Available Evidence for Family-Centred Services for Children affected by HIV and AIDS

Linda Richter

CCABA & IAS

Geneva, 11 February 2010

Outline

- Background and definitions
- Lack of evidence
- Knowledge of status
- Protection and support
- Prevention
  - Adult treatment and survival
  - PMTCT+
- Treatment for HIV+ children

JLICA Recommendations

- Support children through families
- Strengthen community action that backstops families
- Address family poverty through national social protection
- Deliver integrated, family-centred services to meet children's needs

Families

- Families = long-term, mutually supportive relationships
- Intrinsic to human life – for children and adults
- Wide diversity of biological, adoptive, elective families
- Continually recreated – "breakdown" is not an end state
- Need for families greatest during times of stress

Strategies–Child Wellbeing

- 'Orphanhood' – individual frame
- Ecological perspective on child wellbeing
  - Keep children in families
  - Keep family members together or connected
  - Keep families in their homes
  - Keep families in communities and interacting with others
  - Enable families to keep and build on their assets

Family Orientation

- Juncture box, telephone exchange – point of connection for reach and services
- Task shifter, adjunct to health services
- Ally, collaborator in prevention treatment, care – or reduce harm
- Developmental, life course
- Build family capital (relationships, resources, resilience) across generations

Definition - APA

- 1982 - wish for new approach to care for children with special health needs.
- Based on a bio-psychosocial systems approach
- Primary focus of healthcare is the client in the context of their family
- Health needs of family members, across the lifecycle of the child

Lack of Evidence

- Individualistic approach (Rotheram-Borus 2005 – Families living with HIV
- DeGennaro & Weitz (2009)
  - Clinical trials on FC virtually non-existent
  - But individual interventions that comprise FC have been shown to be effective
- Need to advocate for studies of FC

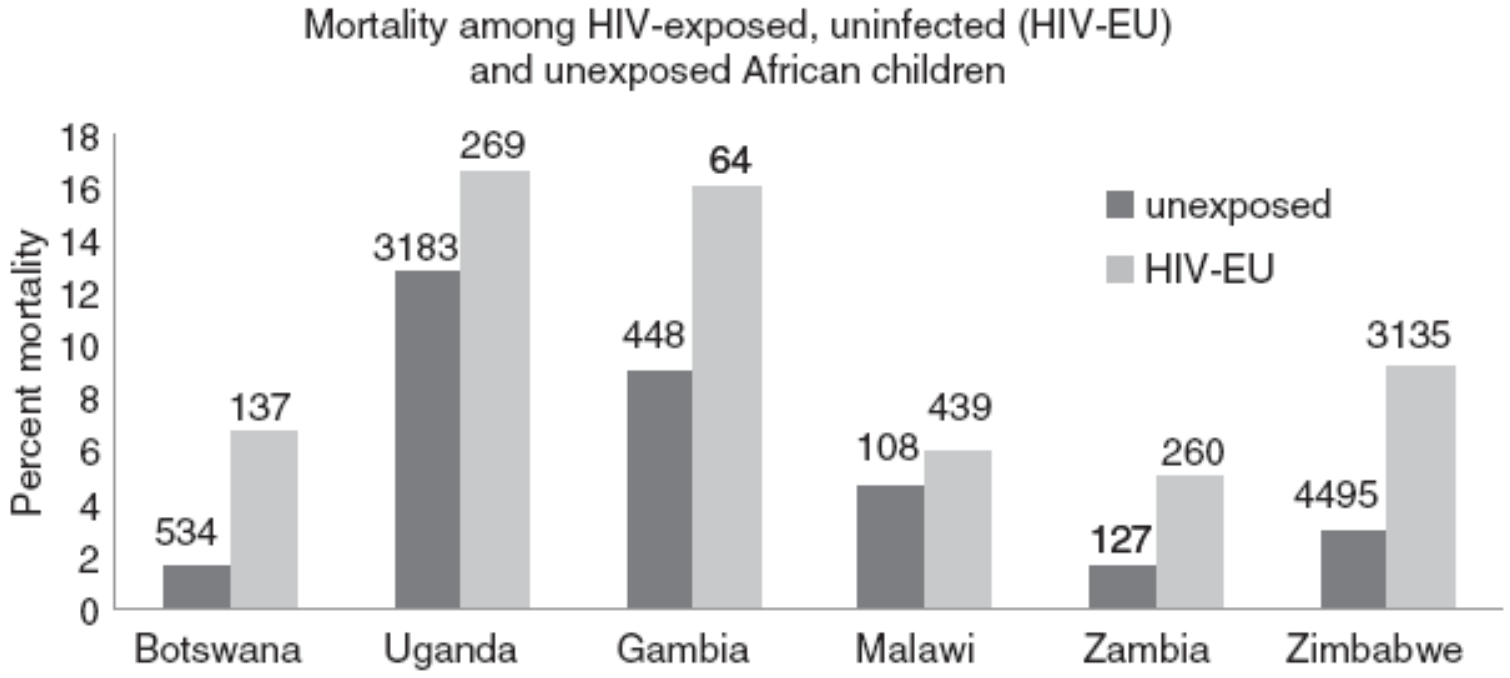
Costs of Not FC Services

- Lack of access to maternal ARVs a deterrent to PMTCT participation
- Provide ART for prevention, but can't test the child till 18 mo, during which time 40% die without treatment
- Counsel on feeding and family planning, but don't provide means of either
- Don't test other older sibs
- No assistance with chronic illness

DeGennaro & Zeitz (2009)

Piecemeal Approaches

Problems experienced by exposed, uninfected children – heightened mortality, morbidity, developmental problems



I Mortality among HIV-exposed, uninfected and unexposed African children. Data are percentages of deaths among

Filteau, 2009

Knowledge of status

- Success of family-based VCT to:
  - Attract clients
  - Detect discordancy
  - Detect new cases, initiate treatment early
  - Increase disclosure
- Couples – Rwanda, Zambia (S Allan et al)
- Households – Uganda, Zambia (J Mermin and others), Lesotho (Okubimichael et al)

Protection & Support

- Treatment of parents (Thirumurthy et al)
  - Increased nutrition, school attendance
  - Decreases child labour
- Survival of parents
  - Increased education
  - Reduces sexual risk (orphan studies)
- Social protection increases consumption, child nutrition, health care school attendance

2 Systematic Reviews

- For *Road to Vienna* process
- Being submitted to JIAS Special Issue
  - Family-centred approaches to PMTCT – PMTCT+ (Betancourt, Abrams et al)
  - Treatment of HIV+ children (Leeper et al)

Child ARV Treatment

- 23 cohorts
- Services depend on location – some HIV care, some comprehensive
  - Primary care for the family
  - TB screening
  - Reproductive health services
  - Nutritional supplementation
  - Terminal care services
  - Etc

Findings

- High adherence (99%) – lowest 78%
- More likely to attend scheduled visits
- Low loss to follow up (<10%)
- 1-year survival high (>90%)
  - Death higher amongst children without a participating family member (Reddi)
- Better management – eg transfer to other sites etc

Challenges

- "Trickle down" referral of children
- Recruiting family members, especially fathers
- Early diagnosis and treatment of infected children
- Protecting children during their first 6 months of HAART
- Staffing and infrastructural limitations

PMTCT+ Review

- Little research
- Mainly components, not package
- Most common components of PMTCT(+) - in order
  - VCT and ART for women and partners
    - Extended to other family members
  - Fathers counseled on infant feeding, other issues

Offer Services to Family

- Pregnant women more likely
  - To accept HIV testing and collect their results
  - Adhere to PMTCT regimens
  - Disclose their HIV-positive status to their partners
- Increased disclosure
  - Greater prevention
  - More support
- Greater adherence – all family members

FC - PMTCT Review

- Bundled package (DeGennaro & Zeitz)
  - Increased testing & testing of HIV+ mothers
  - 1/3 partner enrolment, 2/3 older child enrolment
  - Decreased vertical transmission
  - Reduced infant mortality
  - Decreased malnutrition
  - Lower loss to follow-up

Challenges

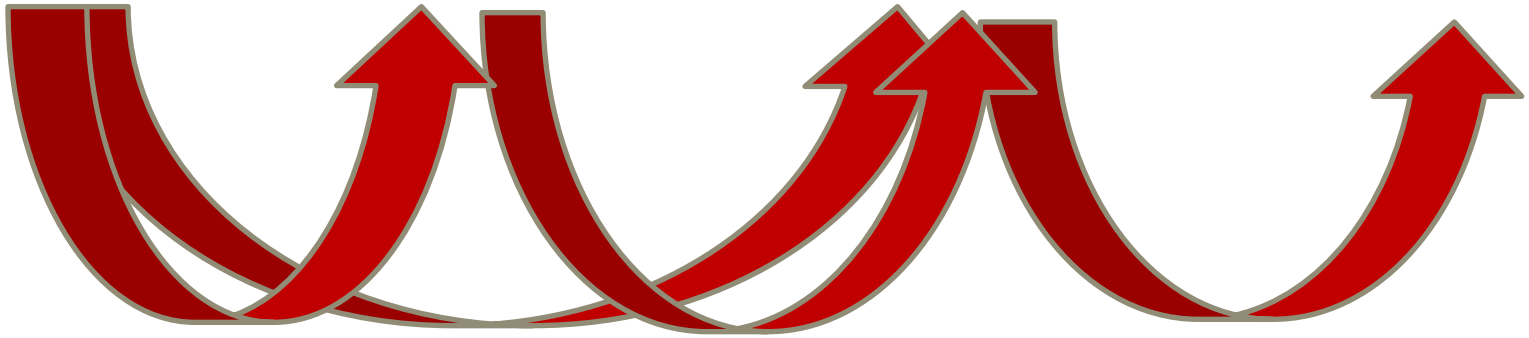
- Inadequate access to antenatal care
- Too few visits
- Transport, opportunity costs
- Lack of CD4 testing, PCR for infants, ARV
- Lack of integration of services

Summary: FC Services

- Whole family, one location
  - Increased case finding
  - Earlier detection
  - Increased uptake of services
  - Decrease treatment lag time
  - Decrease mortality among all family members
- Brazil and Thailand – successful FC models for preventing and treating child HIV infection
- Kenya, Mozambique – FC care models

Completing the Circle

PMTCT Paediatric AIDS OVC Adolescent Prevention



Family-centred services for children affected by HIV and AIDS

Broader Goals

- HIV/AIDS services - basic health care
- FC HIV/AIDS services integrated into PHC
  - Immunization, IMCI, nutrition supplementation, psychosocial & community support
  - Eg cotrimoxasole decrease malaria in families
- Benefit all families in poor settings
- New mechanism, appeal to donors?

"The most effective way to reach HIV positive children (*and those affected by HIV and AIDS*) and also eliminate pediatric HIV infection is to integrate comprehensive family-centred programmes that include PMTCT, ART, MCH and preventive services for the whole family at primary care clinics"

DeGennaro & Zeitz (2009)

HUMAN TOUCH

Thank you!