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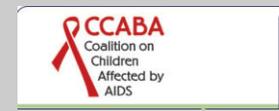
Family-Centered Approaches to the Prevention of Vertical Transmission of HIV



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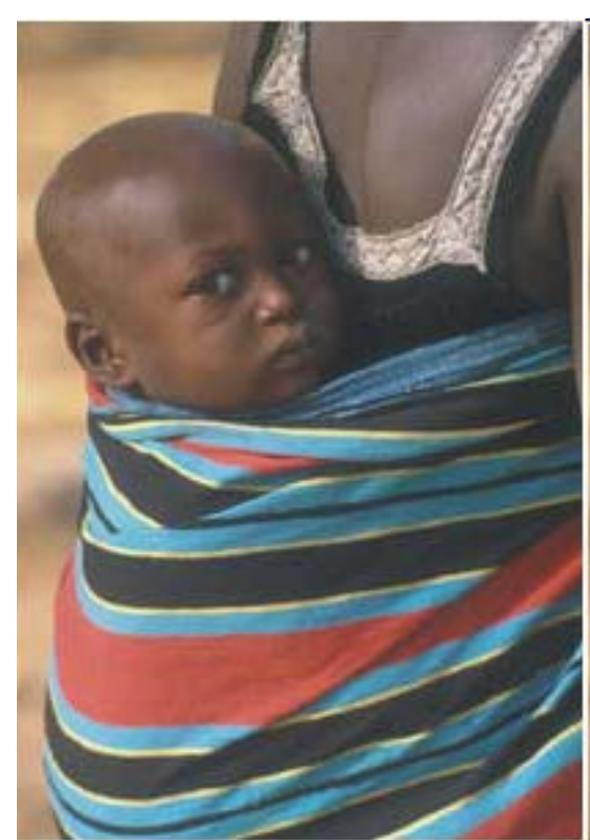


Vertical Transmission of HIV

- Approximately 2.1 million children <15 are living with HIV
- 280,000 died of AIDS in 2008
- 1.4 million pregnant women lack access to antiretrovirals to prevent MTCT
- Over 90% of the children living with HIV are infected through mother to child transmission (MTCT) during pregnancy, around the time of birth or through breastfeeding (UNAIDS, 2009)



HIV is a family disease, but PMTCT is often narrow in scope

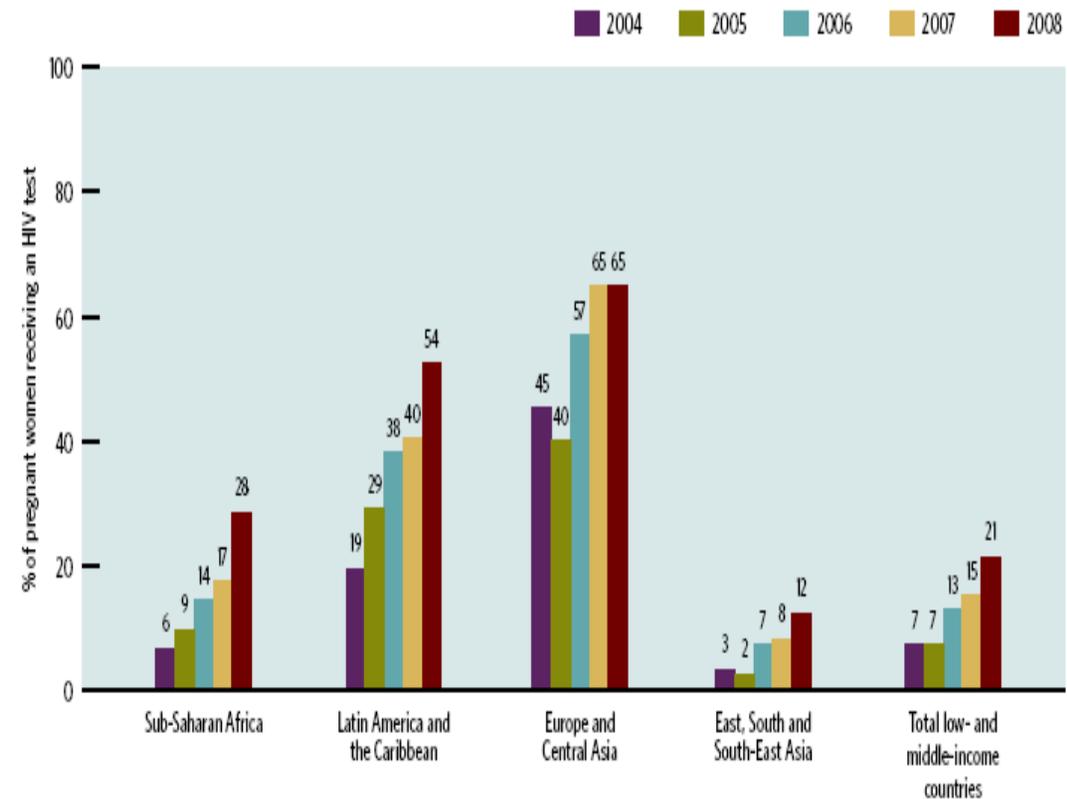


- In resource-limited settings, PMTCT tends to be narrowly focused on targeted biomedical interventions during late pregnancy and delivery
- Lost opportunity to effectively combat the vertical transmission of HIV to children
- MTCT is a largely preventable infection. Applying effective strategies, the rate of mother-to-child transmission of HIV can be lowered to $< 2\%$

Barriers to preventing vertical transmission

- Coverage of HIV testing among pregnant women in low- and middle-income countries is estimated at only 21% (UNAIDS, 2009)
- In many high HIV burden settings, it is difficult to identify HIV+ women before delivery or early in their gestation, when ART or prevention of vertical transmission regimens can be optimized
- Access to antenatal care is routinely insufficient: only 32% of pregnant women in developing countries receive the minimum number of visits recommended by UNICEF and the WHO (UNICEF, 2009)

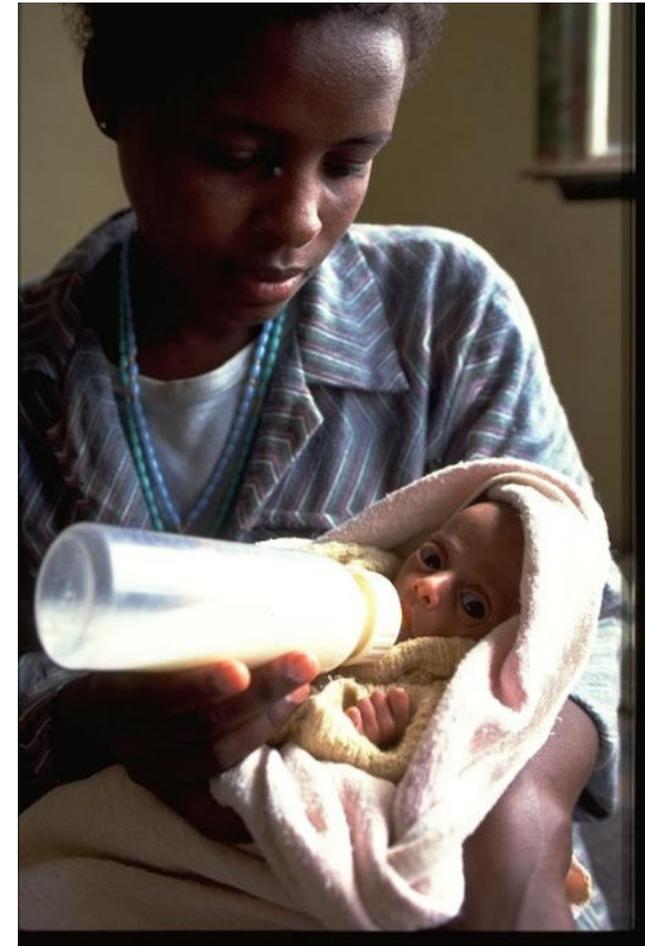
Fig. 5.5. Percentage of pregnant women who received an HIV test in low- and middle-income countries by region, 2004–2008^a



^a Figures on the coverage of HIV testing among pregnant women were recalculated for previous years based on the revised estimates available.

Barriers to preventing vertical transmission (cont.)

- Barriers also limit access to facility-based delivery and follow-up care for new mothers and infants
 - In sub-Saharan Africa, only 40% of births take place at health care facilities (UNICEF, 2009)
- Mothers who have not disclosed their HIV+ status to their partners may have difficulty pursuing alternatives to breastfeeding.



Family-Centered Care

“In pediatrics, family-centered care is based on the understanding that the family is the child’s primary source of strength and support.” (American Acad of Pediatrics, 2003)



1. Respecting each child and his or her family
2. Honoring racial, ethnic, cultural, and socioeconomic diversity and its effect on the family's experience and perception of care
3. Recognizing and building on the strengths of each child and family, even in difficult and challenging situations
4. Supporting and facilitating choice for the child and family about approaches to care and support
5. Ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family
6. Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming
7. Providing and/or ensuring formal and informal support (eg, family-to-family support) for the child and parent(s) and/or guardian(s) during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood

Family-Centered Care

- The need for family-centered approaches to preventing vertical transmission has been increasingly acknowledged by international organizations like the WHO.

“Priority will be given to strengthening linkages between PMTCT and HIV care and treatment services for women, their children and other family members in order to support an effective continuum of care”

-PMTCT Strategic Vision 2010-2015, WHO



UNICEF's MTCT Four-pronged strategy

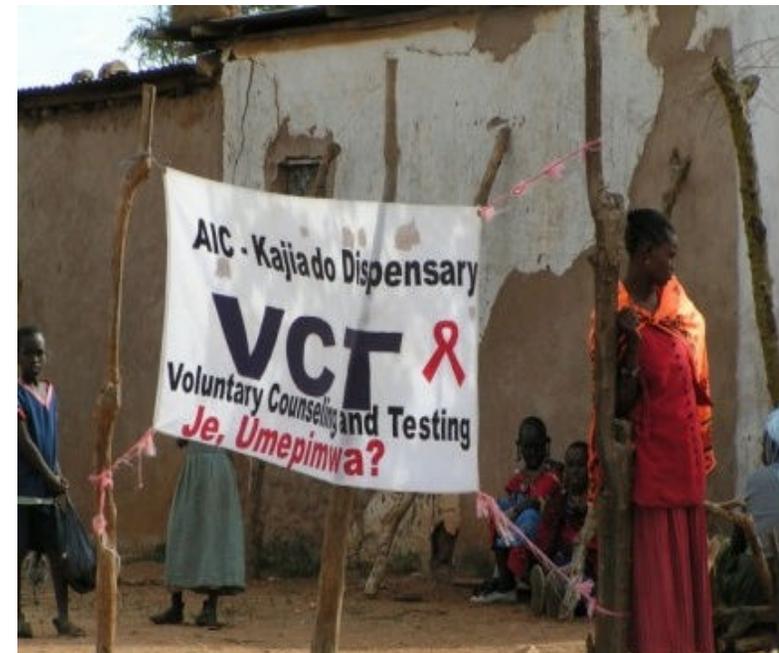
- **First prong** - promotes the delivery of primary prevention interventions within services related to reproductive health: antenatal care, postpartum/natal care and other health and HIV service delivery points
- **Second prong** - emphasizes provision of appropriate counseling and support to women living with HIV to enable them make informed decisions about their future reproductive life
- **Third prong** - targets pregnant women already infected and demands that HIV testing be integrated in maternal child health units where ARVs and adequate counseling are provided on the best feeding option for the baby.
- **Fourth prong** - calls for better integration of HIV care, treatment and support for women found to be positive and their families.

Review of the Literature on Family-Based Prevention of Mother to Child Transmission (PMTCT)

- Using a standard review methodology, we searched PubMed, PsycINFO, and EMBASE from 1990 to November 2009 for all published articles pertaining to family-centered approaches to PMTCT
- We included studies or program descriptions that contained components of family-centered PMTCT in at least one of three categories of HIV care:
 - Family services provided as a part of antenatal care
 - Family services provided around the time of birth
 - Family services provided following the birth of a child
- 12 paradigmatic models of family-based PMTCT were identified through the review process

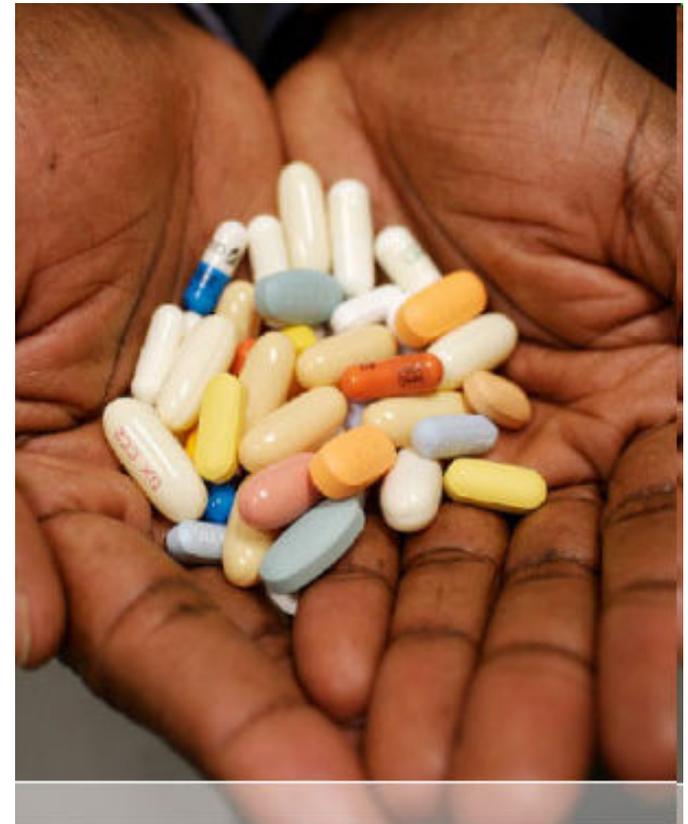
Findings

- Seven models focused on extending HIV counseling and testing to the partners of pregnant women attending ANC clinics
- Partner participation was associated with a number of positive outcomes:
 - Greater use of antiretrovirals among pregnant women (Msuya et al, 2008; Farquhar et al, 2004)
 - Higher acceptance of post-test counseling among pregnant women (Kakimoto et al, 2007)
 - Increased spousal communication about HIV and sexual risk (Desgrees-Du-Lou et al, 2009)
 - When couples received pre- or post-test counseling together, greater use of alternative feeding methods (Farquhar et al, 2004) and greater acceptance of HIV testing (Semrau et al, 2005) observed among women



Findings Cont.

- Two additional models focused on expanding provision of antiretroviral therapy (ART) to partners and other family members
 - High adherence and retention of ART among all participants -women, men and children- was observed (Byakika-Tusiime et al, 2009; Tonwe-Gold et al, 2009)
- A third category of programmatic models assumed a comprehensive approach to family-centered PMTCT (Abrams et al, 2007; Geddes et al, 2008; Mermin, 2005)



Comprehensive Models: The MTCT-Plus Initiative

- The MTCT-Plus Initiative operates at 13 sites in 8 sub-Saharan African countries and Thailand (Abrams et al, 2007)
 - Aims to address the health needs of the mother as well as the infant and recognizes that women's families should also be provided care
 - More than 16,000 individuals enrolled 2003-2008
- Comprehensive package of services extended to all family members includes:
 - Medical care for HIV-positive adults and children
 - Early infant diagnosis
 - Patient education and counseling
 - Reproductive health and family planning services
 - Psychosocial support
 - Adherence and retention promotion
 - Nutrition education and support
 - Follow-up of HIV-exposed infants



Comprehensive Models: The MTCT-Plus Initiative

- Positive findings:
 - Among pregnant women who enrolled their infants, the majority received complex ART regimens (47% received short-course regimens during pregnancy, 20% initiated highly active antiretroviral therapy (HAART), and 30% received single-dose nevirapine)
 - Women initiating HAART during pregnancy exhibited a strong immunologic response (average increase of 451 cells/mm³ after 30 months of treatment)
 - More than 2/3 of index women enrolled another family member
 - Retention in care for MTCT-Plus participants initiating ART was high (82% for pregnant women, 86% for men, and 87% of non-pregnant women at 30 months of follow-up (Toro et al, 2009)
 - Mortality rate for both adults and pregnant women was found to be much lower than that reported by publicly-funded programs (Kaplan et al, 2008; Wang et al, 2008)

Comprehensive Models: CDC-Uganda, Global AIDS Program

- Applying a home-based testing approach to evaluate interventions forming a “preventive care package”
 - Extended home-based voluntary counseling and testing (VCT) for HIV to 6000 family members of HIV-positive individuals (Mermin, 2005).
 - Acceptance rate exceeded 95%. 10% of the children under the age of five years had undiagnosed HIV
 - Cotrimoxazole was provided to individuals
 - Consumption by HIV+ individuals was associated with a 46% reduction in mortality, and 30-70% lower incidence of malaria, diarrhea and hospitalization
 - 63% reduction of mortality among HIV- children whose HIV+ parents were taking cotrimoxazole
 - Distribution of basic health interventions like home-based water purification systems were also provided



Lessons Learned: Involving Partners

Partner involvement is a critical component in facilitating improved family health outcomes

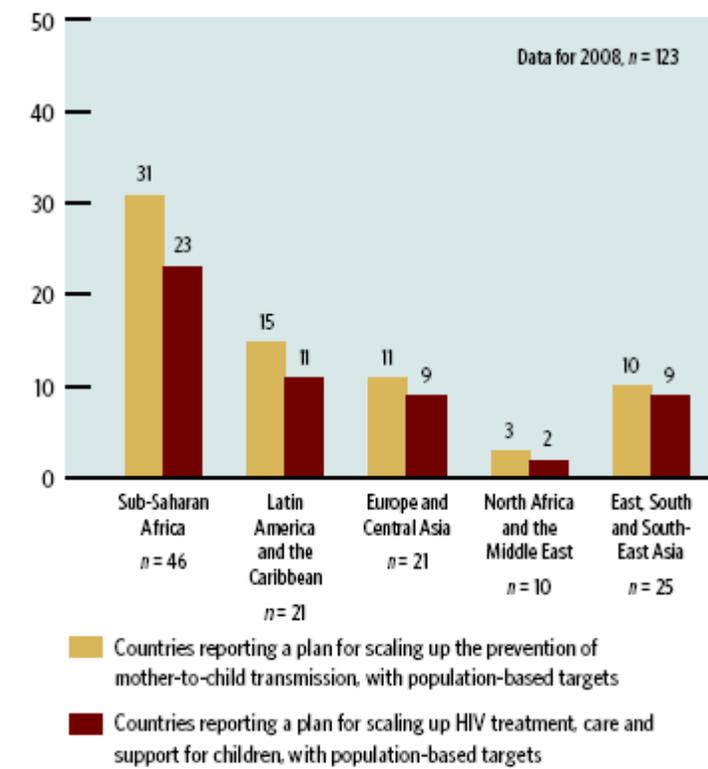
- In Côte d'Ivoire study, when men knew their spouse was HIV+ and they were involved in PMTCT activities, they played an active role in applying advice received, particularly related to exclusive breastfeeding (Tijou Traore et al, 2009)
- Utilizing an opt-out framework, another study (in Uganda) found high levels of uptake of HIV testing during ANC visits (97% for women and men) and during delivery (86% for women and 98% for men) at a rural hospital (Homsy et al, 2006)
- A third study, in Kenya, found that if women were accompanied by their partner for HIV-VCT, they were 3 x more likely to return for ART. Couples post-test counseling was also associated with an 8-fold increase in postpartum follow-up and greater ART utilization (Farquhar et al, 2004)



Lessons Learned: Scaling up Family-Focused Strategies

- Several national PMTCT programmes have utilized family-focused strategies to ensure successful scale-up of services
- PMTCT coverage in Botswana increased from 7% in 2000 to 83% by 2005. Family-centered components included integration of PMTCT with reproductive and child health services, psychosocial support for women, and ART for women's clinical care (Bussmann et al, 2008)
- Similarly, the success of Thailand's PMTCT program seen as linked to its integration within a strong MCH program, promoting close monitoring and follow-up care for women and HIV-exposed infants (Kanshana and Simonds, 2002)

Fig. 5.1. Number of low- and middle-income countries with national scale-up plans including population-based targets for preventing mother-to-child transmission and for HIV care and treatment for children, by region, 2008



Source: Data reported by countries to WHO, UNICEF and UNAIDS in response to the annual reporting form for monitoring the health sector response to HIV/AIDS, 2009.

Ongoing Challenges

- There remains a prevailing focus on simplified medical interventions to reduce vertical transmission.
 - Only a handful of studies investigate family-centered approaches to preventing vertical transmission
 - The evidence base to move this agenda forward requires much more attention
 - Family-centered approaches remain under-documented
 - As seen in our review, there are few formal published evaluations of family-centered PMTCT models and almost no comparative research
 - Trials pertaining to the efficacy of family-centered care versus “segmented delivery of only ART or PMTCT” are nearly non-existent (DeGennaro & Zeitz, 2009)



Conclusions

- Paradigm shift in standard PMTCT needed
- Consider the needs of entire families rather than singular focus on preventing MTCT during pregnancy and delivery
- PMTCT represents an entry point for improving overall family health and functioning and addressing developmental context for HIV exposed children
- Family-centered models remain uncommon but those that exist show promising results; more attention needed to IPV, mental health, early childhood development activities
- Future vision: expanding research and programming on family-centered approaches to preventing vertical transmission



Thank you!



Photo from Serukka et al, LG3

Extension of HIV Counseling and Testing					
Citation, country, sample size	Design	Target group	Family-centered PMTCT programme components	Outcomes	Study Limitations
Desgrees-Du-Lou et al., 2009; Côte d'Ivoire ; 710 women	Prospective cohort	Families	Pregnant women were encouraged to suggest HIV testing to partners Free HIV counseling and testing were provided at request of women's partners and relatives	Prenatal HIV counseling and testing of women was followed by increased spousal communication about HIV and sexual risks, irrespective of HIV status ($P < 0.01$) This communication was associated with increased HIV testing in male partners ($P < 0.05$; OR = 4.03; 95% CI 1.50-10.82)	Study conducted among a population participating in a research program offering routine and systematic prenatal HIV testing and counseling. Thus, the effect of counseling and testing is likely to be higher than in other community settings which do not provide systematic counseling and HIV testing
Farquhar et al., 2004; Kenya; 2836 women and 308 men	Prospective cohort	Pregnant women and partners	Male partners were invited to voluntary counseling and testing for HIV (VCT) at an antenatal clinic Couples were offered posttest counseling Instruction was provided on contraceptive use, safe sex during pregnancy, and breastfeeding practices	Women whose partners came for VCT (10% of total) were 3 times more likely to return for nevirapine ($P = 0.02$), and more than 3 times more likely to report taking maternal and administering infant doses of nevirapine ($P = 0.009$) Couples posttest counseling was associated with an 8-fold increase in postpartum follow-up and greater nevirapine utilization ($P = 0.03$) Couples-counseled HIV+ women were more likely to use substitute feeding methods ($P = 0.03$)	Women whose partners came to the clinic were a select group who may have differed from those whose partners did not come. These differences may have contributed to effects on uptake of interventions. Since 2001, the approach to PMTCT testing, and the method of drug delivery, has changed considerably
Homsy et al., 2006; Uganda; 4462 women and 287 men	Cross-sectional	Pregnant/delivering women and partners	At a rural hospital, opt-out PMTCT education, HIV testing and counseling was provided to pregnant women in antenatal care, as well as attending partners Opt-out intrapartum HIV counseling/treatment were offered to women and partners Couples could choose to attend posttest counseling together or individually	Using this opt-out approach, HIV counseling and treatment acceptance was 97% among women and 97% among accompanying partners in the antenatal care (ANC) ward, and 86% among women and 98% among partners in the maternity ward In ANC, only 51 couples (2.8% of all tested persons in ANC) were counseled together In the maternity ward, 130 couples (37% of all tested persons in maternity) were counseled together	Staffing shortages on evenings and weekends slowed intrapartum HIV counseling and testing uptake until additional labor was hired Given the short follow-up interval, the data did not allow inference as to the rate of hospital delivery among ANC-tested HIV+ women

Extension of HIV Counseling and Testing (continued)

Citation, country, sample size	Design	Target group	Family-centered PMTCT programme components	Outcomes	Study Limitations
Kakimoto et al., 2007; Cambodia; 20757 women and 3714 men	Prospective Cohort	Pregnant women and partners	Partners participated in a "mother class" in which information on VCT, pregnancy, delivery and newborn care was provided VCT was extended to women and their partners, and pre- and post-test couples counseling was offered	85.1% of women accompanied by partners to the mother session accepted pre-test counseling, compared to only 18.7% of women who attended the session alone (P < 0.001; OR = 25.00; 95% CI 22.7-27/8) Acceptance of post-test counseling was also higher among accompanied women (P < 0.005; OR=1.2; 95% CI 1.07-1.37)	Pregnant women were voluntary attendees at a health facility and not randomly selected at the community level
Katz et al., 2009; Kenya; 2104 women and 313 men total	Prospective cohort	Pregnant women and partners	Women attending an antenatal clinic were asked to invite and return with their partners to receive couples or individual VCT Males' attitudes towards VCT were evaluated, as well as the correlates of accompanying partners and receiving couples counseling	16% of men who were informed by their wives of the availability of HIV testing accompanied their partners to the antenatal clinic Among 296 couples for which both partners received testing, 39% were counseled as a couple and 57% of men returned for a follow-up visit 87% of men attended the clinic to receive an HIV test, and 11% because they wanted information on HIV or MTCT.	The study was conducted in a public antenatal clinic serving an urban population. Therefore, it may not be applicable to other resource-limited settings, including rural communities
Msuya et al., 2008; Tanzania; 2654 women and 332 men	Prospective Cohort	Pregnant women and partners	Pregnant women invited their partners to attend antenatal clinics Partners who participated in VCT received HIV, syphilis, and herpes simplex virus 2 (HSV-2) testing, as well as pre- and post-test counseling Couples were invited to a joint counseling session	12.5% of male partners came for HIV counseling and testing 91% of HIV+ women whose partners attended VCT took nevirapine during delivery, compared to 74% of women whose partners didn't attend (OR = 3.45; 95% CI 1.00-12.00) These women were also more likely to choose not to breastfeed and adhere to a selected feeding method (OR = 3.72; 95% CI 1.19-11.63) Women's intention to disclose test results was associated with partner participation (P < 0.001; OR = 5.15; 95% CI 2.18-12.16)	Low male participation may have been due to failure of women to inform partners of VCT availability The researchers had to rely on women's self reports that they invited their partners Males may also have gone elsewhere for testing

Extension of HIV Counseling and Testing (continued)

Citation, country, sample size	Design	Target group	Family-centered PMTCT programme components	Outcomes	Study Limitations
Semrau et al., 2005; Zambia; 9409 women and 868 men	Prospective Cohort	Pregnant women and partners	Within an ongoing study on breastfeeding method and postnatal HIV transmission, women and their partners were offered couples counseling in HIV testing/PMTCT at antenatal clinics Partner involvement was promoted by community outreach	9.2% of women were accompanied by their partners for counseling Among women counseled as a couple, 96% agreed to HIV testing compared to 79% of women counseled alone (P < 0.0001). Disclosure inherent in couples counseling did not significantly increase likelihood of adverse social outcomes (e.g. intimate partner violence)	Adverse consequences of disclosure may have been underreported among women who did not disclose HIV status; thus, adverse outcomes may be overestimated by study

Extension of ART Services

Byakika-Tusiime et al., 2009; Uganda; 177 individuals	Prospective Cohort	Families	At one MTCT-Plus Initiative site in , treatment and therapy for mothers and HIV-infected family members was provided, including basic treatment of HIV-related opportunistic infections, as well as provision of antiretroviral therapy (ART)	In this family-centered model, near perfect adherence to ART was observed: Mean adherence in studied groups ranged from 87.7% to 100% Among adults, depression was significantly associated with incomplete adherence (P = 0.04; OR=0.32; 95% CI 0.11–0.93)	Information was not collected on the time gap between delivery and initiation of therapeutic treatment
Tonwe-Gold et al., 2009; Côte d'Ivoire; 605 women and 582 infants	Prospective Cohort	Families	Through the MTCT-Plus Initiative, HIV prevention and care for family members, including clinical ART services Involvement and support of partners and children	Among cohort of 568 women with a living spouse, 53% disclosed HIV status to their male partner Enrollment of HIV-positive male partners was low (12%) Retention of individuals on ART was high (2.5% index women, 5.5% index partners lost-to-follow-up)	Non-disclosure rates to partners remained high, even in the context of ART access Limited access to children outside the ANC context

Comprehensive Services

Citation, country, sample size	Design	Target group	Family-centered PMTCT programme components	Outcomes	Study Limitations
Abrams et al., 2007 ; 8 countries in sub-Saharan Africa and Southeast Asia; roughly 12,000 individuals	Observational Cohort	HIV-infected pregnant women and their families	As part of the Mother to Child Transmission-Plus (MTCT-Plus) Initiative, women receiving prevention of mother to child transmission (PMTCT) services were invited to enroll in MTCT-Plus, a comprehensive HIV care program, along with their newborn infants as well as HIV+ family and household members	Over 2/3 of index women enrolled their HIV-exposed baby or an HIV-infected family member Retention of participants was very high, with fewer than 600 adults leaving the program, including 190 reported deaths More than 2000 infants, 90% of those who reached 18 months, were determined uninfected, and of the 761 infected children enrolled, 65% received highly active antiretroviral therapy (HAART)	The feasibility of linking the different services represented in this model may be hindered in other contexts by factors like resource constraints, human capacity, and community preferences
Geddes et al., 2008; South Africa; 2624 women	Prospective Cohort	Families	PMTCT integrated into antenatal services Women were encouraged to bring partners for HIV counseling and testing Psychological services provided for discordant couples Cluster of differentiation 4 (CD4) counts measured to determine appropriate form of ART and mode of delivery Polymerase chain reaction (PCR) test given to HIV exposed infants; HIV+ babies were enrolled in children's program	During 18 months, 100% of women attending the clinic received counseling 91% of women and 25% of partners were tested for HIV In 338 cases of maternal HIV+, 70% of live births were by caesarean section and 98% of live babies were given nevirapine; 76% also received AZT Of the 81% of babies tested at 6 weeks (via PCR), 2.9% tested positive	May have been subject to selection bias - 11% of mothers lost to follow-up Participants may have been socio-economically and educationally better off than others who attended public facilities

Qualitative Assessments

Citation, country, sample size	Design	Target group	Family-centered PMTCT programme components	Outcomes	Study Limitations
Mlay et al., 2008; Tanzania; 18 women, 16 men, 11 counselors	Cross-sectional	Women and men of childbearing age	Women and men were asked to identify their views concerning couples voluntary counseling and testing for HIV (CVCT), couples' motivation to receive results together, and effective ways of counseling sero-discordant couples	<p>Categories identified: Community sensitization; male involvement; caring; resentment; abandonment/divorce; violence</p> <p>Recognition of a cultural belief that ANC is exclusively for women</p> <p>Many participants were unaware that sero-discordancy existed</p>	This qualitative study may have been influenced by selective enrollment and shouldn't be viewed as a representative sample
Theuring et al., 2009; Tanzania; 124 men	Cross-Sectional	Male partners	<p>Assessment of male attitudes regarding partner involvement in ANC/PMTCT interventions</p> <p>Examination of barriers preventing regular program attendance</p>	<p>Among the convenience sample of males interviewed, 99% expressed positive regard for joint counseling</p> <p>Among males who were having children, only 46% had attended ANC/ PMTCT services</p> <p>The primary external barrier to ANC/PMTCT services identified was "lack of knowledge and information"</p>	Study sample of men included some individuals aged 50+ years, who are less likely to be involved in family planning
Tijou Traoré et al., 2009; Côte d'Ivoire; 26 women and 10 men	Prospective Cohort	Pregnant women and partners	Assessment of couples' decision-making process concerning infant feeding in the framework of a MTCT-Plus program	<p>Interviews showed that initial individual preferences were subject to conjugal negotiation, and conflicts were often resolved after revelation of HIV status to spouse</p> <p>Most women associated refraining from breastfeeding with an internal moral suffering; this feeling was reinforced by social pressures</p>	<p>Small scale of study is illustrative and not generally applicable</p> <p>Selective enrollment of participants who were receptive to study</p> <p>Attitudes may have been influenced by the project's biomedical model</p>

Acknowledgements

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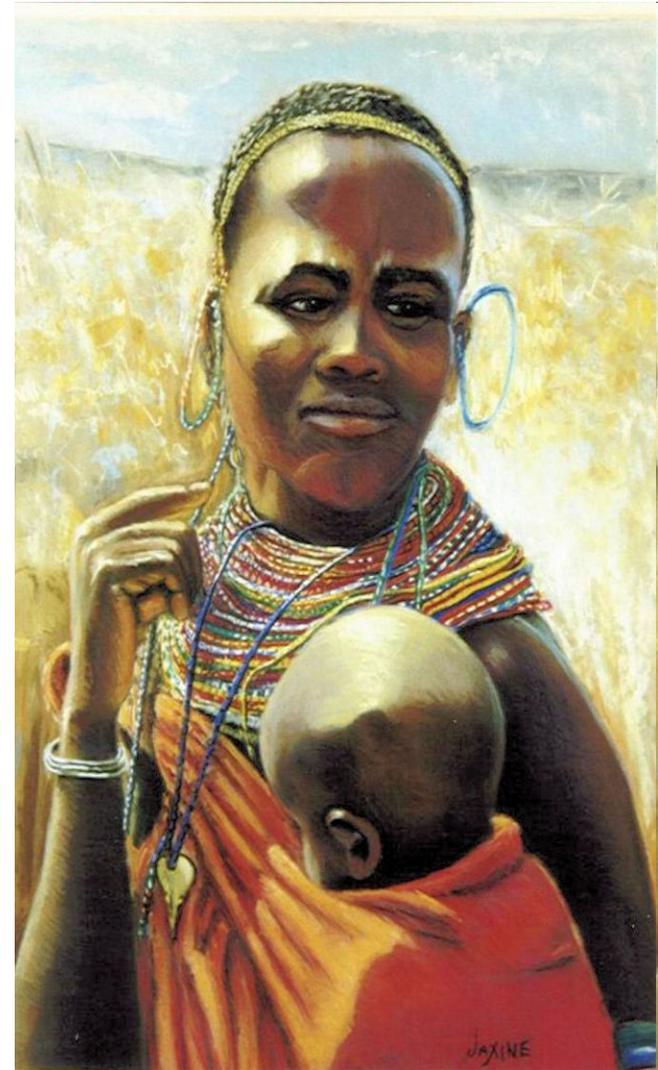
HIV as a Family Illness

- HIV-affected families are at high risk of a broad range of negative health outcomes
- Cascading effects on the health of all family members (Mishra et al, 2007)
 - *By offering HIV testing and treatment to other family members pregnant women may be more likely to accept HIV testing and collect their results, adhere to PMTCT regimens, and disclose their HIV status to their partners*
 - This may result in reduced risk of vertical transmission of HIV if more women accept HIV testing, are tested earlier, and initiate treatment during an earlier time of gestation



Barriers to PMTCT Cont.

- Additional barriers to PMTCT services include:
 - Limited access to ART, as well as to multi-drug prophylactic regimens for PMTCT (Orne-Gliemann et al, 2008)
 - Limited access to CD4 monitoring (Rouet et al, 2006)
 - Limited access to pediatric testing and treatment for HIV (Cavarelli et al, 2008)
 - Infrequent testing of partners (Msuya et al, 2008)
 - Poor adherence, as well as retention, in care after delivery (Haberer and Mellins, 2009)
 - Lack of coordination and integration among services, such as HIV testing, counseling, and distribution of ARVs (van't Hoog et al, 2005)
 - Lack of human and material resources (Nkonki et al, 2007)
 - Often, services are too centralized to reach remote areas (Perez et al, 2004)



The Importance of Family-Centered Care

- Family-centered approaches facilitate broader implementation of preventing vertical transmission programming
 - Aims to address the comprehensive needs of pregnant women who may lack adequate treatment for HIV
 - Serves children as well as other family members
 - Considers HIV to be a family disease
 - Provides a continuum of services over time
- Ultimately, family-centered approaches enrich the developmental context for children born into HIV-affected households

