

# Lessons Learned From Family-Centered Pediatric HAART Models: Current Approaches and Future Directions

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MS2

# Publications

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- **Preliminary outcomes of a paediatric highly active antiretroviral therapy cohort from KwaZulu-Natal, South Africa.** Reddi A, Leeper SC, Grobler AC, Geddes R, France KH, Dorse GL, Mntambo M, Thomas M, Nixon K, Holst HL, Karim QA, Rollins NC, Coovadia HM, Giddy J. BMC Pediatr. 2007 Mar 17;7:13.
- **Antiretroviral therapy adherence in children: outcomes from Africa.** Reddi A, Leeper SC. AIDS. 2008 Apr 23;22(7):906-7. No abstract available.
- **Pediatric highly active antiretroviral therapy in Africa: potential benefits of a family-centered model.** Reddi A, Leeper SC, Sunpath H. J Infect Dis. 2008 Sep 15;198(6):938-9; author reply 939-40. No abstract available.

# Agenda for Today:

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1. Preliminary outcomes of a paediatric highly active antiretroviral therapy cohort from KwaZulu-Natal, South Africa.
2. Literature Review of Other Family-Centered Cohorts
  - Program characteristics
  - Cohort characteristics
  - Lessons learned
  - Goals for the future

Preliminary outcomes of a paediatric  
highly active antiretroviral therapy cohort  
from KwaZulu-Natal, South Africa.

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# **Preliminary outcomes of a paediatric highly active antiretroviral therapy cohort from KwaZulu-Natal, South Africa.**

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## Background

- KwaZulu-Natal (KZN), the most populous province in South Africa, has the highest HIV-1 adult prevalence rate with the antenatal seroprevalence at 40%.
- 40% of the under-five mortalities in KZN are HIV related
- Sixty nine percent of children in this province live in poverty
- In 2004, McCord Hospital's Sinikithemba ("We give hope" in IsiZulu) clinic received funding from the United States' President's Emergency Plan for AIDS Relief (PEPFAR) fund for HAART scale-up.

# **Preliminary outcomes of a paediatric highly active antiretroviral therapy cohort from KwaZulu-Natal, South Africa.**

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## **Background**

- All patients (adult and child) accessing HAART are interviewed about their family members' health, and those at risk are referred for testing and care.
- Referred family members are prioritized for HAART enrollment, and families are given clinic appointments for the same day when possible.
- Fifty-two percent of the pediatric cohort had at least one HIV-positive primary caregiver, and 38.4% had at least one primary caregiver also on HAART at Sinikithemba clinic.

# **Preliminary outcomes of a paediatric highly active antiretroviral therapy cohort from KwaZulu-Natal, South Africa.**

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## **Methods**

- We performed a retrospective cohort study to investigate preliminary outcomes of all children eligible for HAART at Sinikithemba HIV/AIDS clinic in KwaZulu-Natal, South Africa.
- Immunologic, virologic, clinical, mortality, primary caregiver, and psychosocial variables were collected and analyzed.

# **Preliminary outcomes of a paediatric highly active antiretroviral therapy cohort from KwaZulu-Natal, South Africa.**

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## **Results**

- From August 31, 2003 until October 31, 2005, 151 children initiated HAART. The median age at HAART initiation was 5.7 years (range 0.3-15.4).
- Median follow-up time of the cohort after HAART initiation was 8 months (IQR 3.5-13.5).
- Viral loads (VLs) were available for 100 children at 6 months of which 84% had HIV-1 RNA levels  $\leq$  50 copies/mL. At 12 months, 80.3% (n = 61) had undetectable VLs.



# Preliminary outcomes of a paediatric highly active antiretroviral therapy cohort from KwaZulu-Natal, South Africa.

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## Results

- In multivariate analysis of baseline variables against mortality using Cox proportional-hazards model, chronic gastroenteritis was associated with death [hazard ratio (HR), 12.34; 95% CI, 1.27-119.71) and an HIV-positive primary caregiver was found to be protective against mortality [HR, 0.12; 95% CI, 0.02-0.88).

# **Preliminary outcomes of a paediatric highly active antiretroviral therapy cohort from KwaZulu-Natal, South Africa.**

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## **Discussion**

- We hypothesize that HIV-positive primary caregivers on HAART at the same site may be able to provide more informed treatment support for their children resulting in better outcomes.
- Those HIV positive caregivers not yet on HAART may still be more knowledgeable about symptom management and disease progression, more experienced with health care systems and/or more likely to access available health services.

# Literature review of other family-centered HAART cohorts

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# Literature Review: Background

## *The state of the pediatric HIV epidemic*

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- In the 5 countries with the highest adult HIV prevalence worldwide, HIV is the single leading cause of under-5 mortality, responsible for 41-46% of deaths.
- One thousand children were born with HIV every day in 2007

# Literature Review: Background

## *The state of the pediatric HIV epidemic*

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- Of children born with HIV today in Africa, only half are expected to survive until their 2nd birthday without care.
- The CHER study: 76% reduction in mortality for children born with HIV when HAART was started within the first 12 weeks of life.
- However, only 10% of children living with HIV are currently able to access treatment.

# Literature Review: Background

## *The state of the pediatric HIV epidemic*

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- **Barriers to care** (Dumas 2006):
  - clinics that are already overcrowded
  - lack basic equipment for monitoring child health
  - staffed by healthcare workers with insufficient pediatric knowledge.
  - negative community perceptions towards HIV-infected children may lead some parents to delay testing their children.
  - misinformation about AIDS care, for example “antiretroviral drugs are harmful to children”

# Literature Review: Background

## *Why Family-Centered Care?*

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- In some areas, 50-60% of children living with HIV are being cared for by an adult living with HIV.
- In the context of HIV, family members have been shown to either positively or negatively impact other family members in terms of:
  - Physical and mental health, nutrition, access to care adherence, treatment outcomes, mortality (Porricolo, Callaway, Thirumurthy, Mermin, Merenstein, Diabate).

# Literature Review: Background

## *Family-Centered Care in Theory*

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- **Family-centered care** (McDaniel) Family-centered care is based on a bio-psychosocial systems approach where the primary focus of healthcare is the client in the context of their family; and the client, family, and clinician are partners in healthcare.
- **Family-centered approach** (JLCIA) A comprehensive, coordinated care approach that addresses the needs of both adults and children in a family and attempts to meet their health and social care needs, either directly or indirectly through strategic partnerships and/or linkages and referrals with other service providers.
- **Family-centered approach to HIV/AIDS care, prevention, and treatment** (Tolle): Adult and pediatric services are provided together in a single setting.



# Literature Review: Background

## *Family-Centered Care in Theory*

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### UNANSWERED QUESTIONS:

1. Who receives services?
  - Caregivers? Children?
  - Siblings?
  - Infected/Uninfected?
2. What services are available?
  - HIV or “comprehensive” health care? Supplementary?
3. How are services provided?
  - Directly? Indirectly via linkages and partnerships?

# Literature Review: Background *Objectives*

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- The goal of this paper is to review existing literature on family-care models being used to treat children living with HIV/AIDS.
- We will attempt to describe both the features of the HIV/AIDS family-centred care programs and also cohort characteristics including demographics, treatment outcomes, adherence, and retention.
- We will identify lessons learned and recommendations for future interventions and research.

# Literature Review: Background *Objectives*

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- We will focus our attention mainly on the impact of the family care model on the health of children living with HIV, while acknowledging that this is not the only outcome of interest, simply the one which defines the scope of this paper.

# Literature Review: Methods

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- Systematic review of published English-language literature on family-centred HIV care programs. We identified all studies published through August 2009 by searching the PubMed database.
- Additionally, we used the International AIDS Society abstract search to identify abstracts, posters, and presentations from the following conferences: 1<sup>st</sup> – 5<sup>th</sup> IAS Conferences on HIV Pathogenesis and Treatment (2001, 2003, 2005, 2007, 2009), and International AIDS Conferences XIV -XVII (2002, 2004, 2006, 2008).

# Literature Review: Methods

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- We used the following search terms:  
“family” + “HIV” OR “AIDS” OR “HAART”  
OR “antiretroviral” + “care” OR “services”  
OR “clinic.” Also, “MTCT-plus” OR  
“PMTCT plus.”
- Review of the citations within these articles yielded another 3 articles.

# Literature Review: Methods

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- Final inclusion criteria:
  - 1) An HIV care cohort consisting of both adult caregivers and their children
  - 2) A description of at least one of our measures of interest: services provided, cohort epidemiology, service uptake, testing, clinical/lab outcomes, adherence, retention, psychosocial support.

# Literature Review: Methods

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- Formal meta-analytic techniques could not be applied for a comparative analysis because of methodological and data collection discrepancies across studies.
- Data analysis primarily consisted of calculating ranges and measures of central tendency, when possible.

# Literature Review: Limitations

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- Due to the emerging and evolving nature of the family-centered care model, no fixed definition exists to facilitate the classification of programs as family-centered or not – consequently, studies included in this review were chosen on the basis of self-identification.
- Additionally, no consistency across studies exists with regard to program components or data collection, and so comparison and evaluation become extraordinarily difficult.
- We are thus limited here to description except in rare circumstances where studies specifically described a controlled comparison within or between cohorts.



# Literature Review: Results

## *Settings*

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- Ambulatory clinics associated with various types of hospitals (community, teaching, public, pediatric) = 11
- Government primary health centers = 3
- Antenatal clinics (one hospital-affiliated and two community-based) = 3

# Literature Review: Results

## *Staffing*

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- Most programs were staffed by a **core multidisciplinary team** including doctors, nurses, social workers or counselors.
- Some included gynecologists, child life specialists, and/or nutritionists.
- Trained health care worker shortages (especially those trained in pediatric HIV care)
- Several programs took **innovative approaches** to staffing.

# Literature Review: Results

## *Staffing*

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- ICAP/MTCT-Plus: assembled and trained multidisciplinary teams at each site using a specific MTCT-Plus curriculum focusing on the team as a whole (Tonwe-Gold)
- Instead of training adult physicians to treat children, Habibu et al trained pediatricians to manage both children and adults for HIV-related conditions.
- Rwanda/Kenya: Task-Shifting
  - Nurse-based care
  - HIV+ patient peer care

# Literature Review: Results

## *Program Components*

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- Programs vary widely in terms of services provided.
- Comprehensive HIV care to children and adults
- Supplementary services: primary care for all family members (HIV+/-) TB screening and INH prophylaxis, reproductive health services, nutritional supplementation, play therapy for children, terminal care services, and much more.

Author/Date	Region/Timeframe	Cohort	Intake/Referral	Location	Services
Van Griensven 2008	Kigali, Rwanda	2937 adults on HAART 315 children on HAART	Pediatric cohort. Children of HIV+ adult patients (90 %) Orphans (10 %) PMTCT and in-out patient services (< 1%) Transfer from other ART programs (< 1%) MTCT-Plus	Community-based health centers	Primary health care Comprehensive HIV care, including HAART
Torwe 2009	Yopougon and Abobo (Abidjan, Cote d'Ivoire)	605 HIV+ women 69 Male partners 30 Neonates (index pregnancy) 18 children		Community based antenatal clinics	Comprehensive HIV care, including HAART Contraceptive prophylaxis Malaria treatment Psychological and social support Nutritional + infant feeding counseling and support, Referral to family planning and tuberculosis services Minimal fee for transport of patients to the clinic
Okubamichael 2006	Lesotho		MTCT-Plus	Hospital-based antenatal clinic	Comprehensive HIV care, including HAART ART service at clinic run by medical officer 3x/week PMTCT Counseling on breastfeeding, postnatal/under-5 care Comprehensive HIV care, pre-HAART Antiretroviral therapy (ART) was given to limited numbers of children and parents, either through pharmaceutical trials, medical insurance, donations, or through the hospital. Clinic operational on Tuesdays Comprehensive HIV care, pre-HAART Terminal care services Family counseling Family planning service Comprehensive HIV care, including HAART Inpatient consultation service Comprehensive HIV care, including HAART Primary care for HIV+ and HIV- family members Ob/gyn nurse midwife Family nutritionist Family counselors Educational and social activities.
Niekerk 2005	Tygerberg, SA	274 HIV+ children 97 parents (14% fathers)	"Clinical suspicion" in pediatric inpatients The parents were identified through their children and with the input of the adult infectious diseases service	Hospital-based HIV clinic	Comprehensive HIV care, including HAART Adherence nurse Social worker Comprehensive HIV care, including HAART PMTCT Education on appropriate infant feeding Supplementary feeding to HIV affected families Supervised for adherence by treatment helpers selected among HIV+ clients.
Gibbs 1997	London	185 HIV+ children 112 HIV+ adults (24% fathers)	Children precipitate testing of parents	Children's hospital-based HIV clinic	Comprehensive HIV care, including HAART PMTCT Education on appropriate infant feeding Supplementary feeding to HIV affected families Supervised for adherence by treatment helpers selected among HIV+ clients.
Eley 2004	RSA	80 children on HAART 3 mothers on HAART		Children's hospital-based HIV clinic	Comprehensive HIV care, including HAART PMTCT Education on appropriate infant feeding Supplementary feeding to HIV affected families Supervised for adherence by treatment helpers selected among HIV+ clients.
Szendrik 2008 + 2006	Brooklyn, USA	200+ clients	Clients may enroll if they have children at home, or are considering having children.	Hospital-based HIV clinic	Comprehensive HIV care, including HAART PMTCT Education on appropriate infant feeding Supplementary feeding to HIV affected families Supervised for adherence by treatment helpers selected among HIV+ clients.
Habibu 2006	Kano, Nigeria	52 children on HAART 22 parents started on ART.		Specialist hospital-based HIV clinic	Comprehensive HIV care, including HAART PMTCT Education on appropriate infant feeding Supplementary feeding to HIV affected families Supervised for adherence by treatment helpers selected among HIV+ clients.
Kironeni 2006	Malawi	2 infants on HAART 111 parents on HAART (40% fathers)		Hospital-initiated, community-based care	Comprehensive HIV care, including HAART PMTCT Education on appropriate infant feeding Supplementary feeding to HIV affected families Supervised for adherence by treatment helpers selected among HIV+ clients.
Ma 2006	Brooklyn, USA	47 families	The Obstetrics clinics where HIV positive pregnant women were identified Transfers from the Adolescent and Adult HIV clinic Family members of index positive pediatric and adult patients.		Comprehensive HIV care, including HAART PMTCT Education on appropriate infant feeding Supplementary feeding to HIV affected families Supervised for adherence by treatment helpers selected among HIV+ clients.
Laisani	Kinshasa	505 HIV+ children 393 children on HAART Caregivers (n=?)		Pediatric hospital-based HIV clinic	Comprehensive HIV care, including HAART
Yalala 2008	Kinshasa, DRC	174 HIV+ index women 10 HIV+ index neonates 11 HIV+ male partners 2 HIV+ children	MTCT-Plus Women tested at ANC, referred to primary health center for HIV care	Community-based health center	Comprehensive HIV care, including HAART Primary care
Kabogo	Uganda	HIV+ index women (n = ?) HIV+ male partners (n = ?) HIV+ index neonates (n = ?) HIV+ children (n = ?)	MTCT-Plus	Hospital based antenatal clinic	Comprehensive HIV care, including HAART PMTCT
El Sadr 2004	12 programs in 9 countries	981 HIV+ index women 276 HIV+ partners 48 HIV+ index neonates 53 HIV+ children 36 children on HAART	MTCT-Plus		Comprehensive HIV care, including HAART PMTCT
Van Wingen 2008	Kenya	1205 HIV+ children 657 children on HAART	Adult and pediatric HIV care cohort members as index patients – refer family	1 hospital-based HIV clinic + 3 community-based health centers	Comprehensive HIV care, including HAART Primary care

# Literature Review: Results

## *Program Components*

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- Location of the program determined to some extent services offered – antenatal clinic-based programs were better equipped to offer PMTCT services, and pediatric hospital-based programs were well positioned to mobilize inpatient consult teams.

# Literature Review: Results

## *Enrollment - Overview*

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- Enrollment points varied widely, and included: antenatal clinics, PMTCT programs, adult/adolescent HIV clinic, inpatient adult and pediatric wards, maternal and child health clinics
- Subsequent use of “index patients” within the recruited cohort to identify HIV+ family members.
- To a large extent, the enrollment method influenced the inclusion or exclusion of various demographic groups within the treatment cohort.

# Literature Review: Results

## *Enrollment - MTCT Plus*

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- A commonly used and well-documented strategy is the MTCT-Plus initiative.
- Pregnant women are tested at antenatal or PMTCT clinics and, if positive, referred to the family care program – they become the “index women.”
- Upon enrollment, they are encouraged to bring children and male partners for testing and, if necessary, treatment and care.



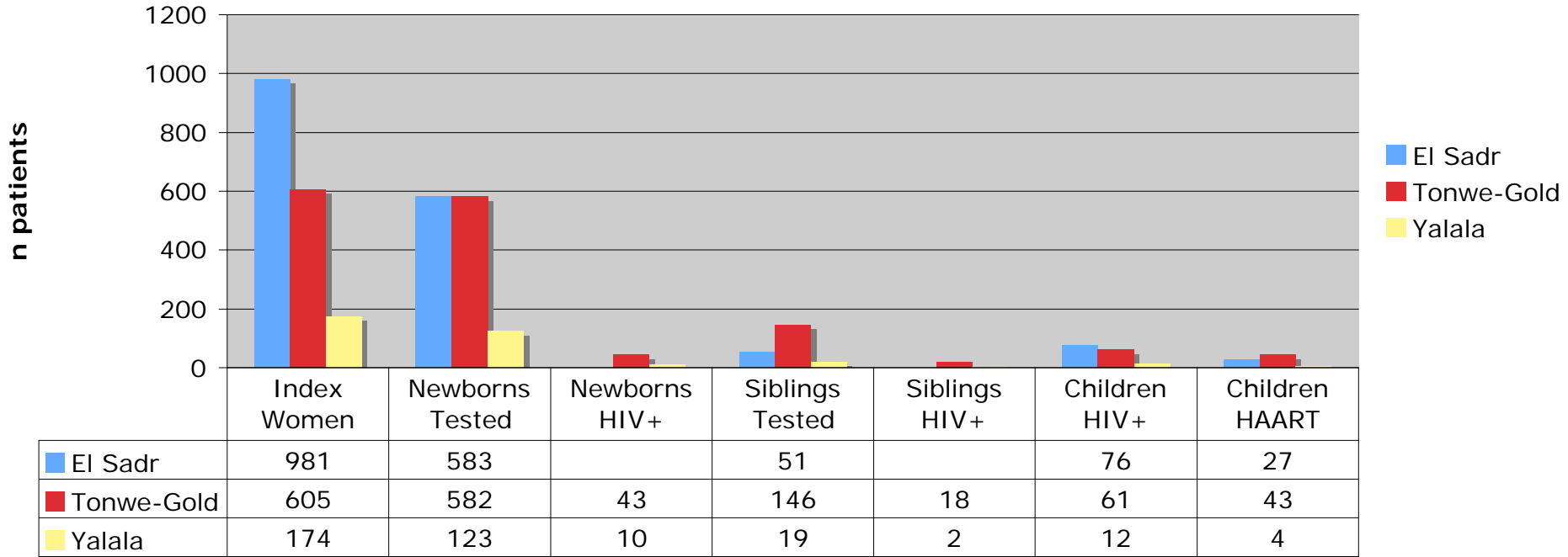
# Literature Review: Results

## *Enrollment - MTCT Plus*

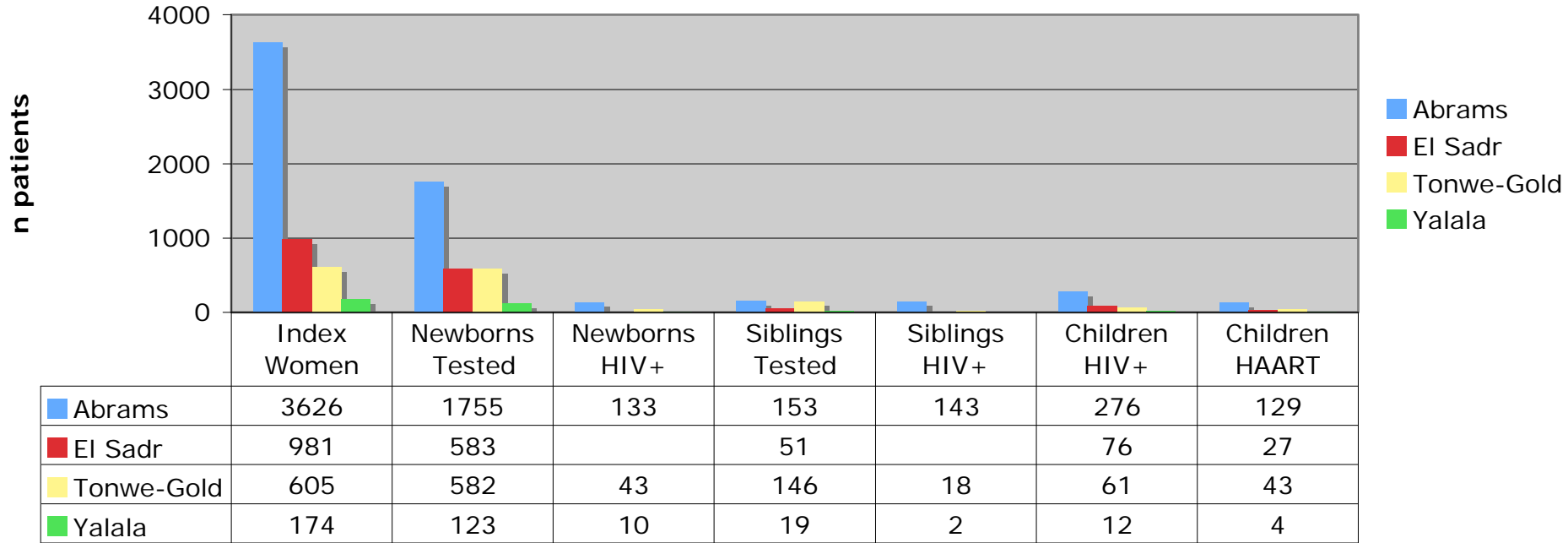
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- Figure 1 describes 3 MTCT-Plus cohorts: Tonwe-Gold in Cote d'Ivoire, Yalala, and El-Sadr describing a composite cohort from 12 programs in 9 countries.
- The three authors describe a combined total of 1446 index women, but they document only 82 children on HAART.

## MTCT-Plus: Children



### MTCT-Plus: Children



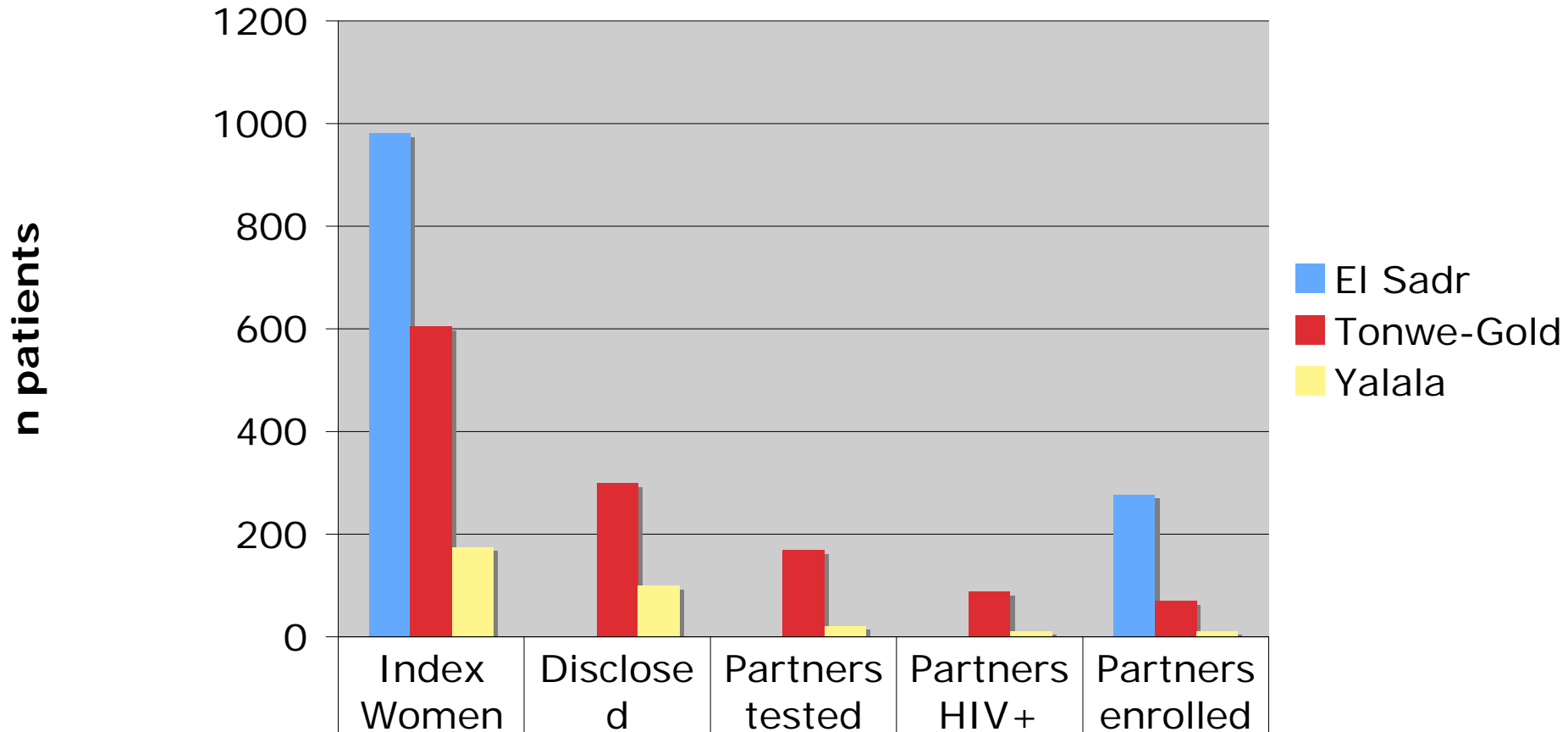
# Literature Review: Results

## *Enrollment - MTCT Plus*

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- The authors pose various theories as to why the uptake of pediatric HAART is so low.
- Tonwe-Gold: “many of the children lived away from the mother’s household with other relatives in distant communities.”
- Low rate of disclosure to a male partner, since revealing the child to be HIV-positive might by extension reveal the mother be HIV-positive.

## MTCT-Plus: Partners



El Sadr	981				277
Tonwe-Gold	605	300	169	88	69
Yalala	174	100	21	11	11

# Literature Review: Results

## *Enrollment - Other Adult IPs*

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- Other cohorts use adults (male and female) in their existing HAART cohorts as index patients to recruit other family members.
- Incentives: Sinikithemba Clinic in Durban, South Africa, offered free pediatric care to children whose parents were enrolled, and referred family members were prioritized for treatment (Reddi). Adult patients in Kenya were allowed to enroll in care at an earlier stage if they had a child in care (Van Wingham).
- The proportion of patients at FACES in Kenya who are children has doubled from 5% to 10% (Marima).
- Ninety percent of the children in a large Rwandan cohort were children of adult HIV+ patients (299/332).

# Literature Review: Results

## *Enrollment - Other Adult IPs*

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- At 5 health facilities in South Africa, HIV-positive patients were given referral cards to pass along to family members.
- Despite the fact that 33% of these adults reported not knowing their children's HIV status, the referred population was primarily adult (mean age 34 years) (Sheehy)

# Literature Review: Results

## *Enrollment - Pediatric IPs*

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- At Tygerberg Academic Hospital Family Clinic in South Africa, hospitalized children with “intercurrent disease or opportunistic infection” = IP
  - Authors report “inadequate utilization by the parents, especially the fathers” – only 18% of potential parents attended the clinic. (Niekerk).
- In South London, children were referred from a variety of sources: district hospitals, social workers, GPs, etc.
  - The majority of parents had not been tested at the time their children first attended the HIV clinic, but in the five-year description of the program, only 17% chose to remain untested (Gibb) but majority registered in care were moms (76%)



# Literature Review: Results

## *Pediatric Cohort Characteristics*

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- Very little data was available on clinical, immunological, or virological outcomes.
- However, most studies well documented adherence, retention in care, and mortality.

# Literature Review: Results

## *Pediatric Cohort Characteristics*

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- Cohorts contained between 43 – 657 children, and approximately one-third served <100.
- Median follow-up time after HAART initiation was recorded for eight cohorts, and ranged from 6.7 months to over 2 years.
- Eight cohorts report average patient age at HAART initiation: half had a median age >5 years old, and half <5 years old, with two <2 years.

# Literature Review: Results

## *Pediatric Cohort Characteristics: Adherence*

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- Adherence data was available for 6 cohorts, and was assessed by methods ranging from patient self-report to pharmacy refill.
- The lowest adherence rate achieved was 77.8%, and 4 cohorts reported >95% adherence for the majority of their patients.

# Literature Review: Results

## *Pediatric Cohort Characteristics: Adherence*

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- Families on ART in Malawi who are supervised for adherence by treatment helpers selected among HIV+ clients have achieved an adherence rate of 99.7%.
- Byakika-Tusiime et al note “near perfect adherence to ART” in both mothers and children when treatment was provided to all eligible HIV-infected family members.
- In a particularly striking case study of a family with 6 HIV-infected members, all of whom were started together on HAART in rural Kenya, “excellent outcomes” were achieved despite a family total of 49 individual pill or syrup administrations daily (Fielder).

# Literature Review: Results

## *Pediatric Cohort Characteristics: Clinic Attendance*

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- Excellent attendance at scheduled clinic visits was documented in several cohorts.
- The GHAIN Project in Kano, Nigeria, reports that in nearly a year of managing 202 children and 90 parents, only 2 clients have missed scheduled clinic appointments (Habibu).
- In fact, family care patients seem to be more likely to attend scheduled visits: in 2007, adults in the Family Program at PATH (the HIV service of Brooklyn Hospital) kept 74% of their medical visits, compared to 44% for PATH's patients overall (Sendzik 2008)

# Literature Review: Results

## *Pediatric Cohort Characteristics:LTF*

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- LTF rates were low in the majority of studies: ten report <11% LTF, including Ida et al, who demonstrated >90% retention during a seven year observation period.
- Three cohorts report zero patients lost to follow up.
- One study, Niekerk et al, report 52% LTF (a pre-HAART -only 22% of the children on HAART through various clinical trials.)

# Literature Review: Results

## *Pediatric Cohort Characteristics: Survival*

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- The probability of survival one year after HAART initiation was 90.9% - 98% (Reddi, van Winghem, van Griensven).
- Mortality was low in studies with a duration up to one year (8.8%), two years (4.9%), three years (1.8%), and four years (8%) (Eley, Tonwe-Gold, Midturi, Lusiana).
- Several studies highlighted a particularly vulnerable period shortly after the initiation of HAART: all of the deaths (7) reported by Eley took place within 6 weeks of HAART initiation, 70% of the deaths reported by Lusiana within 3 months, and all of the deaths (13) reported by Reddi within 5 months.

# Literature Review: Results

## *Pediatric Cohort Characteristics: Predictors of Mortality or LTF*

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- HIV-positive caregivers showed a protective effect against mortality when compared with caregivers who were untested or HIV-negative (Reddi).
- Rate of deactivation/death was higher among children without a family member participating in the program (Lusiama).
- Researchers found better outcomes in family clinic cases compared to pediatric care controls with regard to retention in care, death, LTF, stopped ART, and transfer to other ART sites (Midturi).



# Literature Review: Discussion

## *Lessons Learned - Enrollment*

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- Challenges recruiting one or more types of family members: females, males, and children.
- Fathers were the least likely to access care in all scenarios – as Tonwe-Gold wryly observed, involving males in family services like MTCT-Plus “is known to be very taxing.”

# Literature Review: Discussion

## *Lessons Learned - Enrollment*

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- Failure of HIV+ females to disclose: fear of accusations of infidelity, abandonment, discrimination, loss of economic support, and violence are often cited as primary reasons.
- A review of 17 studies found that between 3.5% and 14.6% of women reported experiencing a violent reaction from a partner following disclosure, and other negative outcomes included separation from partner, abuse by in-laws, or being forced to move away from home (Medley).

# Literature Review: Discussion

## *Lessons Learned - Enrollment*

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- Failure of the “trickle-down” method of pediatric enrollment.
  
- Two interventions:
  - Video for continuous playback in ART clinic waiting rooms encouraging parents in care to bring their children for testing (Sheehy)
  - “In-depth counseling sessions...with the caregivers to discuss testing of children in detail” (Van Griensven).
  
- Children with non-biological caregivers?

# Literature Review: Discussion

## *Lessons Learned - Early Access*

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- DeGennaro suggests that family-centered programs are able to “locate infections at earlier disease stages.”
- A review of pediatric antiretroviral cohorts in Sub-Saharan Africa showed that only about  $\frac{1}{4}$  of their cohorts had a median age of  $<5$  years (Sutcliffe).
- Half of the family-centered HAART cohorts had a median pediatric cohort age of  $<5$  years.
- Half of the family-centered HAART cohorts had a median pediatric cohort age of  $>5$  years, at which point 80% of children born with HIV have died.

# Literature Review: Discussion

## *Lessons Learned - Early Access*

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- MTCT-Plus programs:
- In Uganda, less than 1% of HIV-exposed infants in the program died before testing (Kabugo).
- Abrams et al - 37% of their pediatric cohort <12m
- Replicate this success with infants who have a greater risk of infection?

# Literature Review: Discussion

## *Lessons Learned - 1st 6 months*

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- High mortality at onset of HAART documented by Reddi, Eley, and Lusiana,
- Echoed in other pediatric (Sutcliffe) and adult (Bratstein) reviews.
- 1st month is the most dangerous, risk drops after 6 mos, then 1 year.

# Literature Review: Discussion

## *Lessons Learned - Infrastructure*

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- A survey of NGOs by DeGennaro reveals “lack of healthcare workers trained in pediatrics” as the most common reason for the failure to treat children with HIV.
- Staff can be overwhelmed by the increased volume of patients, or may view the attention to pediatric care/primary care as a burden.
- “There was limited physical capacity of the clinics to cater for child-specific activities and rooms” (Van Wingham).

# Literature Review: Discussion

## *Lessons Learned - Summary*

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1. No standard package of care - difficult to compare programs or interventions
2. Enrolling male partners is a challenge, and may negatively impact the ability of children to access care
3. The “trickle-down” effect of adult index patients is problematic, and active interventions are required to make it work.
4. There is a vulnerable period for children directly after the initiation of HAART.
5. A family-centered care program has staffing and space requirements that existing infrastructure may not be able to meet.



# Literature Review: Discussion

## *Recommendations*

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### **Goal 1: Enroll hard-to-reach populations, earlier access to care for adults and children**

- Immunization sites, postpartum care, sick/well baby clinics, and inpatient pediatric wards.
- Symptomatic/asymptomatic children, PLUS children with non-biological caregivers
- Routine HCT could be successfully incorporated into maternal child health services and pediatric inpatient care, and did in fact identify HIV-exposed children in the early months of life, although they encountered difficulties with understaffing, record keeping, and linkage to care (Obonya, Abraham).

# Literature Review: Discussion

## *Recommendations*

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### **Goal 1: Enroll hard-to-reach populations, earlier access to care for adults and children**

- Support adult HAART patients' referral of their partners and children, and also to encourage the caregivers of pediatric HAART patients to be tested themselves.
- Very real danger faced by many women worldwide when disclosing their status to a partner.
- Counselors should be trained to identify women most at risk for negative outcomes through various screening tools, and provide additional support, including referral to domestic violence services when necessary (Medley).

# Literature Review: Discussion *Recommendations*

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## **Goal 1: Enroll hard-to-reach**

**populations, earlier access to care for adults and children**

- Interventions that might support the positive participation of males in HIV testing and treatment include utilizing male health care workers and counselors, and establishing “fathers’ clinics” or similar male-centered activities as an opportunity for education and peer support (Kiragu).

# Literature Review: Discussion

## *Recommendations*

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### **Goal 2: Develop a family-centered care package**

- Long-term: “implementing (packages) will require substantial and long-term investments in infrastructure and human resources.”
- Short-term: “a framework around which a program may construct its own particular model of care, providing those services for which it is able while finding a reference point for the development of its future capacities.”

-Tolle 2009

# Literature Review: Discussion

## *Recommendations*

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### **Goal 2: Develop a family-centered care package**

- Establishing a consensus as to which interventions define family-centered care would allow us not only to independently validate discrete interventions but also to compare family-based care vs. traditional HIV care.
- At this point, it is difficult to identify which might be the most crucial and efficacious components of a family-centered care program.
- However, a “wish list” assembled from the recommendations of the above studies and others (Tolle, Richter, DeGennaro, and DeBaets) includes interventions listed here.

<b>HIV + TB CARE</b>	<b>ADULT/PEDIATRIC PRIMARY CARE</b>
<p>PMTCT (4)</p> <p>VCT, including viral diagnostic tests for early infant diagnosis (1)</p> <p>Opportunistic infection prophylaxis (3,4)</p> <p>HAART for adults and children</p> <p>Regular TB screening, INH prophylaxis, and treatment (1,3)</p>	<p>Routine neurodevelopmental assessments (3)</p> <p>Nutritional supplementation and infant feeding support (3,4)</p> <p>Reproductive health services, including cervical screening and STD care (1,4)</p> <p>Family planning services (4)</p> <p>Insecticide-treated bednets malaria screening and treatment (1,3,4)</p> <p>Management of other endemic disease – helminthes (3)</p> <p>Management of chronic illness: cardiovascular disease, Type II diabetes, hyperlipidemia (1)</p> <p>Safe drinking water (1)</p> <p>Pain management and palliative care (3)</p> <p>Home health visits for pregnant mothers and young children (2)</p>

<b>PSYCHOSOCIAL + ECONOMIC</b>	<b>ADMINISTRATIVE</b>
<p>Adherence counseling for adults and children (3)</p> <p>Psychosocial support for both HIV+ and HV- caregivers (3)</p> <p>Psychosocial support for children - social and educational activities (3)</p> <p>Early childhood development programs (2)</p> <p>Subsidized patient transport to and from the clinic</p> <p>Income assistance (2)</p>	<p>Follow-up and patient tracking</p> <p>Tight network of referrals and linkages with community-based organizations</p> <p>Monitoring and evaluation systems</p>

# Literature Review: Discussion

## *Recommendations*

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### **Goal 3: Pay special attention to pediatric patients during the first 6 months of HAART**

- Practitioners should develop evidence-based risk-assessment tools to red-flag the most vulnerable patients at initiation.
- Sutcliffe et al have compiled the leading risk factors: low CD4 T-cell percentage, viral load  $>6.0$  log<sub>10</sub> copies per mL, severe malnutrition, presence of TB, gastroenteritis, pneumonia, or *Pneumocystis jirovecii* pneumonia at treatment initiation.



# Literature Review: Discussion

## *Recommendations*

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**Goal 3: Pay special attention to pediatric patients during the first 6 months of HAART**

Long-term:

- Access for all children to early diagnosis and care
- Integration of services may be useful in mitigating some of these risks. Incorporating therapeutic and supplementary feeding with HIV treatment programs could support patients who are malnourished, and combining HIV care with TB screening and treatment might result in a lower TB incidence at baseline.

# Literature Review: Discussion

## *Recommendations*

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**Goal 3: Pay special attention to pediatric patients during the first 6 months of HAART**

**Short-Term:**

- Patients identified as high-risk at baseline “be referred to pediatric inpatient wards or a local palliative (step-down) care center for HAART initiation.” (Reddi)
- Treatment counselors can conduct home visits to support caregivers, especially those w/ little treatment experience.
- Scheduling more frequent follow-up appointments after initiation, and providing more careful clinical monitoring of high-risk patients.

# Literature Review: Conclusion

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- Family-centered care can be implemented in resource-limited settings and produces good outcomes in terms of service uptake, clinical outcomes, adherence, and retention.
- Building personnel and infrastructural capacity, innovating methods for testing hard-to-reach populations within the family, identifying and implementing specialized services for high-risk populations early in treatment, and providing a full range of comprehensive services for all family members are important considerations for future programming.

# Thank you!

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