

Chapter 13

Vertical transmission of HIV – Pregnancy and Infant Issues

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13.1 HIV Prevention in Pregnancy

HIV/AIDS responses during pregnancy can maximally help in terms of prevention treatment and care. Such interventions mark an opportunity for multidisciplinary action enhanced by a truly integrated approach. Pregnancy marks a point where couple relationships are paramount, a point where all provisions for the new infant are concentrated and a point where biomedical and psychosocial models converge. It also typifies the challenge facing the future evolution of HIV/AIDS strategies and a possible turning point in prevention with dramatic long-term ramifications.

In 1996, the dramatic findings of the 076 trial (Connor et al., 1994) revealed the efficacy of antiretroviral treatment in preventing transmission of HIV from mother to child. This marked a turning point in HIV prevention. Yet this intervention has been slow in global implementation with marked barriers created by inadequate responses, political barriers, simplistic models and misunderstandings. This biomedical intervention brought with it a multitude of questions that required a multidisciplinary approach. These included issues around HIV testing in pregnancy, facilitators and barriers to test uptake, treatment uptake and adherence, counselling around decision making, uncertainty, adjustment, behavioural and understanding parenting. This chapter will review many of the complex factors around HIV in pregnancy with a specific focus on psychosocial factors. It will provide an overview of transmission, HIV testing, HIV in pregnancy, interventions and many of the challenging considerations that HIV raises for the mother, the father and the infant. These include consent, decision making, infant feeding, bereavement and the difficult issues associated with gender and young children that are highlighted when HIV and reproduction are considered. Finally some comment on the contribution of social science to understanding the full complexity of the problem will be highlighted.

13.2 HIV Transmission to the Baby ‘Vertical Transmission’

It is well established that HIV infection can occur vertically. This can happen during pregnancy, delivery or post-partum, notably via breast feeding. Most infant infections occur in this way (Gray and McIntyre 2007). The risk of transmission in untreated women is related to maternal health (especially viral load), obstetric factors especially mode of delivery, time between membrane rupture and birth, and infant factors such as premature birth (De Ruiter et al., 2008). Although there is great concentration of interventions and knowledge around the time of pregnancy, it is important that a longer-term view is taken of infant prevention in that prevention of HIV infection to women in the first place would directly reduce rates of infant exposure to HIV. This must clearly be part of a comprehensive HIV prevention response. In addition, the issues of family planning and fertility control also need consideration in that the prevention of unintended pregnancies in women generally, and HIV-positive women specifically, should feature as a component of a comprehensive response to HIV prevention in transmission. Indeed, a recent study (Dube et al., 2008) showed that in Zimbabwe declining maternal HIV prevalence was the major driver of reduced vertical transmission despite the presence of a single-dose Nevirapine programme. These works, utilising complex mathematical models, show that a more efficacious and complex regimen may have doubled the number of averted infections (Dube et al., 2008).

Without any intervention, the rate of HIV transmission to newborns has varied from 13 to 45% in international studies (Sherr, 2005). This variation is difficult to explain and may be a complex effect of stage of infection, background health factors, timing of exposure, virus strain, biomedical factors in both the mother and infant and nature of exposure. It is also well established that the majority of infant infections occur through vertical transmission (Little et al., 2008). Approaches which include the utilisation of combination antiretroviral therapy, elective caesarean section and breastfeeding avoidance all contribute to much reduced transmission –2% or lower, in environments where all avenues are available (ECS, 2005). The setting may define the relative safety of interventions such as caesarean sections and avoidance of breastfeeding, and the current knowledge base on the relative benefits and hazards of these interventions is complex. A number of recommendations have provided for reduced intervention packages in resource or facility constrained environments. Although these have been effective in reducing transmission, there are confounding problems of resistance, elevated transmission and uptake (WHO, 2006; Gray and McIntyre, 2007).

13.3 Antiretroviral Treatment in Pregnancy

Antiretroviral treatment in pregnancy has revolutionised the prognosis and marked substantial policy changes and developments. As early as 1994 the ACTG 076 trial demonstrated that antiretroviral treatment reduced infant infection (Connor et al.,

1994). Since the 076 trial the treatment has evolved and been refined. The nature of the regimen, the duration, initiation and consequences vary and has been well studied. The efficacy of ART for prevention of vertical transmission of HIV has been reported in numerous studies in a variety of settings in low-, middle- and high-income countries (Lallemant, 2000; Lallemant et al., 2004; Mandelbrot et al., 2001). Efficacy seems to vary according to breastfeeding, type of regimen, number of compounds, adherence and timing. Although transmission to infants has been lowered, it has not been eliminated (Dabis et al., 1999; Guay et al., 1999; Jackson et al., 2003; Leroy, 2003; Leroy et al., 2002; Petra study group, 2002; Wiktor et al., 1999). The findings of a number of key studies are summarised below by way of example of variation, setting and outcome (Table 13.1). Psychological considerations relate to uptake, adherence and concerns around the effects of treatment on the mother and the infant.

As medical intervention and treatment are efficacious, availability, testing and access rights have been a challenge (Hudson et al., 1999). As a result, many countries have operationalised programmes to offer HIV testing to all pregnant women, with the idea of identifying positive pregnant women and providing treatment (Suk-somboon et al., 2007). This straightforward strategy, however, is fraught with policy and implementation challenges (JLICA 2008). Clearly the successful implementation of this strategy, in its fullest form, is the single-most dramatic intervention currently available to prevent children from being infected with HIV, and as an entry for mothers (and fathers) into treatment and support programmes. In Europe, over the period 1997–2003, HIV-positive women have been provided with antiretroviral treatment at an accelerated rate from 5 to 92% (European Collaborative Study, 2005). Transmission rates have been reduced to 0.99% in Europe (European Collaborative Study, 2005), and 2% in the USA (Mofenson, 2004). However, in low- and middle-income countries such programmes have not achieved universal coverage. HIV testing in pregnancy varies dramatically according to resources and by 2007 only 34% of those eligible to receive antiretroviral treatment actually did (UNAIDS, 2008). This figure may be a gross overestimation as it is directly affected by the success of HIV testing programmes and only refers to known HIV-positive pregnant women.

Future concerns around treatment need to be considered in ongoing monitoring, and as the evidence base develops policy and practice should evolve (Coovadia and Schaller, 2008). Issues that require long-term monitoring include logging and monitoring any toxicities, heightened pre-eclampsia in the presence of treatment, abnormalities, long-term effects on those born to be HIV negative and birthweight.

13.4 Mode of Delivery

Early twin studies showed that both infants were not necessarily infected. This led researchers to highlight the timing of infection around delivery and proposed that elective caesarean section may avoid infection. Trials of this procedure showed, indeed, a significant protective effect. However, in the presence of antiretroviral

Table 13.1 Studies of interventions to reduce vertical transmission

Study	Regimen	Initiation/duration	Efficacy	Consequences
Connor et al., 1994	AZT	36 weeks	65% reduction	First trial
WHO, 2006	ART triple therapy (AZT,3TC, NVP)	28 weeks	<2%	Variation depending on maternal CD4 count (<or>350 cells/mm
Cooper et al., 2002				Resistance offset by AZT/3TC tail
HIVNET 012	Single dose NVP	Onset of labour	8.1%	Needs to be taken >2 hours before birth.
Jackson et al., 2003		Single dose to infant		45% NVP resistance in infants (Martinson 2006) and mothers (Shapiro 2006)
ANNECCA 2006 (Modified Thai)	AZT	34–36 weeks initiation and hourly during labour. Infant 7-day regiment	4.7–10.5%	
Lallemant 2000, Shaffer 1999				
Partners in Health	Triple therapy AZT, 3TC NVP	28 weeks, 14-day AZT/3TC tail post-partum	<2%	Good history and variations according to clinical status, previous exposure to antiretroviral treatment and time of presentation
Cooper et al. 2002		7-day AZT to infant		
Lallemant et al., 2004	AZT, NVP	28 weeks, 3 hourly AZT in labour and NVP at onset. 7 day AZT and single dose NVP to infant.	2.8%	Extended infant treatment if mother presents late and has reduced treatment.
Shapiro et al., 2006	AZT and NVP	34 weeks start and NVP in labour. Infants AZT 1 month and single-dose NVP birth.	4.3%	NVP resistance -- strategy of targeting infants only for NVP to reduce maternal resistance
WHO and PIH Cooper, 2002	ART (AZT,3TC, NVP)	28 weeks. AZT 3 hourly 7-day AZT and 3TC and single-dose NVP to infant	<2%	Variation depending on time of presentation and treatment to mother.

treatment, this effect is now unclear and it would be difficult to have a sufficiently powered trial to address this question, given the very low transmission rates in the presence of treatment. In a developing setting, surgical delivery may have special considerations based on availability of subsequent treatment, infection risk and hospital provision. Furthermore, complex issues of psychological ramifications of caesarean section on the mother need to be considered.

13.5 Infant Feeding

Currently, there is also debate around the best way to manage risk of infection via breastfeeding. Many options have been considered, including recommendations to avoid breastfeeding, exclusive breastfeeding, early weaning or treatment of the mother during lactation to reduce the chances of transmission to the infant. There is a balance between the availability of options, the social pressures and benefits of breastfeeding and the desire to avoid or minimise this route of transmission. Early recommendations that suggested avoidance of breastfeeding in the west with different suggestions for resource poor settings entrenched the problems rather than solving them. Currently, there is still much debate and the benefits of breastfeeding, especially for an ill infant are weighed in the balance. Breastfeeding is an emotive topic and any interventions must consider such cultural and emotional factors if they are to resonate with women (Coovadia et al., 2008).

13.6 Contribution of Social Science

Although the basic medical intervention may be relatively straightforward, social science has shed light on many of the complexities around initiating PMTCT programmes and understanding the wide implications of HIV in pregnancy. The intervention seems straightforward: identify all pregnant women with HIV, administer prevention medication and ensure a number of risks are avoided such as breast feeding. The reality is much more complex. Social science has shown the complexities of operationalising HIV testing in pregnancy. It has pointed out the many barriers to test uptake and provided insight into counselling which may facilitate the process as well as address risk behaviour in a broader public health model of provision. Once tested for HIV, social science has provided some insight into the experience of HIV diagnosis especially in terms of emotional trauma, stigma and relationship strains. Furthermore, studies have shown which factors are associated with treatment uptake and thereby point out pathways to enhance uptake and ameliorate the burden of HIV. Much of the current PMTCT model is individually based with a perspective from either the pregnant woman or the infant. However, social science has clearly pointed to the family-based nature of HIV infection and provided a model of provision and care based on a family perspective. Both mental health and cognitive development are relatively neglected areas.

13.7 HIV Testing as the First Step in Prevention

Intervention availability is contingent on establishing HIV status. Thus HIV testing has been integrated into routine pregnancy care and quite considerable attention has been paid to mechanisms of offer, patient entitlement, type of testing, type of counselling and efforts to extend the reach of HIV diagnosis in or before pregnancy. Historically, all HIV testing was accompanied by pre- and post-test counselling. This was seen as a vital component for various reasons. The test itself may potentially signify a lifelong and fatal condition, preparation for the test may enhance coping and adjustment, understanding risk and introduction of prevention and future risk avoidance was seen as opportune.

The policy rollout of antenatal HIV testing and treatment seems to have two major limitations. The first is that it has failed to be comprehensively rolled out in those settings where the epidemic is most severe. And the second is that it is a narrow-focused strategy which overlooks parents and family in treatment. It thereby contributes little to the long-term sustainability of intact families, HIV prevention and HIV treatment through family networks. At the same time, individually oriented services mark women out with diagnosis, stigma, trauma and unmet provision (Sherr et al., 2008).

Treatment is contingent on establishing HIV status, either pre-pregnancy or in early pregnancy (Bergenström et al., 1999). For treatment to work it needs to be available, introduced and accepted. The science around the exact compounds and the regime of administration is not fully established (Dabis et al., 2000; Jackson et al., 2003; Petra study group, 2002). In addition to preventing HIV infection to the baby (primary prevention), treatment of the mother represents urgent secondary prevention. This will ensure her ongoing good health and keep the family intact, which is of fundamental importance to a developing child. This has been clearly established as policy, but is often not reflected in current practice (BHIVA, 2007; WHO, 2006). As HIV can be transmitted during breastfeeding, there is a need to continue prevention efforts until the baby is weaned. In resource-poor settings, this is a challenge. There is a hiatus in clear, implementable recommendations, and the challenges around breastfeeding have still not been resolved (Coovadia and Kindra, 2008).

Treatment for the infant only is short sighted. Many of the regimes still rely on one compound, despite the fact that it is well established that exposure to monotherapy affects efficacy and resistance development (Phillips et al., 2002; Arrivé et al., 2007). This remains problematic in terms of the regimens on offer for many pregnant women. Current state-of-the-art provision relies on combination therapy (De Ruiter et al., 2008).

13.8 Situation in Sub-Saharan Africa and South Africa

Given the high HIV prevalence in women and infants in South Africa, a number of programmes have been initiated and monitored. These clearly demonstrate the need

for evidence-based evolution in policy and reveal the efficacy of roll out in many settings. A number of delays have impeded the full roll-out treatment in South Africa (Lancet, 2008). Yet roll out seems feasible as shown by Geddes et al. (2008) who describe a comprehensive service offered to 2,624 pregnant women in a Durban state-aided hospital where all received HIV counselling and 91% tested for HIV. Thirteen percent were HIV positive and 89% completed their delivery at the hospital. Furthermore, this study managed to reach 668 partners for HIV testing. Interventions resulted in 70% caesarean section deliveries and 98% roll out of Neviripine. Seventy-five percent also were given AZT. At 6-week follow-up, 81% of infants were given a polymerase chain reaction test revealing a transmission rate (of those tested) of 2.9%. Government policies in South Africa marked a severe interruption to provision for infant prevention.

13.9 Psychological Considerations

For all women, it is well documented that an HIV diagnosis has a profound emotional impact. Knowledge of status affects mood, relationships, social functioning, legal and human rights. This is compounded by the fact that for many women HIV diagnosis comes during pregnancy, which brings with it urgent decisions, complex adjustment and a need for quality medical support. Kwambota (2002) in Zambia noted heightened psychological trauma for those diagnosed during pregnancy compared to those who knew their status prior to conception. In South Africa, Rochat et al. (2006) have documented heightened levels of depression in HIV-positive pregnant women. Psychological provision in terms of therapy, response and programme integration varies according to the skill base, the availability of time and resources, the historical provision of mental health services and the quality of services. Psychological need and effects do not seem to differ dramatically between women in very different settings; however, resources to provide and respond to these do differ.

13.10 Reproductive and Sexual Health Counselling for all HIV-Positive women

Studies have shown that HIV infection disrupts sexual functioning (Bell et al., 2006; Florence et al., 2004; Keegan et al., 2005). Brown and Rundell (1993) in a small study of 20 women noted lowered sexual drive and decreased frequency of sex, with 50% of the sample abstinent. In a follow-up study, Brown showed that 32% of their sample reported reduced sexuality on entry and 33% showed similar findings after more than 2 years follow-up. The loss of joy was seen as chronic in a third of women. Hankins et al. (1998) showed that 66% of Canadian HIV-positive women continued or resumed sexual activity, with 44% being sexually active within 1 month of HIV test results. However, many (85%) reported sexual adjustment problems. Madge et al. (1998) in a study of 505 women note that for half (49%) HIV was the first sexually transmitted disease.

All HIV-positive women and men should have an opportunity to discuss and explore sexuality and reproduction. This needs to be done in an objective and constructive way to overcome any reluctance to talk by those who fear discrimination and pre-set attitudes condemning or discouraging childbirth. The desire for parenting is universal and many women with HIV actively desire a child and many have unprotected sex in the absence of contraception of any form. The presence of HIV may affect pregnancy desire, and indeed the advent of treatment may, in turn, also affect such plans. General pregnancy decision making should be understood especially in relation to factors that may be relevant in the presence of HIV. Some couples are unaware of their partner's HIV status and the absence of family or couple testing often contributes to this. Clearly, a policy-level provision of couple testing would facilitate informed couple decision making. In discordant couples (i.e. one partner is positive and the other negative) conception and pregnancy poses a risk of exposure to HIV for the negative partner (Sherr et al., 2000). There is growing evidence that HIV-positive women may have reduced fertility (Brunham et al., 1991; Brunham et al., 1993; Coll et al., 2002; Waters et al., 2007). A recent study in Europe noted that one in six pregnant HIV positive women had sought assistance with conception (Fiore et al., 2008), while pregnancy rates were greatly reduced in a population study in Uganda (Gray et al., 1998).

The advent of improved diagnosis, treatment, management and prognosis may affect women's decisions about becoming pregnant (Ergin et al., 2002). Pregnancy decision making is affected by a number of contextual factors (Nyamath and Stein, 1997) including social expectation (Semple et al., 1993), partner influences, psychosocial factors, traditional gender roles (Sowell et al., 2002) and a wish to create something of value, which will survive beyond the woman's death (Ahluwalia et al., 1998). Motherhood has special meaning for women in terms of its fulfilment as well as its vision as a career in itself (Kurth, 1993). A recent study in Europe (Fiore et al., 2008) showed that maternal well-being, having an uninfected partner and no previous children were associated with conception.

In discordant couples, where one partner is HIV positive and the other HIV negative, the risk of transmission depends on factors such as treatment, viral load and other sexually transmitted infections. The literature clearly shows that there is a risk of transmission (Fakoya et al., 2008). In seroconcordant couples – where both partners are HIV positive – there are no studies which provide definitive risk of superinfection and clearly the issue of resistance must be one to consider in counselling. Parenting options that can be considered in the presence of HIV in one or both members of a couple include semen washing, donor insemination and adoption (depending on resources available), artificial insemination to reduce exposure for HIV-negative men and an array of assisted fertility treatments. Special considerations of facilities available should inform such decisions given the infection control and universal precautions needed and the inability to apply some infection control techniques to human gametes and embryos (Gilling-Smith et al., 2005).

13.11 HIV Counselling for All Pregnant Women

Knowledge of HIV status is a key turning point to a stream of actions. An HIV test has been available from early in the epidemic. Although a simple biological test, this is a test with complex psychological and medical ramifications. Couple testing is seen as most cost-effective (Postma et al., 2000), yet in most environments, testing is targeted at women, with little policy or provision for men.

Over the last decade, there has been marked increased testing availability in pregnancy, yet termination and family clinic provisions are slower to follow (Bergenström et al., 1999). There is much debate on the procedures associated with HIV testing in pregnancy. How should the issue be raised? Should the tests be optional or routine? Should the paradigm on offer be one of ‘opt in’ or ‘opt out’? Who should do the counselling and how should this be carried out? In resource-poor settings the questions relate to quality and effectiveness of counselling. Where there is no tradition of counselling and limited trained staff, counselling is often reduced to lay counselling, menu-driven information provision or brief discussions. Counsellor dynamics are pivotal in determining test uptake (Varga and Brookes, 2008). The literature suggests that competent counselling includes five key components:

1. *Informed consent* – whereby the test is introduced and the recipient understands and agrees to the test.
2. *Risk assessment* – this discussion helps understand risk behaviour, HIV transmission and future prevention. It is relevant irrespective of eventual test outcome.
3. *Behaviour change* – this complex component addresses a variety of behaviours, most notably sexual risk and also health protection behaviours and issues such as relationship navigation and disclosure (Simbayi et al., 2007).
4. *Therapeutic care* – counselling around care include an understanding of available interventions, coping, support needed and linking into care systems.
5. *Decision making* – this is a vital component and is relevant at all stages from the decision to test, to the decision to disclose, undertake treatment and delivery/feeding options.

The chapter on ‘Voluntary counselling and testing (VCT)’ (Chapter 12 in this volume) describes many of these issues. It highlights the important components of risk reduction, HIV testing and how they apply to pregnancy. Testing uptake is affected by the mode of offer, the motivation of the pregnant women, the availability of interventions and a number of additional psychosocial components which either facilitate or hinder uptake. Counselling support extends beyond pre- and post-test counselling. Emotional trauma, decision making and coping are all challenges during a positive pregnancy.

13.12 Intervention Pathways and Decision Making

The decision pathway and intervention opportunities for parents during pregnancy are quite complex. The pathway includes pregnancy, pre-test counselling, HIV

testing, result provision, post-test counselling, intervention decision making, post-partum testing of infant and post-partum follow-up. Clearly, comprehensive and reliable systems need to be operational and functioning in order to help families navigate the system and in order to prevent drop out. To date, the success has been low. For example, by 2006 only 9% of women who were known to be HIV positive during pregnancy received interventions to prevent infant infection. Two years later, by 2008, this figure had climbed to 34%. This marks a steep increase, but falls dramatically short of target. Two-thirds are lost and figures only relate to those who are known to be HIV positive. The figure is probably considerably higher given that HIV testing is not universal in pregnancy care. Data derived from two studies, Manzi et al. (2005) in Malawi and Shetty et al. (2008) in Zimbabwe, is used to demonstrate the uptake and pathway through the system. In Malawi where 3,136 women attended antenatal clinics, the data shows 2,996 counselled, 2,965 receiving HIV testing, 2,965 post-test counselling (31–1% refusal), 646 testing HIV positive, and only 288 receiving Neviripine interventions and 122 attending for 6-month post-natal check up with their infant. In Zimbabwe, where there were 19,279 pregnant women, 18,817 underwent pre-test counselling, 10,513 went on to test for HIV, of which 1,986 were HIV positive. Results were collected by 9,696. Only 288 men tested (no such data provided for Malawi). From the 1,986 positive, 1,387 were given a Neviripine tablet to take home, and 691 were reported to take NVP at onset of labour and 615 infants received Neviripine. At the 6-week follow-up, 396 mothers returned and 209 completed three follow-up visits. Both these show severe attrition throughout the process. This picture is not atypical and clearly sets out the challenge of comprehensive service delivery and engagement if continuity of care is to be achieved. Clearly, the focus on HIV testing and uptake has been efficacious, but the programmes tail off, like so many others, when the ongoing comprehensive care and engagement is monitored.

13.12.1 Mother/Father and Couple Testing

The majority of programmes in pregnancy have focussed on mothers. Although mothers play a key role and clearly are a priority group entitled to have HIV testing available, there are strong arguments that this should be extended to fathers as well. Shetty et al. (2008) note that of 19,279 pregnant women of whom 10,513 test for HIV, only 288 men test for HIV (despite the fact that 1,986 women test HIV positive). Using a family rather than an individual lens to observe infant exposure to HIV, it is clear that the priorities for the family is to avoid infection of all members, to maintain good health of those who are infected and to ensure parental survival and quality family environment for optimum child development. Field studies have shown that much stigma and discrimination are associated with positive HIV status, and couple testing would obviate the erroneous assumption of ‘first tested first infected’. Many women report social recriminations and are fearful of disclosure because of such ramifications. ‘Women only’ testing compounds this. Couple testing has been seen as feasible in many settings (Guthrie et al., 2007). If a

woman tests HIV negative, it is important to establish if her partner is HIV positive. Unprotected sex during pregnancy is common (it is difficult to convince women already pregnant to consider or negotiate condom use). Thus women are particularly vulnerable to new infection. Furthermore, it is well established that newly infected people will have a heightened viral load, and this is associated with elevated transmission. Another option to monitor new infections during pregnancy would be repeat HIV testing in late pregnancy. Both of these procedures are seen as highly cost-effective (Postma et al., 1999; Postma et al., 2000)

13.12.2 Consent and Result Collection

Consent and informed consent are important considerations in HIV testing (Irwin et al., 1996). As with any medical test, the considerations include the ability of the individual to provide full consent, the environmental context of the HIV test offer and provision (Sherr, 1999; Sherr et al., 2000). Historically informed consent has been seen as vital in all HIV testing situations, specifically pregnancy, given the lifelong ramifications of a positive test result. Full understanding as well as the power imbalance of medical interviews may make people unable or inhibited to decline testing as a result of a variety of fears or misconceptions, a willingness to please or fear of negative consequences (Fitzgerald et al., 2002; Abdool Karim et al., 1998; Sherr et al., 2001). Given treatment efficacy, the benefits of testing outweigh the benefits of ignorance. Care and attention is needed to protect consent and informed consent, and pre- and post-test counselling has resulted in benefits in terms of preparation for results and addressing risk behaviour. Many studies have documented a discrepancy between testing uptake and result collection. This has been documented with different client groups, in different geographic environments and with different HIV testing schedules (home/clinic; rapid same day results vs. delayed results) (Cartoux et al., 1998). This may be associated with consent where those who felt coerced or unclear actually decline by default by not returning for their results. It may also be associated with practical issues such as costs of repeat attendance or the time gap between testing and results. Streamlined provision has allowed for rapid and same-day testing to overcome the latter.

Consent is a problematic area, and there are numerous studies testing for women who ‘declined’, ‘refused’ or ‘withheld consent’ (Sherr, 1999). Larsson et al. (1990) report on ‘a blind analysis of the blood specimens from the 58 women who declined the test was performed.’ Hull et al. (1988) discuss an HIV prevalence rate of 3.8% among STD clinic attendees who declined HIV antibody testing. Similarly, Jenum (1988) notes that 2% of women who declined HIV testing were positive. Barbacci ‘assess the prevalence of HIV in women who did not volunteer for testing’ and Simon et al. (1996), in a study of 20,125, note a refusal of 35%. Jones et al. (1993), ($n = 1,926$) describes 21% of HIV test refusers being tested, as does Behrendt et al. (1994), ($n = 2,842$) where 53% of refusers were tested and MacDonald et al. (2001) who records ‘no pre test counselling prior to HIV testing by 25% obstetricians, 9% family practitioners and 5% hospitals.’ Henry reported on HIV-testing practices

in 371 US hospitals where consent was obtained and documented in only 50% of the cases, and counselling was provided in only 51% of cases. Denayer et al. (1990) found that 49% of Belgian gynaecologists tested for HIV without informing patients and Dalzell et al. (1995) using a sample of 538 women found that 77% were invited to undergo testing, 15% for which 'no consent' was recorded, some who agreed were not actually tested. With the changes over time, HIV testing in pregnancy has increased, but consent and counselling seem to have been enhanced. For example, Rey et al. (1998) in France (1992, 1994 and 1996) report that routine prenatal HIV screening has not changed (89%) but that, with time, systematic consent was more often requested (38.2% vs. 65.5%). In recent years, the advent of 'opt out testing' and 'provider initiated testing,' are both systems to enhance HIV testing uptake. This has specific benefits for pregnant women, but needs to be balanced with quality provision in terms of both testing and counselling procedures as well as follow-up resources for longer-term care for those who have been identified as HIV positive.

13.12.3 Stigma and Disclosure

Test outcome knowledge of HIV status – whether positive or negative – involves issues of disclosure, which is often not universal or immediate (Antelman et al., 2001). Reluctance is often as a result of fears of violence, rejection, abandonment, judgement or avoidance (Medley et al., 2004; Simbayi et al., 2007). There are many studies which have documented such experiences (Jones, 2008), but, on the other hand, there are also those describing acceptance and setting out how strong social support is a predictor of coping and adjustment (Maman, 2003). Thus disclosure issues need to be considered during counselling in order to prepare support and provide skills if needed (Sullivan, 2005). The burden of secrecy and non-disclosure has a high mental health cost (Mayfield et al., 2008). South African studies have described how young women would go to extreme lengths to avoid disclosing their status to obstetric staff, even if this meant no antiretrovirals (Varga and Brookes, 2008). Such barriers and stigma need to be overcome and novel approaches to both counselling and other provisions may enable women to disclose, such as the provision of legal services and materials within pregnancy clinics (Maman et al., 2007).

Studies of partner testing have shown that between 20 and 80% of partners of women testing HIV positive are themselves HIV negative (Freeman et al., 2004). Disclosure patterns reveal that disclosure of status is not automatic, increases with time and lack of disclosure to sexual partners is systematically recorded in many studies (Table 13.2).

13.12.4 After Testing HIV Positive

An HIV-infected pregnant woman will have a wide range of needs. These can be summarised as psychological, practical, social and medical.

Table 13.2 Disclosure of HIV status to sexual partner

Study	% Non-Disclosure	Finding
Niccolai et al., 2006 <i>n</i> = 63 USA	44%	Delayed 22% none 24%, full disclosure 54%,
Niccolai et al., 1999 <i>n</i> = 147 USA	24%	24% did not disclose to last partner, 23% no condom when no disclosure
Marks and Crepez, 2001 <i>n</i> = 206 USA	48%	48% no disclosure 25% unsafe sex, disclosure not associated with safer sex
Raj et al., 2006 <i>n</i> = 124 USA		Buying sex and >1 partner (6/12) associated with non-disclosure
Olley et al., 2004 <i>n</i> = 69 South Africa	78%	78% not disclosed 46% did not know partner's status
Parsons et al., 2004 USA IDU		More disclosed to positive partner than negative partner
Dawson et al., 1994 UK <i>n</i> = 677	72%	72% of partnerships with UAI did not involve mutual knowledge
Ciccarone et al., 2003 <i>n</i> = 1421 USA	42% gay 19% het. men 17% women	42% gay, 19% heterosexual men, 17% women sex no disclosure
Kalichman, 1999 USA <i>n</i> = 266	41%	41% not disclosed to sex partners
Antelman et al., 2001 Rwanda <i>n</i> = 1078 women	78%	78% not disclosed by 2 months, 60% not disclosed by 4 years
Mamam et al., 2003 Tanzania <i>n</i> = 245	36%	36% positive and 21% negative not disclosed result to partners
Wolitski et al., 1998 USA <i>n</i> = 771	11%	11% non-disclosure primary partner 66% non-disclosure to other partners
Stein et al., 1998 USA <i>n</i> = 203	40%	40% did not disclose to all partners
Petrak et al., 2001 UK <i>n</i> = 95	32%	32% did not disclose to significant others
Geary et al., 1996 USA <i>n</i> = 321 adolescents	58%	58% did not disclose
Simbayi et al., 2007. South Africa (<i>n</i> = 1054)	42%	42% had not disclosed to sexual partners

Psychological Needs – This relates to the trauma of discovery of status, the desire to experience and express severe emotions, the immediate requirement for support and the ability to adjust and gain in coping skills. There is the need to identify and explore ways of addressing difficulties, sharing emotions, talking to others who face similar experiences and adjust to life in the face of HIV.

Practical Needs – Often these needs take precedence and until they are addressed, the deeper emotional needs may be delayed, suppressed, ignored or bypassed. Access to health-care provision, information and detailed personalised education are immediate. Treatment options for all affected (mother, father, infant, siblings) need careful dialogue and action. The direct effect on employment, economics and relationships present an urgent need.

Social and Family Needs – These refer to avenues of support from either service providers, family or peer groups. They involve help with everyday life and subsequent challenges that may be linked to HIV status, such as discrimination, the needs of other children and future planning. Relationships, future sexual behaviour and partner considerations also represent an immediate need.

Pregnancy and disease progression. Although early data seemed to correlate pregnancy with disease progression, these findings have not been endorsed, and it seems that time was probably a confounder when this has been studied systematically.

13.13 Fathers

A chapter on pregnancy cannot be complete without specific mention of fathers. They are involved in conception, relationships and parenting. As such, they should not be marginalised and the issue of fathering has been seen to be a consideration for most HIV-positive men. Currently, much of pregnancy and maternity care is women focussed. Traditional gender roles may have highlighted the front-line roles of women and the biology of pregnancy enhances this focus. However, fathers play a key role and a holistic approach to pregnancy should include fathers at all stages such as:

- Inclusion in antenatal HIV testing
- Inclusion in decision making
- Inclusion in risk management
- Fathering

Studies of fathers have shown that in the presence of HIV, many report elevated levels of parenting and psychological stress. Wiener et al. (2001) in a study of 31 fathers of 6–16-year-olds with HIV reported that over half revealed elevated levels of parenting and psychological stress and almost all (97%) needed services. Family configuration is important to understand in terms of parenting and support. Pelton et al. (2001) looked at 249 families and found 40% had an HIV-positive mother. Such families were less likely to have a father at home or in contact with them. Sherr and Barry (2004) looked at pregnancy and fathering intentions of HIV-positive men and found that many would consider adoption or fostering. A total of 50% heterosexual men would consider unsafe sex in order to conceive. Sadly, nearly a quarter would withhold their status at the antenatal clinic for fear of discrimination. Three-quarters felt that fatherhood was important and the majority (81%) described fatherhood as giving meaning to their life.

13.14 Infant Testing

It is vital to establish the HIV status of the infant for a number of reasons. Firstly, the simple feedback to the parents is needed. Secondly, given that HIV-related

illnesses may rapidly affect infants, it is important to know the status in order to intervene early with prophylaxis as well as antiretroviral treatment. Yet, HIV testing in infancy is made complex by the fact that maternal antibody is present in infant blood samples for as long as 18 months of age. Thus straightforward antibody tests are of limited use. If the infant tests negative, clearly there is no antibody. However, the converse is not true. If infants test positive, it is not possible to differentiate between maternal- and infant-generated antibody. The infant may well not be HIV positive. Polymerase chain reaction tests can establish the presence of HIV DNA for a more definitive diagnosis. Yet these are costly and require specialised laboratory facilities. Innovative facilities have utilised dry spot techniques which allow for easy collection, storage and transport to a specialised centre for such results to be made available within rural, isolated or resource-poor settings (Sherman et al., 2005). Clearly, counselling and support needs to be supplemented by accurate knowledge and targeted coping and treatment (WHO, 2006) which is hampered by unknown HIV status.

13.15 Child Development in the Presence of HIV

Child development can be affected in the presence of HIV directly by the virus for HIV-positive children, potentially due to exposure for HIV exposed by negative children and indirectly through family infection to HIV-negative children living in families where one or many members are positive. As HIV clusters in families, children are often multiply affected.

HIV in the family or community may affect a variety of environmental factors, which contribute to a greater or lesser extent to child development. HIV in the family can affect a number of environmental factors in different ways. At the most extreme, parental illness and death has a profound effect on a child's future. Both illness and death may affect the quality of the environment in which a child grows up. Social stimulation, parental availability and emotional environment may affect social learning, cognitive development and stability. A family with a sick or struggling carer may have reduced time, inclination or ability to provide optimum environments for healthy child development. HIV-positive children may themselves be ill, which limits their availability to take in such stimulation either by way of their ill health, their hospitalisation episodes or medication effects. Cognitive effects on children have been systematically monitored. A variety of standardised tests have been used, most of which, when sufficiently powered and controlled, have demonstrated deficits (Sherr et al., 2008). The shortcomings in this area are the absence of standardised measures, and the absence of studies in the highest prevalence countries (vast majority of studies are US based – vast majority of affected children are Africa based). Yet studies have used an array of measures, which are revealing. A more important barrier is the absence of systematic and regular monitoring and the linking of such outcome to treatment and care strategies. Clearly, prevention coupled with special provisions may be required. Thriving, nutrition, schooling, growth and emotional well being is often associated with good functioning families.

13.16 Bereavement and HIV

Grief reactions have been monitored at many stages of HIV life course. They can occur at the point of HIV diagnosis, illness, premature birth and death. Bereavement studies are surprisingly few. Multiple bereavement is the norm, and literature suggests that adaptation and accommodation after multiple bereavement is more difficult than single bereavement. Life changes that are linked to bereavement also have emotional ramifications. These are associated with job loss, separation, movement, couple dissolution, abandonment, economic loss, housing loss and poverty.

13.17 A Way Forward – Integrated Provision

Existing medical models divide reproduction into obstetrics and paediatrics. The divisions are carried through in services where there is a disconnect between paediatric and obstetric services. On closer observation, the vertical care model not only divides into departments, but does not integrate other child- and pregnancy-related services such as early child development, social welfare, mental health and education. HIV interventions at the point of pregnancy have been well established since the mid-1990s. These interventions marked a turning point in prevention as well as a turning point in the worldview of treatment and care as a global right. Yet after 12 years of knowledge, progress has been slow. The reach of the straightforward interventions has not been total, and there has been a steep learning curve as the psychosocial aspects of HIV infection have been inadequately understood and inconsistently addressed.

Dedication This chapter is dedicated to Lilian Isaacs, Pnina Koorlander, Susan Cohen, Cherry Cornell, Andrea Whyte, Lyne Joseph, Danielle Wagerman, Zoe Klaff, Kate Laws and Liora Sherr – the intergenerational social support team.

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