventions
  - “Although findings overall indicate the value of community interventions ... the quality and rigour of evidence is varied”

- **Cochrane collaborative, King et al., 2009**
  - 12 studies as potentially relevant: zero eligible
  - “This systematic review has identified the need for high quality intervention studies”
Intervention for parents with AIDS and their adolescent children: Rotheram-Borus et al.

- New York 1993-1995
- 307 parents with AIDS and 412 adolescent children (all aware of parents’ HIV status)
- Randomized controlled trial
- Intervention:
  - Module 1: parents alone – 8 sessions on 4 Saturdays
  - Module 2: parents and adolescents – 16 sessions on 8 Saturdays
- Follow-up every three months
Intervention for parents with AIDS and their adolescent children: Rotheram-Borus et al.

**Multiple Problem Behaviors (log)**

**Conduct Problem (log)**

**Family Events (log)**

**Self-Esteem**

Amer J Pub Health 2001; 91 (8):1294
6 years later:

<table>
<thead>
<tr>
<th>Adolescent Outcomes</th>
<th>Intervention Youth (N=156)</th>
<th>Comparison Youth (N=161)</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>In school or employed</td>
<td>82.6 %</td>
<td>68.9 %</td>
<td>2.17 (1.24 to 3.78)</td>
</tr>
<tr>
<td>Is a parent</td>
<td>34.6 %</td>
<td>44.1 %</td>
<td>0.67 (0.43 to 1.06)</td>
</tr>
<tr>
<td>Somatic symptom score</td>
<td>0.24 (0.23)</td>
<td>0.31 (0.22)</td>
<td>-0.07 (-0.13 to -0.01) *</td>
</tr>
<tr>
<td>Grief inventory score</td>
<td>3.86 (0.96)</td>
<td>3.74 (0.99)</td>
<td>N.S.</td>
</tr>
<tr>
<td>Overall symptom inventory</td>
<td>0.44 (0.58)</td>
<td>0.41 (0.45)</td>
<td>N.S.</td>
</tr>
</tbody>
</table>

* Data are given as mean difference
### Adolescent Outcomes

<table>
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* Data are given as mean difference
Family support program for children with AIDS
– Started in 1988, funded by:
  • Paul Newman Foundation
  • Public Welfare Foundation
– Evolved into Connecticut’s Ryan White Program for children and families affected by HIV
– Continues to provide services in New Haven, Hartford and Bridgeport
Women & Health

Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/wwah20

The Impact of Structured Support Groups for Pregnant South African Women Recently Diagnosed HIV Positive

Jonathan P. Mundell a, Maretha J. Visser b, Jennifer D. Makin a, Trace S. Kershaw c, Brian W. C. Forsyth d, Bridget Jeffery a & Kathleen J. Sikkema e
Kgolo Mmogo Project

- Randomized clinical trial
- HIV-infected mothers and their uninfected children, ages 6 – 10 years

**Aims:**

1. Demonstrate the effect of parental HIV disease on young children
2. Assess the efficacy of a theory-based support intervention on improving child outcomes
3. Identify maternal psychological and medical factors that contribute to changes in child outcomes
Methods

- Enrolled at Kalafong Hospital AIDS clinic and primary care clinics in SW Tshwane
- Mothers HIV positive and all children HIV negative
- Support group intervention for both mothers and children
- Evaluations at baseline, 6, 12 & 18 months
- Baseline comparison with children of HIV negative mothers
# Intervention

<table>
<thead>
<tr>
<th>MOTHER’S SESSIONS</th>
<th>CHILDREN’S SESSIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1</strong></td>
<td>Let’s get to know one another (Group rules, building trust)</td>
</tr>
<tr>
<td>Introduction, group norms, building relationships of trust</td>
<td><strong>2</strong></td>
</tr>
<tr>
<td><strong>2</strong></td>
<td>Developing relationships in the group (Develop trust, group cohesion, sharing happy feelings)</td>
</tr>
<tr>
<td>How to look after myself. Living positively with HIV (Basic HIV/AIDS information, treatment options)</td>
<td><strong>3</strong></td>
</tr>
<tr>
<td><strong>3</strong></td>
<td>Who am I? (Knowing yourself as part of family and community; body mapping, family drawing, family values, asset mapping)</td>
</tr>
<tr>
<td>How do I disclose my status? (Share experiences of disclosure, advantages, obstacles, role play, how to deal with stigma)</td>
<td><strong>4</strong></td>
</tr>
<tr>
<td><strong>4</strong></td>
<td>I have, I am, I can (Identifying personal strengths; understanding family interaction)</td>
</tr>
<tr>
<td>HIV in intimate relationships (negotiating condom use, gender roles, power relationships, women’s position in society)</td>
<td><strong>5</strong></td>
</tr>
<tr>
<td><strong>5</strong></td>
<td>What can I do? What am I good at? (Create strengths map; learn to cope with specific stressors through puppet play)</td>
</tr>
<tr>
<td>How do I feel: Emotional experience of HIV (Draw life maps and share personal stories of HIV)</td>
<td><strong>6</strong></td>
</tr>
<tr>
<td><strong>6</strong></td>
<td>How can I do it? (Problem solving skills, solve problems through story telling)</td>
</tr>
<tr>
<td>How do I cope: Coping, problem solving and stress management (Identify problem-focused and emotion-focused coping, relaxation)</td>
<td><strong>7</strong></td>
</tr>
<tr>
<td><strong>7</strong></td>
<td>Protecting myself (Develop sense of safety, personal boundaries, children’s rights, saying no when unsafe, safety board game)</td>
</tr>
<tr>
<td>HIV in the household (how to protect family members, communication, human rights, understanding and dealing with stigma)</td>
<td><strong>8</strong></td>
</tr>
<tr>
<td><strong>8</strong></td>
<td>Socializing with peers (Learn social skills - respect, acceptance, friendship, through story telling)</td>
</tr>
<tr>
<td>Knowing myself as a parent (Parenting styles, how to take good care of child, listening)</td>
<td><strong>9</strong></td>
</tr>
<tr>
<td><strong>9</strong></td>
<td>How do I feel? (Identify, understanding and expressing own emotions, play board game)</td>
</tr>
<tr>
<td>Knowing myself as a parent (Disciplining skills, role play difficult scenarios, how to help child to deal with problems)</td>
<td><strong>10</strong></td>
</tr>
<tr>
<td><strong>10</strong></td>
<td>How do others feel? (Identify emotions of other people, how to respond, express scenarios through puppet play)</td>
</tr>
<tr>
<td>Knowing my child (Developmental tasks of children 0-18 years, what children need to be resilient, external and internal assets, how to deal with difficult scenarios)</td>
<td><strong>11</strong></td>
</tr>
<tr>
<td><strong>11</strong></td>
<td>Survival skills (Learn to help with household tasks, show how to make tea, wash dishes, wash socks, sweep floor)</td>
</tr>
<tr>
<td>Children and HIV (effect of parent’s HIV on children, age appropriate disclosure to children, understanding children’s grief, role play disclosure to children)</td>
<td><strong>12</strong></td>
</tr>
<tr>
<td><strong>12</strong></td>
<td>Let’s practice survival skills (Make soup/fruit salad, grow seedlings, wash dishes)</td>
</tr>
<tr>
<td>Life planning and goal setting (short and long term goals: socio-economic survival, plans for children, health care, draw future maps, focus on empowerment and hope)</td>
<td><strong>13</strong></td>
</tr>
<tr>
<td><strong>13</strong></td>
<td>Let’s live life (Identifying meaning, purpose and future orientation, play imaging game)</td>
</tr>
<tr>
<td>Knowing me, knowing you (mothers and children getting to know each other, working together to enhance bonding, preparing for picnic, playing games; second session: structured activities that enhance interaction, communication and trust)</td>
<td><strong>14</strong></td>
</tr>
<tr>
<td><strong>14</strong></td>
<td>Let’s make a family memory (Creating a legacy by developing a memory box as a means of expression and interaction; take photographs, make family tree; tell family stories, preparation for loss)</td>
</tr>
<tr>
<td>Let’s have fun together (Interaction between mother and child to enhance communication, working together, understanding each other; activities such as body mapping, making clay, sculpting, bead work, making masks)</td>
<td><strong>15</strong></td>
</tr>
<tr>
<td><strong>15</strong></td>
<td>Let’s have fun together (Interaction between mother and child to enhance communication, working together, understanding each other; activities such as body mapping, making clay, sculpting, bead work, making masks)</td>
</tr>
<tr>
<td>Mother and child sessions revisited</td>
<td><strong>16</strong></td>
</tr>
<tr>
<td><strong>16</strong></td>
<td>Let’s dream together (Planning for the future, helping each other to make wishes come true)</td>
</tr>
<tr>
<td>Let’s celebrate life: family celebration (Future planning, communication, closure)</td>
<td><strong>17</strong></td>
</tr>
</tbody>
</table>
Kgolo Mmogo

- Cultural adaptation and translation of instruments into four different languages
- Piloting of groups
- Preparation of manual
  - objectives
  - ice-breaker
  - activities
- Training of group leaders
Measures

Maternal characteristics
- Depression (CES-D)
- Support
- Coping
- Experience of violence

Parenting
- Coping with children’s negative emotions scale (CCNES)
- Parenting Stress Index

Child outcomes

Parent-reported measures
- Behavior (CBCL)
  - Externalizing
  - Internalizing
- Adaptive functioning (Vineland)

Child-reported measures
- Depression (CDI)
- Anxiety (RCMAS)
- Emotional intelligence (Bar-On)
Comparison of “HIV-affected” children and children of HIV-negative mothers

Comparison of CBCL scores for externalizing and internalizing behavior problems.

- Uninfected mother
- Non-symptomatic HIV+ mother
- Symptomatic HIV+ mother

Significant difference: * P<.0001
### Socio-demographic characteristics

<table>
<thead>
<tr>
<th></th>
<th>Intervention (N = 201)</th>
<th>Comparison (190)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal age</td>
<td>33.0</td>
<td>33.2</td>
<td>0.78</td>
</tr>
<tr>
<td>Married / with partner</td>
<td>67.2 %</td>
<td>72.1 %</td>
<td>0.29</td>
</tr>
<tr>
<td>Education:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>12.9 %</td>
<td>14.3 %</td>
<td>0.69</td>
</tr>
<tr>
<td>Secondary</td>
<td>85.1 %</td>
<td>82.5 %</td>
<td></td>
</tr>
<tr>
<td>Tertiary</td>
<td>2.0 %</td>
<td>3.2 %</td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>21.9 %</td>
<td>34.2%</td>
<td>0.007</td>
</tr>
<tr>
<td>Housing score</td>
<td>3.58</td>
<td>3.62</td>
<td>0.84</td>
</tr>
<tr>
<td>Persons in house</td>
<td>6.50</td>
<td>6.23</td>
<td>0.36</td>
</tr>
<tr>
<td>Maternal health:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptomatic</td>
<td>37.8 %</td>
<td>46.3 %</td>
<td>0.09</td>
</tr>
<tr>
<td>CD4 &lt; 200</td>
<td>46.2 %</td>
<td>40.3 %</td>
<td>0.31</td>
</tr>
<tr>
<td>Taking ARVs</td>
<td>45.3 %</td>
<td>43.2 %</td>
<td>0.67</td>
</tr>
<tr>
<td>Pregnant</td>
<td>10.9 %</td>
<td>14.2 %</td>
<td>0.33</td>
</tr>
<tr>
<td>Mean time known HIV+ (months)</td>
<td>21.2</td>
<td>25.2</td>
<td>0.17</td>
</tr>
<tr>
<td>Reason for testing:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illness</td>
<td>35.8%</td>
<td>45.3%</td>
<td>0.06</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>41.8%</td>
<td>36.3%</td>
<td>0.27</td>
</tr>
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</table>
Child Characteristics

<table>
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<th>Intervention (N = 201)</th>
<th>Comparison (N = 190)</th>
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<tbody>
<tr>
<td>Age (years)</td>
<td>8.25</td>
<td>8.50</td>
<td>0.10</td>
</tr>
<tr>
<td>Gender: male</td>
<td>52.2 %</td>
<td>51.1 %</td>
<td>0.81</td>
</tr>
<tr>
<td>Has been told mother’s HIV status</td>
<td>7.5 %</td>
<td>7.4 %</td>
<td>0.97</td>
</tr>
<tr>
<td>Has known HIV+ person who has died</td>
<td>17.7 %</td>
<td>17.1 %</td>
<td>0.90</td>
</tr>
<tr>
<td>Has experienced death of someone close</td>
<td>4.7 %</td>
<td>5.9 %</td>
<td>0.59</td>
</tr>
</tbody>
</table>
Results
Number of group sessions attended

- None
- 1 to 12
- 13 to 18
- 19 to 24
CBCL: Externalizing Behaviors (T Scores)

Comparison group
Intervention attenders
(> 50% of sessions)
CBCL: Internalizing Behaviors (T Scores)

Comparison group

High Attendance

Enrollment  6 months  12 months  18 months
Externalizing Behaviors
Effect estimates using mixed linear analysis

Girls

Total Externalizing: P=.035
Aggressive: P=.046
Attention Problems: P=.042

Boys

Total Externalizing: P=.39
Aggressive: P=.12
Attention Problems: P=.039

Legend:
- Blue: Intervention
- Green: Comparison
Internalizing Behaviors
Effect estimates using mixed linear analysis

Girls

<table>
<thead>
<tr>
<th>Category</th>
<th>Intervention</th>
<th>Comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Internalizing</td>
<td>P = .063</td>
<td></td>
</tr>
<tr>
<td>Anxious/Depressed</td>
<td>P = .05</td>
<td>P = .10</td>
</tr>
<tr>
<td>Withdrawn/Depressed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Boys

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<tbody>
<tr>
<td>Total Internalizing</td>
<td>P = .05</td>
<td></td>
</tr>
<tr>
<td>Anxious/Depressed</td>
<td>P = .035</td>
<td>P = .16</td>
</tr>
<tr>
<td>Withdrawn/Depressed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Adaptive Functioning (Vineland)
Effect estimates using mixed linear analysis

Girls
- Communication: P=.008
- Living Skills: P=.21
- Socialization: P=.13

Boys
- Communication: P=.003
- Living Skills: P=.12
- Socialization: P=.043

Intervention vs. Comparison
Summary of results to date

• There was little effect on maternal psychological and parenting variables

• There were significant effects of the intervention on child outcomes:
  – Girls improved in all externalizing behaviors while boys had only a decrease in attention problems
  – Boys improved in total internalizing behaviors and both boys and girls exhibited a decrease in anxious/depressed behaviors
  – In adaptive functioning, both boys and girls had significant improvement in communication and boys also improved in socialization skills
Conclusions ... to date

- Poor attendance is a major drawback for a center-based intervention.
- For those who attended more than half the sessions, the intervention did have a positive effect on child functioning and behaviors, with there being some differences between boys and girls.
- More analyses required:
  - Potential effect of more complete attendance and attendance at specific groups of sessions: parenting, parent-child interaction.
  - Understanding effect of child’s gender.
  - Examination of child-completed instruments.
  - Potential moderators.
The story of the HIV-exposed, uninfected (HEU) infant:

The example of South Africa

- With the success of efforts to prevent HIV transmission from mothers to children, transmission rates are now about 5%
- In an area where 25% of pregnant women are HIV positive, about one in four babies born are “HIV-exposed, uninfected”
HIV-Exposed Uninfected Infants

Increased rates of:

• Mortality

• Morbidity – infectious illnesses

• “Stunting”

• +/- developmental delay
Mortality of HIV-exposed uninfected (HEU) infants

(Filtau S: Trop Med Int Health, 2009)
Mechanisms which may contribute to poor health and survival of HEU infants (adapted from Filteau, 2009)

- HIV exposure
- Poor maternal health
- Inadequate infant care
- Reduced breast feeding
- Immune system abnormalities
- Poor growth and nutrition
- Increased exposure to infections
- Increased mortality
- Antiretroviral exposure
Antibody levels in HEU infants
Jones CE et al, JAMA 2011; 305(6):576
Mechanisms which may contribute to poor health and survival of HEU infants (adapted from Filteau, 2009)

- Antiretroviral exposure
- HIV exposure
- Maternal depression
- Poor maternal health
- Inadequate infant care
- Reduced breast feeding
- Increased exposure to infections
- Immune system abnormalities
- Poor growth and nutrition
- Increased mortality
- Reduced breast feeding
- Increased mortality
- Antiretroviral exposure
- Poor growth and nutrition
- Increased exposure to infections
Depression scores over time in a cohort of women diagnosed HIV positive during pregnancy

Mean depression scores

- **Score at each interview**
- **Only women attending all 4 interviews**

Time of interview:
- Baseline
- 3 months
- 9 months
- 18 months

Depression score:
- 0
- 2
- 4
- 6
- 8
- 10
- 12
- 14
### Effect of Maternal Depression on Child Stunting in Non-HIV-Infected Populations

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patel, 2003</td>
<td>India</td>
<td>R.R. 2.3 (1.1, 4.7)</td>
</tr>
<tr>
<td>Baker-Henningham, 2003</td>
<td>Jamaica</td>
<td>Depression significantly different (P&lt;.01), but mainly explained by economic factors</td>
</tr>
<tr>
<td>Rahman, 2004</td>
<td>Pakistan</td>
<td>O.R. 3.9 (1.9, 7.8)</td>
</tr>
<tr>
<td>Anoop, 2004</td>
<td>India</td>
<td>O.R. 7.4 (1.6, 38.5)</td>
</tr>
</tbody>
</table>
| Harpham, 2005                | Ethiopia, India, Peru, Vietnam | N.S.  
N.S.  
N.S.  
O.R. 1.4 (1.1, 1.8) |
| Tomlinson, 2006              | South Africa    | No significant relationship between postnatal depression and growth at 18 months |
| Adewuya, 2008                | Nigeria         | O.R. 4.21 (1.4, 13.2)                                                 |
...what about the development of HEU children?

Functioning and behavior of HEU and non-HEU children at age three years

<table>
<thead>
<tr>
<th></th>
<th>HIV-Positive Mothers (N = 35)</th>
<th>HIV-Negative Mothers (N = 49)</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptive functioning (Vineland)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Communication</td>
<td>84.3 (19.3)</td>
<td>84.2 (17.3)</td>
<td>N.S.</td>
</tr>
<tr>
<td>- Daily living skills</td>
<td>90.5 (15.9)</td>
<td>98.1 (14.0)</td>
<td>0.02</td>
</tr>
<tr>
<td>- Socialization</td>
<td>93.7 (14.0)</td>
<td>99.2 (14.7)</td>
<td>0.09</td>
</tr>
<tr>
<td>Behaviour Problems (CBCL)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Internalising</td>
<td>13.3 (9.7)</td>
<td>11.0 (8.1)</td>
<td>N.S.</td>
</tr>
<tr>
<td>- Externalising</td>
<td>17.0 (10.6)</td>
<td>12.0 (8.7)</td>
<td>0.02</td>
</tr>
</tbody>
</table>
Model examining mediating effect of parenting: analyses using data collected at baseline

**MATERNAL CHARACTERISTICS**
- SES
- Depression
- Avoidant Coping
- Positive coping

**PARENTING**
- Parental Distress
- Parent-child dysfunction
- Negative Parenting
- Positive Parenting

**CHILD OUTCOMES**
- Adaptive functioning (Vineland)
  - Communication
  - Daily living skills
  - Socialization
- Behavior (CBCL)
  - Internalizing
  - Externalizing

β values shown, * P < 0.001, ** P < 0.0001, *** P < 0.000,
indicates weak, but significant effect
Where to next?

• Do HEU children have poorer development than children who are not HIV-exposed?

• What contributes to the poor outcomes among HEU children?
  • Maternal depression?
  • In-utero environment?
  • Other?

• Intervention for very young children of HIV-infected mothers
  • Including home visiting component
  • Focus on parenting
Final conclusions

• More work needs to be done to understand the potential effects on HEU children

• Children can be helped most by keeping their parents healthy

- another reason to start antiretroviral treatment early
Comparison of “HIV-affected” children and children of HIV-negative mothers

![Comparison of Behavior Problems](image)

- *P < .0001

- CBCL score
  - Externalizing Behavior Problems
  - Internalizing Behavior Problems

- Uninfected mother
- Non-symptomatic HIV+ mother
- Symptomatic HIV+ mother
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