Published in final edited form as:

Future Virol. 2011 June ; 6(6): 687–696. doi:10.2217/fvl.11.45.

Towards a family-centered approach to HIV treatment and care for HIV-exposed children, their mothers and their families in poorly resourced settings

Tamsen Jean Rochat^{†,1}, Ruth Bland^{1,2}, Hoosen Coovadia^{3,4}, Alan Stein⁵, and Marie-Louise Newell^{1,6}

¹Africa Centre for Health & Population Studies, University of KwaZulu-Natal, South Africa

²University of Glasgow, UK

³Maternal, Adolescent & Child Health (MatCH), Department of Obstetrics & Gynecology, University of Witwatersrand, South Africa

⁴University of KwaZulu-Natal, South Africa

⁵Section of Child & Adolescent Psychiatry, University of Oxford, UK

⁶University College London, UK

Abstract

This article provides a summary of emerging psychosocial evidence relevant to the success of comprehensive family-centered approaches to HIV prevention, treatment, care and support programs in poorly resourced settings. This report synthesizes current evidence on maternal, paternal and family experiences of HIV prevention, diagnosis, treatment, adherence and disclosure, with special focus on HIV-infected mothers and HIV-exposed children. Taking a developmental approach, we explore the current challenges and opportunities towards a family-centered approach within the continuum of HIV treatment and care, beginning in pregnancy and following the course of childhood. The discussion is limited to early and middle childhood and excludes discussion of special issues emergent in adolescence, which would warrant discussion outside the scope of this article. Attention is drawn to the complexity of problems arising within the family context and the need for improvements in the integration of aspects of treatment, care and support. While this article focuses on examples from sub-Saharan Africa, the lessons learnt and future challenges outlined are applicable to most low- and middle-income countries, and to poorly resourced contexts in higher-income countries.

Keywords

adherence; care; child development; disclosure; family-centered; HIV-exposed children; HIV-infected mothers; prevention; treatment

© 2011 Africa Centre for Health and Population Studies/University of KwaZulu-Natal

[†]Author for correspondence: Tel.: +27 355 507 623 ■ Fax: +27 355 507 565 ■ trochat@africacentre.ac.za.

Financial & competing interests disclosure The authors have no other relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.

No writing assistance was utilized in the production of this manuscript.

HIV has a significant and growing impact on families across the globe, especially in poorly resourced contexts, where already-struggling public health systems face an increasing burden of care. Progress in HIV treatment, care and support has been made over the last 5 years, particularly in heavily affected areas such as sub-Saharan Africa. Successful pediatric and family treatment cohorts have emerged, either as a result of increased political will, as in South Africa, or with the implementation of donor-funded public–private partnerships, as in Botswana. Emerging programs have provided opportunities to tackle the barriers to successful treatment [1], and there is increasing support for family-centered approaches to treatment and care. Models that can be delivered at scale within existing health systems in an integrated manner are still some way off. Current scaling-up of HIV treatment and care provides exciting possibilities for the development of strategic and comprehensive family-centered approaches to HIV treatment, care and support in poorly resourced settings [2].

Opportunities are now emerging to optimize prevention and the continuum of care in order to improve not only the physical, but also the psychological, social and developmental outcomes of young children. This article will examine those opportunities along the continuum of care, firstly among at-risk women before and during pregnancy, following delivery and through the early postnatal period. Secondly, among young HIV-exposed children, we explore opportunities for early initiation of HIV treatment and for the development of comprehensive care strategies for HIV-infected mothers and HIV-exposed but -uninfected children, including the promotion of early child development and stimulation. Lastly, we examine opportunities to support maternal adherence and disclosure within the family context throughout childhood.

Challenges & opportunities in family planning, antenatal care & prevention

The most significant way to impact on the HIV epidemic in children is to prevent new infections in women of childbearing age and unintended pregnancies in HIV-infected women [3]. Despite this, available evidence suggests that family planning efforts within maternal care services are either nonexistent or failing, with as many as 80% of women testing for HIV during pregnancy reporting an unplanned pregnancy [4,5]. Family planning and contraceptive services to prevent unintended pregnancies and reinfection of HIV-positive women are not well integrated with HIV treatment and care or prevention of mother-to-child transmission (PMTCT) programs. Furthermore, while many HIV-positive women, men and couples want to have children [6–8], few services provide counseling or support regarding the options, risks and benefits [9,10]. Family-centered approaches need to consider these childbearing aspirations. The success of family planning requires effective targeting of the sexually active individual, including male partners and sexually active adolescents [11]. Given the high HIV risk to women aged 15–24 years, efforts to improve prevention of unwanted pregnancies and family planning could benefit from models that extend beyond the primary healthcare environment and harness the potential of both school- and community-level reproductive health awareness and prevention [12]. These may include early sexuality and gender equality educational interventions and adolescent-friendly services [13,14]. Furthermore, improved use of every client contact within HIV services should include incorporating family planning and dual contraception messages, particularly given the traditionally heavy reliance on injectable contraception in poorly resourced contexts [5,15]. Similarly, engaging male partners [16], reducing stigma and encouraging couples counseling [17–19], which are often neglected in poorly resourced settings because of logistical and practical barriers, are cornerstones of family-centered approaches. Similarly, HIV prevention tends to focus on premarital and extramarital sexual behavior, but in areas with high HIV prevalence, the protective needs of married and cohabiting couples are just as important [20]. Conceptual frameworks for integration have been developed [21],

but health provider training, skills and attitudes remain a major barrier to the successful integration of family planning and HIV services in poorly resourced settings.

Following this, prevention efforts should focus on identifying and intervening with pregnant HIV-infected women to reduce the risks to both themselves and their unborn child [22]. Increasing the identification of HIV during pregnancy requires that all pregnant women test for HIV during pregnancy and that HIV-negative women retest in later pregnancy to detect acute primary HIV infection [7,23]. Increasing the involvement of the male partners in antenatal voluntary counseling, testing and attendance improves women's adherence with PMTCT programs [13], but work is still required to encourage not only male testing, but also to reduce stigma regarding services and increased disclosure practices within antenatal settings [24].

Once HIV-infected women have been identified during pregnancy, WHO PMTCT guidelines [101] and infant feeding guidelines [102] make specific and clear recommendations for the prevention of transmission from HIV-infected women to infants, based on robust evidence of the effectiveness of antiretroviral therapy (ART) administered antenatally, during delivery and in the early postnatal and breastfeeding period, to substantially reduce perinatal mother-to-child transmission [25]. In developing countries, these treatment practice models are often limited by critical shortages of healthcare professionals. Increasing evidence suggests that task shifting of primary care and prevention functions to community healthcare workers can improve the health outcomes of populations at a reasonable cost [26]. This includes service delivery of ART by community healthcare workers, which has shown similar clinical outcomes to regular professionally driven healthcare [27]. Harnessing this potential in models of delivery of both HIV prevention and treatment could improve ART rollout and increase access to treatment while expanding the capacity of healthcare institutions in resource-constrained environments [28].

Aside from the biomedical aspects of prevention and treatment in pregnancy, recent research from poorly resourced settings has also begun to articulate the psychological challenges involved in adjusting to maternal HIV infection, both during pregnancy and in the postnatal period [4,29]. Approaches to HIV testing and PMTCT have long raised concern in developed countries, in particular regarding ethical considerations and approaches to testing during pregnancy, informed consent and choice [30,31]. Qualitative research highlights the need to protect women's rights to consent and ensure that HIV testing is sensitive to the far-reaching implications of learning that one is HIV positive during pregnancy [32]. In high-prevalence areas, concern is raised that women may be blamed or stigmatized as the 'HIV infector' if they are the first to test in a partnership. In poorly resourced settings, gender inequality and intimate partner violence are common during pregnancy [33,34], linked in turn to both depression and risk of HIV [35,36]. Stigma and discrimination often result in low levels of disclosure among pregnant women, lowered support and minimal partner engagement in PMTCT [2]. Women are expected to carry a significant and disproportionate load of the burden of responsibility towards PMTCT.

While recent studies in sub-Saharan Africa show that opt-out testing and group counseling approaches to HIV testing in poorly resourced settings are successful and acceptable to women [37], very little is known about how or whether psychological and social status interact with testing, decision making and experiences of PMTCT. In addition, qualitative work has highlighted the complex calculations women need to make between the risks and the benefits of health and social decision making to ensure prevention of transmission, particularly as they relate to disclosure of HIV status and compliance with preventative medication, which could be further compounded by psychological distress [38]. Preliminary evidence suggests that prevalence of depression among HIV testers is high (33–41%)

antenatally [4] and postnatally [39], and may impact on a woman's ability to engage with HIV testing and preventative programming, potentially altering women's perceptions regarding the consequences (healthcare or otherwise) of testing for HIV during pregnancy [4]. Similarly, access to ART has been shown to improve quality of life and psychosocial health [40]. This evidence points to the importance of the inclusion of mental healthcare in family-centered approaches and to the role the social and relational context of pregnancy plays in preventative decision making [41].

Whether it is following the failure of PMTCT or during a period of illness and hospitalization in early infancy or childhood, learning one's child's or one's own HIV diagnosis is never easy [29,42,43]. A metasynthesis of 45 qualitative studies [38] on HIV-positive motherhood found that negative taxonomies were common to the experience of HIV-positive motherhood. Furthermore, HIV during pregnancy often introduces emotional difficulties and stressors as mothers begin to see themselves in terms of a deviant motherhood status, which is accompanied by feelings of remorse and inadequacy, resulting in barriers to seeking antenatal care and support. This is often misplaced guilt or shame since it is more likely a failure in health service delivery or preventative services (or a complete lack thereof, as is common to many poorly resourced settings) that has resulted in the infection of the infant. As treatment becomes more available, there is an opportunity to reframe post-diagnosis defeatist experiences into positive and empowering experiences of successful motherhood where treatment access and compliance is a marker of achievement, with all its cumulative psychological spin-offs in terms of self-efficacy and empowerment. This is a challenge for services that may have previously pitted the child against the mother – often inadvertently – by the use of limited approaches, failures to engage and support mothers and with individualistic models that overlooked couples and families [44], although this is being addressed in some programs [2,45].

Challenges & opportunities in postnatal prevention, treatment & care

Beyond prevention, the early postnatal care and support of HIV-infected women, their HIV-exposed infants and their partners and families is frequently neglected in comprehensive service delivery and has been noted in Countdown 2008 to have been a common source of failure to meet the interim targets of the Millennium Development Goals [46]. Furthermore, effective integration of pediatric treatment with antenatal, postnatal and primary healthcare services enhances and enables early diagnosis of HIV in exposed children and timely access to HIV treatment. Family-centered approaches are being increasingly advocated for, along with growing advocacy for the important role played by male partners and fathers in the care of children [2,11,47].

However, despite the recent efforts to roll out ART to children in poorly resourced settings, particularly in sub-Saharan Africa, there is still a large unmet need for pediatric treatment [48]. Early ART has been shown to increase survival and decrease morbidity [49], but HIV-infected children in poorly resourced settings still begin ART relatively late, owing to their being diagnosed because of ill health or hospital admissions when they are already of school age [50,51]. Those starting treatment are often at an advanced stage of HIV disease, are frequently already malnourished and a significant proportion have pulmonary TB [50,52]. Several operational challenges are present in settings where resources are poor, transport services are limited, numbers of health personnel are inadequate to cope with demand, laboratory infrastructure is limited, links with education are fragmented and primary healthcare clinics are not structured to cope with chronic diseases on the scale caused by the HIV pandemic [53].

Several strategies exist for improving early infant diagnosis (Box 1) that mainly depend on optimizing opportunities that already exist at the clinic level and using every child encounter with the health services to ensure the child's HIV status is known.

The family-centered approaches to care noted in Box 1 also ensure that HIV-infected mothers and fathers are regularly assessed and receive treatment as required, thus keeping parents healthier for longer, with benefits for both their infected and uninfected children [54]. The introduction of ART provides an opportunity for working with the healthier parent or guardian who is more able to engage in supporting the child, and so is, in essence, providing the family support.

Aside from the life-saving benefits of pediatric ART, the introduction of ART has raised questions regarding the development of young children infected with HIV and receiving ART. A systematic review of the cognitive effects of HIV on child development has shown the urgent need for standardized measures and interventions to prevent or ameliorate the developmental effects of HIV on young children [55]. To date, relatively little research has been conducted in Africa and other poorly resourced settings, but what is clear is that HIV has the potential to affect various domains of cognitive development through a variety of mechanisms, and that the most severe forms of encephalopathy have been arrested by the early introduction of ART [56]. One of the most important questions is whether the introduction of ART actually reverses some of these neurological deficits. Some studies show that ART leads to increased performance in memory, attention, executive function, behavior and motor function [57–59], while other studies have shown minimal improvement or even some deterioration [60]. One of the key deficits for children who are both infected and potentially affected by HIV is that of attentional capacity. This is important because of the evidence that these capacities are likely to be affected by HIV [61], and more recent follow-up work has shown that children in a US cohort growing up with HIV are at particular risk of suffering from attention deficit–hyperactivity disorder [62]. Research in South Africa has shown similar findings related to attention deficit–hyperactivity disorder [63]. These challenges may necessitate that models of family-centered care include rehabilitative services (including occupational and speech therapy and physiotherapy) aimed at maximizing the developmental capacity among HIV-infected children on ART.

For the much larger group of HIV-exposed but -uninfected children, given that both biological and environmental factors play a key role in early child development (particularly attention and cognitive development), the increased and regular parental contact that results from engagement in HIV treatment provides an important opportunity to work with mothers and fathers to enhance their children's attentional capacities and cognitive development. It is known that attentional capacity is critical to learning, memory and executive function in general. Furthermore, by extending this to fathers and other family members directly engaged in childcare, these strategies can ensure the best family environment for a young infant to thrive in. However, when a parent is stressed or even depressed, it is difficult to provide this form of parental attention and responsivity [64,103]. Parents could be helped to focus on the infant's facial cues and behavior, think about what the infant is communicating and respond contingently. This type of intervention could make use of locally available health resources and is developed for nonspecialists [65–67].

Challenges & opportunities in adherence, disclosure & support

Evidence from existing and emerging treatment programs suggests that adherence among parents and children on ART is good and better than expected [68–72]. Barriers to adherence are frequently cited as being financial and social in nature and less frequently related to interpersonal experiences and challenges such as bad-tasting medications,

unpleasant side effects, treatment stigma or lack of family support. Systematic and literature reviews of adherence illustrate a growing body of evidence that can guide practical strategies for maximizing adherence in poorly resourced settings [73,74]. Adherence behavior is seen to be influenced by many factors [75] including characteristics of the child, the caregiver(s) and family, the ART regimen and society and culture. Adherence strategies emphasize adopting a multidisciplinary team-based approach to anticipating challenges in adherence for parents and children, and using a variety of strategies, including assessing adherence as part of routine clinical care, providing ongoing case management to address situational barriers such as mental health issues, housing instability and substance abuse, and using behavioral strategies such as treatment buddies, stages of change counseling, family therapy, gastrostomy tubes, pill-swallowing techniques and flavoring agents. Ideally, strategies should be considered for delivery over time and not delivered solely for intensive periods.

While early indications of patient-level adherence are good, adherence is not a static concept and once achieved it must be maintained over time [76]. Keeping caregiving adults motivated once HIV illness abates and HIV is no longer a visual and salient physical threat, once longer-term side effects have begun to manifest and once treatment fatigue sets in is a challenge that will need to be faced. Similarly, as HIV-infected children grow older, enter adolescence and begin to demand more autonomy, maintaining treatment adherence for them can become a greater challenge, requiring more and somewhat different support approaches [74]. Disclosure support, whether it is disclosure of a child's own HIV status or disclosure of a caregiver's HIV status to a child, is considered to be an integral support component of comprehensive treatment programs [77,78]. Generally, evidence suggests that while caregivers have common concerns that disclosure may harm their children and cause difficulties in their caregiving relationships, this is seldom the case [79,80]. Instead, a lack of disclosure has been shown to increase behavioral and emotional difficulties among children and can jeopardize treatment outcomes in HIV-infected children. Research from other chronic and terminal illnesses such as cancer confirm that children are able to understand and conceptualize illness at far younger ages than generally perceived and that they benefit from an open dialogue and reassurance. Recommendations for practice suggest that school-aged children can and should be told their HIV status in order to improve their access to support [81]. Disclosure can improve the parent-child relationship and the child's ability to understand and participate in HIV treatment and care. Parental, contextual and child-specific factors play an important role in the disclosure process. For the much larger group of HIV-exposed but -uninfected children, disclosure of maternal HIV status also plays an important role in the child's well-being. Some of the known benefits of disclosure for mothers living with HIV are outlined in Box 2.

However, disclosure levels among HIV-positive mothers to their uninfected children are often low (between 30 and 45%) [80], are delayed until late in childhood or early adolescence and disclosure is made more often to girl children than boy children [79]. This is a matter for concern, as high levels of HIV prevalence in sub-Saharan Africa makes it very likely that children will learn about HIV at increasingly younger ages, and delaying disclosure in such scenarios could worsen psychological and social outcomes for children. Furthermore, the heightened vulnerability of girl children in these contexts cannot afford to be further amplified, and low disclosure tends to limit exposed children's social networks and support safety nets, often with adverse consequences such as increasing the burden of care placed on children when their adult caregiver succumbs to illness [82-84]. Evidence from research on disclosure in the USA and Europe suggests that disclosure is most commonly linked to the age and gender of the child and the stage of disease or illness of the mother [79]. Few mothers will disclose before their child is 7 years of age and most will disclose by the time their child reaches 10 years of age. In terms of maternal mental health, a

mother's disclosure to children has been linked to lower anxiety and depression, higher perceived social support and family cohesion and better emotional and behavioral outcomes for children [80]. There is a distinct lack of evidence and models of practice to support disclosure in poorly resourced settings.

Future perspective

Evidence-based medical guidelines on when and how to prevent and treat HIV are increasingly clear. Family-centered approaches represent the most appropriate and cost-effective models for responding to the challenge of HIV prevention, treatment and care in poorly resourced settings. As a first priority, programs need to ensure the provision of appropriate prevention, treatment and care to women before and during pregnancy and motherhood. Furthermore, maternal and child health services need to be integrated to ensure that children have timely access to treatment and that early child development is supported. Lastly, it is essential to find ways to work with local community resources and to engage with caregivers and infants in order to provide not only for their treatment, but also their health and development, and to enhance their coping skills and, ultimately, their life opportunities.

Importantly, given the challenges that HIV introduces to the family, one of the greatest emerging opportunities for large-scale programming in poorly resourced settings is to offer humanity and sensitivity regarding the interpersonal challenges facing mothers, fathers and families at any entry point to HIV treatment and care, while still delivering effective prevention treatment and care services. Disclosure and adherence, as cornerstones of the success of ART treatment, may be supported by healthcare practitioners, but cannot exclusively occur in healthcare facilities. Instead, positive living, adjustment to treatment and longer-term adherence and coping with HIV can occur and must be supported within the day-to-day lived experiences of children, their caregivers and the families. Living positively on ART, achieving optimal adherence and dealing with the social aspects of HIV disclosure all reside in the family context. In poorly resourced contexts, the family is often invisible, absent or difficult to engage because of logistical and structural barriers and service delivery models that are often highly centralized. Evidence suggests that larger investments in decentralized family-friendly services may hold significant benefits in terms of both cost and clinical outcomes.

Acknowledgments

The Africa Centre for Health and Population Studies is funded by a core grant from the Wellcome Trust (Grant number 082384/Z/07/Z), and A Stein was supported by the Wellcome Trust (Grant number 071571) (www.wellcome.ac.uk).

Bibliography

Papers of special note have been highlighted as:

- of interest
 - ■ of considerable interest
1. Ojikutu B, Makadzange AT, Gaolathe T. Scaling up ART treatment capacity: lessons learned from South Africa, Zimbabwe, and Botswana. *Curr. Infect. Dis. Rep.* 2008; 10(1):69–73. [PubMed: 18377818]
 2. Betancourt T, Abrams E, McBain R, Fawzi M. Family-centred approaches to the prevention of mother to child transmission of HIV. *J. Int. AIDS Soc.* 2010; 13(Suppl. 2):S2. [PubMed: 20573284]

- Provides a comprehensive and recent review of family-centered approaches to HIV treatment, care and support.
- 3. Sweat MD, O'Reilly KR, Schmid GP, Denison J, De Zoysa I. Cost-effectiveness of nevirapine to prevent mother-to-child HIV transmission in eight African countries. *AIDS*. 2004; 18(12):1661–1671. [PubMed: 15280777]
- 4. Rochat TJ, Richter LM, Doll HA, Buthelezi NP, Tomkins A, Stein A. Depression among pregnant rural South African women undergoing HIV testing. *JAMA*. 2006; 295(12):1376–1378. [PubMed: 16551708]
- 5. Ngubane N, Patel D, Newell M-L, et al. Messages about dual contraception in areas of high HIV prevalence are not heeded. *S. Afr. Med. J.* 2008; 98(3):209–212. [PubMed: 18350224]
- 6. Nakayiwa S, Abang B, Packel L, et al. Desire for children and pregnancy risk behavior among HIV-infected men and women in Uganda. *AIDS Behav.* 2006; 10(Suppl. 4):95–104.
- 7. Rollins N, Mzolo S, Moodley T, Esterhuizen T, Van Rooyen H. Universal HIV testing of infants at immunization clinics: an acceptable and feasible approach for early infant diagnosis in high HIV prevalence settings. *AIDS*. 2009; 23(14):1851–1857. [PubMed: 19491653]
- 8. Becquet R, Bland R, Leroy V, et al. Duration, pattern of breastfeeding and postnatal transmission of HIV: pooled analysis of individual data from West and South African cohorts. *PLoS One*. 2009; 4(10):E7397. [PubMed: 19834601]
- 9. Ndlovu V. Considering childbearing in the age of highly active antiretroviral therapy (HAART): views of HIV-positive couples. *SAHARA J.* 2009; 6(2):58–68. [PubMed: 19936407]
- 10. Smee N, Shetty AK, Stranix-Chibanda L, et al. Factors associated with repeat pregnancy among women in an area of high HIV prevalence in Zimbabwe. *Womens Health Issues*. 2011; 21(3):222–229. [PubMed: 21411336]
- 11. Sherr L. Fathers and HIV: considerations for families. *J. Int. AIDS Soc.* 2010; 13(Suppl. 2):S4. [PubMed: 20573286]
- 12. Harrison A, Newell M-L, Imrie J, Hoddinott G. HIV prevention for South African youth: which interventions work? A systematic review of current evidence. *BMC Public Health*. 2010; 10(1): 102. [PubMed: 20187957]
- 13. John FN, Farquhar C, Kiarie JN, Kabura MN, John-Stewart GC. Cost effectiveness of couple counselling to enhance infant HIV-1 prevention. *Int. J. STD AIDS*. 2008; 19(6):406–409. [PubMed: 18595879]
- 14. Gallant M, Maticka-Tyndale E. School-based HIV prevention programmes for African youth. *Soc. Sci. Med.* 2004; 58(7):1337–1351. [PubMed: 14759680]
- 15. Mnyani CN, McIntyre JA. Preventing mother-to-child transmission of HIV. *BJOG*. 2009; 116(Suppl. 1):71–76. [PubMed: 19740178]
- 16. Katz DA, Kiarie JN, John-Stewart GC, Richardson BA, John FN, Farquhar C. Male perspectives on incorporating men into antenatal HIV counseling and testing. *PLoS One*. 2009; 4(11):E7602. [PubMed: 19881884]
- 17. Desgrees-Du-Lou A, Brou H, Djohan G, et al. Beneficial effects of offering prenatal HIV counselling and testing on developing a HIV preventive attitude among couples. Abidjan, 2002–2005. *AIDS Behav.* 2009; 13(2):348–355. [PubMed: 17985231]
- 18. Traore, A Tijou; Querre, M.; Brou, H.; Leroy, V.; Desclaux, A.; Desgrees-Du-Lou, A. Couples, PMTCT programs and infant feeding decision-making in Ivory Coast. *Soc. Sci. Med.* 2009; 69:830–837. [PubMed: 19586699]
- 19. Semrau K, Kuhn L, Vwalika C, et al. Women in couples antenatal HIV counseling and testing are not more likely to report adverse social events. *AIDS*. 2005; 19:603–609. [PubMed: 15802979]
- 20. Katz DA, Kiarie JN, John-Stewart GC, Richardson BA, John FN, Farquhar C. HIV testing men in the antenatal setting: understanding male non-disclosure. *Int. J. STD AIDS*. 2009; 20(11):765–767. [PubMed: 19833691]
- 21. Catalan J. Psychological interventions in infection with the human immunodeficiency virus. *Br. J. Psychiatry*. 1995; 167(1):104–111. [PubMed: 7551590]
- 22. Maheswaran H, Bland R. Preventing mother-to-child transmission of HIV in resource-limited settings. *Future Virol.* 2009; 4(2):165–175. ■■ Provides a detailed review that is relevant to researchers and practitioners working in resource-limited settings.

23. Rollins N, Little K, Mzolo S, Horwood C, Newell ML. Surveillance of mother-to-child transmission prevention programmes at immunization clinics: the case for universal screening. *AIDS*. 2007; 21(10):1341–1347. [PubMed: 17545711]
24. Katz D, Kiarie J, John-Stewart G, Richardson B, John F, Farquhar C. HIV testing men in the antenatal setting: understanding male non-disclosure. *Int. J. STD AIDS*. 2009; 20:765–767. [PubMed: 19833691]
25. Coovadia H. Current issues in prevention of mother-to-child transmission of HIV-1. *Curr. Opin. HIV AIDS*. 2009; 4(4):319–324. [PubMed: 19532071] ■ ■ Summarizes current scientific evidence leading to the recent revisions of WHO guidelines for HAART during pregnancy and infant feeding.
26. McPake B, Mensah K. Task shifting in health care in resource-poor countries. *Lancet*. 2008; 372(9642):870–871. [PubMed: 18790295]
27. Selke HM, Kimaiyo S, Sidle JE, et al. Task-shifting of antiretroviral delivery from health care workers to persons living with HIV/AIDS: clinical outcomes of a community-based program in Kenya. *J. Acquir. Immune Defic. Syndr*. 2010; 55(4):483–490. [PubMed: 20683336]
28. Rajaraman D, Palmer N. Changing roles and responses of health care workers in HIV treatment and care. *Trop. Med. Int. Health*. 2008; 13(11):1357–1363. [PubMed: 19055620]
29. Lazarus R, Struthers H, Violari A. Hopes, fears, knowledge and misunderstandings: responses of HIV-positive mothers to early knowledge of the status of their baby. *AIDS Care*. 2009; 21(3):329–334. [PubMed: 19280410]
30. Sherr L, Bergenstrom A, Hudson N. Consent and antenatal HIV testing: the limits of choice and issues of consent in HIV and AIDS. *AIDS Care*. 2000; 12(3):307–312. [PubMed: 10928208]
31. De Bruyn M, Paxton S. HIV testing of pregnant women – what is needed to protect positive women’s needs and rights? *Sexual Health*. 2005; 2(3):143–151. [PubMed: 16335542]
32. De Zulueta P, Boulton M. Routine antenatal HIV testing: the responses and perceptions of pregnant women and the viability of informed consent. A qualitative study. *J. Med. Ethics*. 2007; 33(6):329–336. [PubMed: 17526682]
33. Ketchen B, Armistead L, Cook S. HIV infection, stressful life events, and intimate relationship power: the moderating role of community resources for black South African women. *Women Health*. 2009; 49(2–3):197–214. [PubMed: 19533510]
34. Jewkes RK, Dunkle K, Nduna M, Shai N. Intimate partner violence, relationship power inequity, and incidence of HIV infection in young women in South Africa: a cohort study. *Lancet*. 2010; 376(9734):41–48. [PubMed: 20557928]
35. Jewkes R, Nduna M, Levin J, et al. A cluster randomized-controlled trial to determine the effectiveness of Stepping Stones in preventing HIV infection and promoting safer sexual behaviour amongst youth in the rural Eastern Cape, South Africa: trial design, methods and baseline findings. *Trop. Med. Int. Health*. 2006; 11(1):3–16. [PubMed: 16398750]
36. Jewkes R, Nduna M, Levin J, et al. Impact of stepping stones on incidence of HIV and HSV-2 and sexual behaviour in rural South Africa: cluster randomised controlled trial. *BMJ*. 2008; 337:A506. [PubMed: 18687720]
37. Mugore L, Engelsmann B, Ndoro T, Dabis F, Perez F. An assessment of the understanding of the offer of routine HIV testing among pregnant women in rural Zimbabwe. *AIDS Care*. 2008; 20(6):660–666. [PubMed: 18576167]
38. Sandelowski M, Barroso J. Toward a metasynthesis of qualitative findings on motherhood in HIV-positive women. *Res. Nurs. Health*. 2003; 26(2):153–170. [PubMed: 12652611]
39. Chibanda D, Mangezi W, Tshimanga M, et al. Postnatal depression by HIV status among women in Zimbabwe. *J. Womens Health*. 2010; 19(11):2071–2077.
40. Patel R, Kassaye S, Gore-Felton C, et al. Quality of life, psychosocial health, and antiretroviral therapy among HIV-positive women in Zimbabwe. *AIDS Care*. 2009; 21(12):1517–1527. [PubMed: 20024731]
41. Pereira M, Canavarro MC. Relational contexts in adjustment to pregnancy of HIV-positive women: relationships, social support and personal adjustment. *AIDS Care*. 2009; 21(3):301–308. [PubMed: 19280407]

42. Catalan J, Pugh K. Suicidal behaviour and HIV infection – is there a link? *AIDS Care*. 1995; 7(Suppl. 2):S117–S121. [PubMed: 8664351]
43. Leiberich P, Engeter M, Olbrich E, et al. Longitudinal development of distress, coping and quality of life in HIV-positive persons. *Psychother. Psychosom*. 1997; 66(5):237–247. [PubMed: 9311027]
44. Richter LM, Sherr L, Adato M, et al. Strengthening families to support children affected by HIV and AIDS. *AIDS Care*. 2009; 21(Suppl. 1):3–12. [PubMed: 22380973]
45. Abrams E, Myer L, Rosenfield A, El-Sadr W. Prevention of mother-to-child transmission services as a gateway to family-based human immunodeficiency virus care and treatment in resource-limited settings: rationale and international experiences. *Am. J. Obstet. Gynecol*. 2007; 197:S101–S106. [PubMed: 17825640]
46. Countdown Coverage Writing Group; Countdown to 2015 Core Group. Bryce J, Daelmans B, Dwivedi A, et al. Countdown to 2015 for maternal, newborn, and child survival: the 2008 report on tracking coverage of interventions. *Lancet*. 2008; 371(9620):1247–1258. [PubMed: 18406859]
47. Richter LM, Sherr L, Adato M, et al. Strengthening families to support children affected by HIV and AIDS. *AIDS Care*. 2009; 21(1 Suppl. 1):3–12. [PubMed: 22380973]
48. Cooke GS, Little KE, Bland RM, Thulare H, Newell ML. Need for timely paediatric HIV treatment within primary health care in rural South Africa. *PLoS One*. 2009; 4(9):E7101. [PubMed: 19771168]
49. Violari A, Cotton MF, Gibb DM, et al. Early antiretroviral therapy and mortality among HIV-infected infants. *N. Engl. J. Med*. 2008; 359(21):2233–2244. [PubMed: 19020325]
50. Janssen N, Ndirandgu J, Newell M, Bland R. Successful paediatric HIV treatment in rural primary care in Africa. *Arch. Dis. Child*. 2010; 95(6):414–421. [PubMed: 19880392]
51. Sutcliffe CG, Van Dijk JH, Bolton C, Persaud D, Moss WJ. Effectiveness of antiretroviral therapy among HIV-infected children in sub-Saharan Africa. *Lancet Infect. Dis*. 2008; 8(8):477–489. [PubMed: 18652994]
52. Bolton-Moore C, Mubiana-Mbewe M, Cantrell RA, et al. Clinical outcomes and CD4 cell response in children receiving antiretroviral therapy at primary health care facilities in Zambia. *JAMA*. 2007; 298(16):1888–1899. [PubMed: 17954540]
53. Coovadia H, Bland R. From Alma-Ata to Agincourt: primary health care in AIDS. *Lancet*. 2008; 372(9642):866–868. [PubMed: 18790293]
54. Newell ML, Coovadia H, Cortina-Borja M, Rollins N, Gaillard P, Dabis F. Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: a pooled analysis. *Lancet*. 2004; 364(9441):1236–1243. [PubMed: 15464184]
55. Sherr L, Mueller J, Varrall R. A systematic review of cognitive development and child human immunodeficiency virus infection. *Psychol. Health Med*. 2009; 14(4):387–404. [PubMed: 19697250] ■ Outlines current evidence of the effects of HIV on child development. Provides useful summary tables of evidence.
56. Stein A, Krebs G, Richter L, Tomkins A, Rochat T, Bennish ML. Babies of a pandemic. *Arch. Dis. Child*. 2005; 90(2):116–118. [PubMed: 15665160]
57. Martin SC, Wolters PL, Toledo-Tamula MA, Zeichner SL, Hazra R, Civitello L. Cognitive functioning in school-aged children with vertically acquired HIV infection being treated with highly active antiretroviral therapy (HAART). *Dev. Neuropsychol*. 2006; 30(2):633–657. [PubMed: 16995830]
58. Shanbhag MC, Rutstein RM, Zaoutis T, Zhao H, Chao D, Radcliffe J. Neurocognitive functioning in pediatric human immunodeficiency virus infection: effects of combined therapy. *Arch. Pediatr. Adolesc. Med*. 2005; 159(7):651–656. [PubMed: 15996999]
59. Wolters PL, Brouwers P, Moss HA, Pizzo PA. Adaptive behavior of children with symptomatic HIV infection before and after zidovudine therapy. *J. Pediatr. Psychol*. 1994; 19(1):47–61. [PubMed: 8151495]
60. Koekkoek S, Eggermont L, De Sonnevle L, et al. Effects of highly active antiretroviral therapy (HAART) on psychomotor performance in children with HIV disease. *J. Neurol*. 2006; 253(12):1615–1624. [PubMed: 17093898]

61. Esposito S, Musetti L, Musetti MC, et al. Behavioral and psychological disorders in uninfected children aged 6 to 11 years born to human immunodeficiency virus-seropositive mothers. *J. Dev. Behav. Pediatr.* 1999; 20(6):411–417. [PubMed: 10608370]
62. Mellins CA, Brackis-Cott E, Leu CS, et al. Rates and types of psychiatric disorders in perinatally human immunodeficiency virus-infected youth and seroreverters. *J. Child. Psychol. Psychiatry.* 2009; 50(9):1131–1138. [PubMed: 19298479]
63. Zeegers I, Rabie H, Swanevelder S, Edson C, Cotton M, Van Toorn R. Attention deficit hyperactivity and oppositional defiance disorder in HIV-infected South African children. *J. Trop. Pediatr.* 2010; 56(2):97–102. [PubMed: 19656842]
64. Stein A, Lehtonen A, Harvey AG, Nicol-Harper R, Craske M. The influence of postnatal psychiatric disorder on child development. Is maternal preoccupation one of the key underlying processes? *Psychopathology.* 2009; 42(1):11–21. [PubMed: 19023230] ■ Provides a detailed review of the evidence in support of the effect of caregiving on child development. This article provides a readable overview for the nonspecialist reader.
65. Bolton P, Bass J, Betancourt T, et al. Interventions for depression symptoms among adolescent survivors of war and displacement in northern Uganda: a randomized controlled trial. *JAMA.* 2007; 298(5):519–527. [PubMed: 17666672]
66. Cooper PJ, Tomlinson M, Swartz L, et al. Improving quality of mother-infant relationship and infant attachment in socioeconomically deprived community in South Africa: randomised controlled trial. *BMJ.* 2009; 338:B974. [PubMed: 19366752]
67. Rahman A, Iqbal Z, Roberts C, Husain N. Cluster randomized trial of a parent-based intervention to support early development of children in a low-income country. *Child Care Health Dev.* 2009; 35(1):56–62. [PubMed: 18991970]
68. Bock P, Boulle A, White C, Osler M, Eley B. Provision of antiretroviral therapy to children within the public sector of South Africa. *Trans. R. Soc. Trop. Med. Hyg.* 2008; 102(9):905–911. [PubMed: 18656217]
69. Davies MA, Boulle A, Fakir T, Nuttall J, Eley B. Adherence to antiretroviral therapy in young children in Cape Town, South Africa, measured by medication return and caregiver self-report: a prospective cohort study. *BMC Pediatr.* 2008; 8:34. [PubMed: 18771599]
70. Eley BS. Antiretroviral therapy during infancy: essential intervention for resource-limited settings. *Expert Rev. Anti Infect. Ther.* 2008; 6(5):585–589. [PubMed: 18847398]
71. Reddi A, Leeper SC, Grobler AC, et al. Preliminary outcomes of a paediatric highly active antiretroviral therapy cohort from KwaZulu-Natal, South Africa. *BMC Pediatr.* 2007; 7:13. [PubMed: 17367540]
72. Van Griensven J, De Naeyer L, Uwera J, Asiimwe A, Gazille C, Reid T. Success with antiretroviral treatment for children in Kigali, Rwanda: experience with health center/nurse-based care. *BMC Pediatr.* 2008; 8:39. [PubMed: 18831747]
73. Simoni JM, Amico KR, Pearson CR, Malow R. Strategies for promoting adherence to antiretroviral therapy: a review of the literature. *Curr. Infect. Dis. Rep.* 2008; 10(6):515–521. [PubMed: 18945394]
74. Simoni JM, Montgomery A, Martin E, New M, Demas PA, Rana S. Adherence to antiretroviral therapy for pediatric HIV infection: a qualitative systematic review with recommendations for research and clinical management. *Pediatrics.* 2007; 119(6):E1371–E1383. [PubMed: 17533177] ■ Provides a useful review of the existing evidence regarding pediatric adherence, and contains a helpful set of research and practice recommendations.
75. Haberer J, Mellins C. Pediatric adherence to HIV antiretroviral therapy. *Curr. HIV/AIDS Rep.* 2009; 6:194–200. [PubMed: 19849962]
76. Simoni JM, Pearson CR, Pantalone DW, Marks G, Crepaz N. Efficacy of interventions in improving highly active antiretroviral therapy adherence and HIV-1 RNA viral load. A meta-analytic review of randomized controlled trials. *J. Acquir. Immune Defic. Syndr.* 2006; 43(Suppl. 1):S23–S35. [PubMed: 17133201]
77. Gerson AC, Joyner M, Fosarelli P, et al. Disclosure of HIV diagnosis to children: when, where, why, and how. *J. Pediatr. Health Care.* 2001; 15(4):161–167. [PubMed: 11462122]

78. Lesch A, Swartz L, Kagee A, et al. Paediatric HIV/AIDS disclosure: towards a developmental and process-oriented approach. *AIDS Care*. 2007; 19(6):811–816. [PubMed: 17573602]
79. Hawk ST. Disclosures of maternal HIV infection to seronegative children: a literature review. *J. Soc. Pers. Relat.* 2007; 24(5):657–673. ■ ■ Comprehensive review examining the effects of and reasons for disclosure and nondisclosure among mothers. This article provides a detailed review of the evidence on both the processes for and the consequences of disclosure for both mother and child.
80. Murphy DA. HIV-positive mothers' disclosure of their serostatus to their young children: a review. *Clin. Child. Psychol. Psychiatry*. 2008; 13(1):105–122. [PubMed: 18411869] ■ ■ Detailed review examining what has been learnt from intervention studies on disclosure. Reports on the factors known to influence decisions to disclose, examines the effects of both disclosure and nondisclosure and the factors influencing children's reactions to disclosure.
81. Naeem-Sheik A, Gray G. HIV disclosure in children. *S. Afr. J. HIV Med.* 2005; 21:46–48. ■ ■ Useful set of clinicians guidelines for HIV disclosure to children who are infected with HIV. Includes a summary of the recommendations of the American Academy of Pediatrics and offers advice on what to expect in response to disclosure and how to manage disclosure in healthcare settings.
82. Cluver L, Gardner F, Operario D. Poverty and psychological health among AIDS-orphaned children in Cape Town, South Africa. *AIDS Care*. 2009; 21(6):732–741. [PubMed: 19806489]
83. Cluver L, Orkin M. Cumulative risk and AIDS-orphanhood: interactions of stigma, bullying and poverty on child mental health in South Africa. *Soc. Sci. Med.* 2009; 69(8):1186–1193. [PubMed: 19713022]
84. Cluver LD, Gardner F, Operario D. Effects of stigma on the mental health of adolescents orphaned by AIDS. *J. Adolesc. Health*. 2008; 42(4):410–417. [PubMed: 18346667]

Websites

101. WHO. Rapid advice: use of antiretroviral drugs for treating pregnancy women and preventing HIV infection in infants. 2010. www.who.int/hiv/pub/guidelines/en
102. WHO. HIV and infant feeding. 2010. www.who.int/hiv/pub/mtct/advice/en
103. Richter, L. The importance of caregiver–child interactions for the survival and healthy development of young children: a review. 2004. www.who.int/child_adolescent_health/documents/924159134X/en

Box 1**Strategies to improve early diagnosis of HIV-infected children**

- Educate and provide counseling to all HIV-infected mothers and fathers on the importance of early testing for HIV of their infants, support laboratory systems to ensure results are processed in a timely manner and encourage caregivers to ask for test results, while encouraging staff to provide such results
- Ensure that all HIV-exposed infants have a PCR test taken at approximately 6 weeks of age (where this test is available) and after cessation of breastfeeding, and that families know the reason for the test, receive adequate counseling and preparation and are given results
- Check that caregivers of all HIV-exposed infants who have had a PCR test taken are given the results at subsequent clinic visits and that HIV-infected children are immediately referred for treatment
- Immediately refer infants (<12 months of age) confirmed to be HIV infected for treatment preparation and initiation, including proper counseling of caregivers/guardians
- Use every visit to a health facility as an opportunity to assess the HIV status of children, and ensure continuity of information in relation to child status across healthcare interactions and settings using 'Road to Health' or 'Under-Five Clinic' cards
- Use clinic or community immunization and vitamin A campaigns to assess the HIV status of all children
- Encourage provider-initiated counseling and testing of children admitted to hospital
- Forge closer links between TB, malnutrition and HIV services, ensuring that all children with TB and/or malnutrition are tested for HIV
- Forge closer links between adult services so that all children of HIV-infected parents are included in service provision, from the provision of HIV testing to treatment and care

Box 2**Benefits of disclosure for mothers living with HIV**

- Mothers' disclosure to children has been linked to lower anxiety and depression and to higher perceived social support and family cohesion [79,80]
- Disclosure alleviates stress regarding the need to hide physical and emotional functioning and allows older children to participate in future decision making [79]
- Recommended treatments for HIV may require changes in lifestyle and family communication that benefit mothers [79]
- Children can be a major motivation for mothers to increase their longevity [79,80]
- After learning their diagnoses, many mothers focus on reducing their own health-risk behaviors and improving family relationships [79,80]
- Mothers perceive better relations with children following disclosure, citing more closeness, expressed affection and supportive behaviors to their children [80]

Executive summary

A new era of antiretroviral therapy in poorly resourced settings

- The progress emerging from a growing number of antiretroviral treatment (ART) cohorts is encouraging, suggesting that concerns over patient adherence, the development of resistance and cost and operational limitations should not be allowed to dominate or delay the provision of life-saving ART for those who need it.
- In light of this, there are opportunities to develop family-centered approaches to treatment and care towards the successful delivery of HIV treatment, care and support.

Family planning, antenatal care & prevention

- Scientific evidence and clear guidelines exist to support the importance of primary prevention, improvements in the effectiveness of vertical transmission and the safety of breastfeeding for women in developing-country contexts.
- A broad-based approach to preventing mother-to-child transmission can and needs to be cost-effective and promote the integration and scaling-up of health facilities.
- Family planning and preventative services need to more effectively target sexually active adults, including men and adolescents, and should include family-centered approaches that engage male partners and consider the childbearing aspirations of HIV-positive couples.

Postnatal prevention, treatment & care

- It is critical to strengthen the links between prevention of mother-to-child transmission programs and maternal and child health services, ensuring that all HIV-exposed children are tested for HIV early, that parents are counseled and prepared for testing and treatment initiation, that results are available, that children are referred in good time and that mothers and fathers themselves receive appropriate follow-up and support.
- Early care and prevention needs to consider the important developmental milestones of early childhood, and family-centered programs need to support HIV-infected parents to improve their mental health and ensure adequate and sensitive child care. Early child development stimulation programs and rehabilitative services for HIV-infected children receiving ART need to be integrated into HIV treatment services.

Adherence, disclosure & support

- Initial indications suggest that adherence to ART is good, although challenges are likely to emerge as treatment programs mature and patients begin to deal with longer-term management of treatment and treatment fatigue.
- Increased disclosure of HIV status has benefits for both HIV-infected children and HIV-exposed but -uninfected children, and guidelines for health practitioners and parents need to be developed to support increased age-appropriate and supportive disclosure practices.
- Current models of practice regarding adherence and disclosure support most commonly focus on healthcare centers and practitioners as modes of delivery. Adherence and disclosure support should also be delivered and supported within the family context.