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## **Psychosocial Consequences of Early Diagnosis of HIV Status in Vertically Exposed Infants in Johannesburg, South Africa**

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**Abstract:**

Mother-to-child transmission (MTCT) is the most common source of HIV infection in children. One topic that has received virtually no attention in MTCT-related research and programming is the psychosocial consequences among parents and families of receiving a definitive diagnosis of infant HIV status. This study explored experiences of HIV-infected mothers in Johannesburg, South Africa regarding infant testing and diagnosis. Data collection entailed a key informant workshop and repeat interviews with a convenience sample of 31 HIV-infected mothers. While early testing was desirable, diagnosis had both beneficial and detrimental psychosocial effects, especially in instances of sero-discordance. Programmatic implications are discussed.

## Introduction

Mother-to-child or vertical HIV transmission is the most common source of HIV infection in children under the age of 15 years. At least ninety percent of all HIV infections in children are a result of vertical transmission with the vast majority of cases occurring in sub-Saharan Africa (UNAIDS, 1999). In 2003 an estimated 580,000 to 660,000 new infections occurred among children in the region (UNAIDS/WHO, 2003). South Africa alone is home to over 100,000 children living with HIV/AIDS (Coutsoudis et al. 2002). While HIV infection rates are said to be stabilizing in South Africa, the most recently available sentinel surveillance figures derived from public sector antenatal clinics revealed a sero-prevalence of 27.9% (Department of Health, 2004). The prevalence rate among women attending antenatal services at Johannesburg's Coronation Women and Children's Hospital (CWCH), site of the study reported here, is currently 28%. Without intervention the relative risk of vertical HIV transmission in South Africa is estimated at 31% (Akue et al. 2000, Health Systems Trust, 2002). This combination has made provision of quality voluntary counseling and testing (VCT) services a matter of increasing concern in the context of prevention of mother-to-child HIV transmission (PMTCT) programs.

In sub-Saharan Africa available literature on VCT as part of PMTCT efforts has focused primarily on counseling and testing matters concerning the mother. Such work has addressed issues including cost and quality of service provision (Bassett, 2002), acceptability of testing and counseling services (Marjan & Ruminjo 1996, Cartoux et al. 1998, Kilewo et al. 2001, Msellati et al. 2001), and determinants and consequences of maternal disclosure following diagnosis (Antelman et al. 2001). One topic that has received virtually no attention in this context is the psychosocial consequences of receiving a definitive diagnosis of infant HIV status. Our literature review revealed a single published study – this outside sub-Saharan Africa - examining the relationship between maternal psychological well-being and infant HIV status. Bennetts et al. (1999) found recently diagnosed infant HIV status was strongly predictive of HIV-related worry among HIV-positive mothers in Bangkok, Thailand. Women with an HIV-infected infant had significantly higher levels of worry than those with an uninfected infant.

## Background

In 2001 the South African National Department of Health began the implementation of a pilot PMTCT initiative in two public sector antenatal clinic sites in each of the country's nine provinces (18 clinic sites in total). As an add-on component to existing antenatal care offered by the government, all aspects of the PMTCT initiative were provided free of charge to pregnant women attending the services. The initiative's key components included: voluntary HIV counseling and testing (VCT) for pregnant women, dispensing of the anti-retroviral (ARV) drug nevirapine to both mother and infant (consisting of a single dose for the mother to be taken within two hours of labor onset and a single dose for the infant, administered within 72 hours of delivery), counseling on infant feeding and a 6 month supply of infant formula for those intending to practice exclusive formula feeding (typically dispensed at the clinic in allotments of a few weeks' to a month's supply at a time), and infant health check-ups and HIV testing at 12 months of age. While the pilot initiative had been implemented in all nine provinces by the end of 2001, during that year certain provinces - Gauteng and Western Cape in particular - also proceeded with expanding PMTCT services beyond pilot sites. The PMTCT component of the antenatal services offered by Coronation Women and Children's Hospital (CWCH) in Johannesburg is part of this expansion in Gauteng Province.

Infant HIV testing is a primary element of South Africa's PMTCT efforts. Current national PMTCT guidelines recommend that all vertically exposed children be followed to 12 months of age before their HIV infection status is determined by means of an HIV ELISA test. In 2002 an early HIV diagnostic study was undertaken at CWCH with the objective of deriving an accurate, affordable diagnostic protocol to establish the HIV status of infants born to infected women within the first few months of life. HIV exposed infants enrolled in this study had their HIV infection status established by 4 months of age through 2 concordant HIV DNA PCR tests.

As part of the project, a small sub-study was undertaken among mothers to examine social environmental factors that influence mothers' PMTCT-related choices and

practices. One specific study objective was to explore psychosocial issues surrounding the timing of receiving an infant HIV diagnosis. In this respect our aim was to ascertain women's attitudes concerning and experiences in receiving an early (4 months post-partum) diagnosis of their infants' HIV status. We report on the results of this portion of the sub-study here.

The study design is based on two principles. First, consideration of (socio-cultural, institutional, community, family and household) context is vital in order to understand human behavior and its determinants. Thus, as a complement to the clinical diagnostic study, this work explored the relationship between mothers' social and cultural environment and their PMTCT-related practices. As part of this goal we also focused on the impact of the PMTCT initiative (including the infant diagnostic study) on women's lives. Second, accurate description and assessment of such contextual factors necessitates a scientifically rigorous and triangulated study design. The research methodology used in this work was based on the Narrative Research Method (NRM; WHO, 1993). NRM has been the basis for much of our previous research in South Africa on vertical HIV transmission dynamics (Varga, 2002a, 2003a, Brookes et al. 2003) and adolescent sexual and reproductive health (Varga, 2002b, 2003b). A central aspect of the narrative approach is the development of a generalized case study or life history story as the basis for exploring the contextual dynamics that affect the outcome(s) of a given sexual or reproductive health situation; in this case vertical HIV transmission. The case study is developed and explored through a series of four data collection steps: 1) a key informant workshop; 2) focus groups; 3) community-based (quantitative) surveys; and 4) in-depth interviews. Thus, each data collection step provides a complementary – and in combination holistic - perspective on the case study and its outcome(s). A potential limitation of NRM is that the case study is restricted by focus on a single generalized case profile. This can at least partially be remedied by asking the workshop group to construct stories around several “index character types” whose socio-demographic profiles are deemed representative of the study population. This variation on NRM has proven successful in our other PMTCT research (Varga, 2002a, 2003a, Brookes et al. 2004).

For this research, time and budgetary constraints prevented us from undertaking all four narrative steps. As a result we relied on the key informant workshop and a series of in-depth interviews with women enrolled in the early HIV diagnostic study. The purpose of the workshop is to construct the case study itself. Thus, it serves as the basis for all subsequent research steps. Within the NRM framework, in-depth interviews are typically undertaken with individuals who have experienced first-hand the scenario depicted in the case study. This is done in order gain a personal or 'real life' outlook on the situation and the dynamics surrounding it. Here we extended this angle even further by conducting repeat interviews with HIV-positive mothers. This longitudinal perspective afforded the opportunity to track on how women's lives changed over time and how they adapted to their circumstances. Prior to initiating fieldwork the University of the Witwatersrand (WITS) Ethics Review Board approved the study design. All participants provided written consent before being recruited into the study.

### Methods

Fieldwork was carried out between December 2002 and August 2003. Data collection was undertaken in two phases. The first phase entailed a one-day key informant workshop with various community stakeholders (health care providers, lay counselors, representatives from local community-based organizations and women who had been through PMTCT services at CWCH). These individuals were purposely chosen for their expertise and experience with PMTCT-related issues; the rationale being that they were able to offer both an informed and personal perspective as well as a more objective opinion regarding the broader social context of vertical transmission dynamics and service utilization.

The purpose of the workshop was to create through discussion and role-plays a generalized case study depicting a local pregnant woman's typical experiences with PMTCT services and life as an HIV-positive mother. The case study contained several characters, a well-defined plot with discrete episodes, and a distinct beginning, middle and ending. Participants created the story of Thandi, a 24 year-old woman who had migrated from a coastal province to live in one of CWCH's catchment communities with

her boyfriend James and his extended family. The story opened with a pregnant Thandi enrolling in antenatal services at CWCH and being offered VCT. Through counseling she decided to get tested and thus discovered she was infected with HIV/AIDS. The rest of the story concerned her experiences in the PMTCT program and the manner in which she engaged with James and other family members on PMTCT-related issues such as infant feeding, taking nevirapine, avoidance of breastfeeding and use of hospital-distributed formula, and infant HIV testing. The story ended with the index infant's last post-natal check-up at one year of age.

A unique feature of case study development is the flexibility to consider multiple episode or storyline endings depending on characters' choices or actions. For example, the group may choose to discuss and role-play how the story would be resolved if Thandi disclosed her HIV status to James compared to how it would unfold if she kept her HIV status secret. Or they could explore how an early (4 months) vs. conventional (12 months) infant HIV test would influence the story's outcome. In this manner, case study development illustrates contextual or situation-specific decisions and outcomes. The workshop was co-facilitated by two of the authors (CV and JM). It was conducted in a mix of English, Afrikaans and Zulu and tape-recorded.

The second data collection phase involved a series of repeat in-depth interviews with a convenience sample of 31 mothers enrolled in the infant diagnostic study. Mothers were interviewed at the clinic for the first time within three months of having received their infants' HIV diagnosis. Repeat semi-structured interviews were conducted with mothers through 12 months post-partum as they brought their infants to the clinic for regular check-ups. On average, two interviews were collected for each mother enrolled in the study. A female interviewer (JM) conducted each interview in the participant's language of choice. If the participant was willing, sessions were tape-recorded. Women refused tape-recording in less than ten percent of the interview sessions. In such cases the interviewer relied on hand-written notes taken during the interview and personal written observations after it had concluded.

### Data Analysis

A grounded theory approach was used in analyzing the data (Strauss & Corbin 1998). Once the workshop and in-depth interview data were transcribed and translated, content analysis of the transcripts was performed using QSR NUD\*IST (1997) qualitative data analysis package. An additional important aspect of data analysis was the regular meeting of the research team to discuss experiences in data collection and interaction with participants, and informally interpret results as they became available.

### Results

Urban working class and impoverished Johannesburg communities of mixed ethnicity characterize the catchment population of Coronation Women and Children's Hospital. These settlements are also distinguished by an increasing number of immigrants from countries bordering South Africa. The 31 mothers who agreed to be interviewed were reflective of this socio-demographic profile. Mean age of interview mothers was 28.9 years (range 21-42 years) and average parity was 2.6 births. Just over half (53%) were unemployed and most were living with a partner (42%) or married (29%). Ethnicity was mixed: Zulu (46%), Tswana (24%), the remainder including North and South Sotho, Sepedi, Shona (Zimbabwe) and Chechewa (Malawi). Among interview mothers, 2 (7%) infants tested HIV positive. This infant HIV sero-prevalence is roughly consistent with the 8.7% vertical transmission rate among mothers enrolled in the overall (diagnostic) study (Sherman et al. 2004).

Study results suggest there are both favorable and potentially detrimental psychosocial effects associated with early infant HIV diagnosis. Workshop participants cautioned that while early diagnosis is preferable from the perspective of medical management and care, timing of infant testing - at least in so far as informing the mother - depends on the extent to which the mother has been psychologically prepared for receiving the news. For example, in the workshop case study two infant testing scenarios were considered: Thandi receiving an HIV-positive infant test result at 4 months versus undergoing the conventional PMTCT process and having the same diagnosis at 12 months. Based on role-plays and discussion of both scenarios the group concluded that in the absence of



proper counseling and support Thandi was psychologically unable to cope with an early (i.e. 4 month) HIV-positive diagnosis. In constructing, enacting and analyzing the role plays, workshop members made the assumption that Thandi had *not* received regular follow-up counseling or participated in a support group. While CWCH is known for its strong PMTCT-related counseling and support services, at the time the study was conducted many PMTCT programs in South Africa did not contain this element. Thus the group chose to model what they considered a typical experience in this respect.

At 4 months post-delivery, Thandi's emotional upheaval upon receiving the news of the baby's HIV-positive diagnosis led her to blurt out the news to James without considering the consequences of disclosure; an act that left her vulnerable to physical and verbal abuse by James as he blamed her for the baby's test result. Further, her inability to stand up to James led to his abandoning her and the index infant. In contrast, by 12 months Thandi was better equipped to handle her infant's diagnosis. After considering her and the baby's needs she chose to disclose to her immediate family rather than to James. Her family accepted the situation and served as a source of care and support for both her and the baby. Group consensus was that without appropriate counseling and support services – a scenario faced by the majority of HIV-infected mothers in South Africa attending public sector antenatal facilities - she might need or even prefer to wait 12 months before having her infant tested.

In the interview segment, irrespective of the infant's HIV status mothers reported finding early diagnosis desirable because it allowed them to care for their infants appropriately. Both of the mothers whose babies tested positive for HIV were upset and even disillusioned by the diagnosis because they felt they had done everything to avoid vertical transmission. Nonetheless they also acknowledged the importance of an early diagnosis in order to ensure they would provide their infants proper care. The 26 year-old mother of one of the HIV-infected infants explained her viewpoint:

It's unfair... [T]hey tell you what to do [to avoid vertical transmission] and you get this feeling of hope. You just hold onto the hope that your baby will be safe [HIV negative]. I followed all the right procedures and [still] my baby got HIV. That hurt me, you cannot imagine... I

remember in the Bible when God says ‘I will punish the children because of their parents’ wrong ways’. It is because of me that my baby is infected. But still, I wanted to know [about the baby’s HIV status] early. I wish they could have tested him as soon as he was born. That way I would know what to do if he got a fever ... Now I know that I should do this and that when he has a problem...I don’t take a chance by waiting, I take him to the doctor right away...

In a later interview, this same mother remarked on the beneficial role of support groups and counseling in adjusting to her own and her infants’ HIV status:

They [the counselors] gave us an opportunity to bring out whatever was within us. [One counselor in particular] made me strong...She played an important role because she is also HIV positive and she also has a baby ... like mine [HIV positive]....She had put herself in my shoes.

Among mothers of HIV negative infants, many stated that not knowing the baby’s HIV status made them excessively anxious over minor childhood ailments; often leading them to (incorrectly) interpret these as signs of infant HIV infection. A negative infant HIV diagnosis relieved the emotional stress and fear associated with not knowing and motivated women to keep themselves healthy so they could take better care of the index infant. The following interview quotes from mothers of HIV-negative infants illustrate these sentiments:

I wanted to know [the baby’s test results] as soon as possible, not this thing of waiting for so long. Sometimes not knowing would hurt... would weigh me down... [When] I heard the baby’s [HIV negative] results...I started afresh...It’s better to have the news soon so [I] can recover...for both of us. I feel proud and happy. That [the early test] is what I wanted... (mother aged 42)

I don’t have to worry now [that I know the baby is HIV negative]. It has made my life simpler. I don’t have that kind of stress. Now I have only to worry about myself. I must survive for her, to raise her (mother aged 27)

For families of HIV negative infants another beneficial consequence of early HIV testing was greater bonding with the index infant. Several mothers described how a negative HIV test led to the father and other family members interacting with the infant in a more

meaningful way and being more loving toward it; largely because they now felt free to emotionally invest knowing that the baby would likely survive beyond early childhood.

In contrast, discordant test results between mother and index infant (i.e. mother tested HIV positive, infant tested HIV negative) sometimes led to tension and misunderstandings at home. In the key informant workshop two mothers revealed that they retracted their own HIV-positive status when their infants' tests were negative. One woman's motivation in recanting was to ease the pressure in her household surrounding who should take the responsibility for caring for her and her baby, "I told my family my test result was a mistake. I said to them, 'See the baby is fine and so am I. [My HIV test result] was all a mistake.' Among interview mothers, in several cases for both mothers themselves and family members the concept of HIV discordance appeared to be difficult to accept or comprehend. As with mothers in the key informant workshop, at least one interview mother used her index infant's negative HIV test to recant her own HIV positive status. A few interview mothers noted that discordant results led family members to question the reliability of the HIV test itself; as a result they either doubted the mother's infected status or the fact that the baby was *not* infected. One interview mother, a 35 year-old woman with three children, described the confusion wrought within her family by sero-discordance in the following manner:

Both my mother and my boyfriend started thinking maybe this means I am also not HIV positive. Maybe it was all a mistake. They don't believe I am infected anymore. My mother said not to worry about this HIV... I myself also don't understand why they [clinic staff] keep telling me I am HIV positive. There is nothing in my body that feels different. I feel the same as before I got the results. And now with the baby's test...

### Conclusion

This was a small exploratory study among a clinic-based convenience sample of HIV positive mothers. Nonetheless, the experiences and opinions chronicled here reveal issues for programmatic consideration in both early infant HIV diagnosis and infant testing in general. First, irrespective of the actual test result, early HIV diagnosis appears to have a

variety of psychosocial benefits for infants and their families. In the case of an HIV positive result, early diagnosis helps ensure comprehensive HIV management that includes both medical care and support services. In the event of a negative HIV test result, early diagnosis can provide tremendous emotional relief for infants' families and motivate mothers to stay healthy and active. An early negative diagnosis may also facilitate emotional bonding between the index infant, its parents and other family members; important factors in facilitating adequate care and support of both mother and infant. Further, while the Thai study by Bennetts et al. (1999) was conducted in the context of a more conventional infant HIV testing regimen (i.e. definitive diagnosis 18-24 months post-partum), it is possible that mothers of HIV negative infants experienced psychosocial benefits similar to those revealed in this study; thus leading to decreased levels of HIV-related worry. Finally, for a number of mothers a negative diagnosis helped them defend – both to themselves and often to their families – the choice to exclusively formula feed their infants despite the social stigma associated with this practice. In many South African communities mixed infant feeding - a combination of breast milk, formula, solids and liquids - from as early as the first few days of life is culturally normative. In addition, the practice of breast-feeding is considered symbolic of good motherhood and the psycho-emotional benefits to both mother and child are widely recognized (Richter & Griesel 1998). Thus, mothers who avoid breastfeeding entirely are often the objects of considerable negative social attention (Varga, 2002a, 2003a, Brookes et al. 2004). In this study, many women described elaborate strategies – including lying, avoiding public places or certain social situations, and making up false medical diagnoses – to justify avoidance of breast-feeding to friends and family members. All these sentiments are reflected in the words of one such mother in describing her feelings upon receiving her infant's HIV-negative test result, “I just thought to myself ‘Well now it [withstanding the pressure to breastfeed] has all been worth it. My baby is safe’”.

In situations where the mother is known to be HIV-infected, infant HIV diagnosis may also have harmful psychosocial effects. For example, Bennetts et al. (1999) found that women with HIV-infected children had significantly higher HIV-related worry scores than those with uninfected children. Our data suggest that, as exemplified by the case of

Thandi, in the absence of strong counseling and support networks the negative impact of an early (HIV-positive) infant diagnosis may stem from the timing of such news. Further, as evidenced in this study, an infant's positive test may result in a mother doubting PMTCT regimens and blaming herself for her child's infection. Sero-discordance between a mother and the index infant can be confusing and upsetting for families who have adjusted to living with and caring for infected family members. Sero-discordant test results may also lead to a mother's recanting or engender doubts regarding her own HIV status; factors that could result in reduced care and support of the mother, her infant or both.

These data highlight the psychosocial complexity of infant HIV diagnosis. Our results also underscore the need to address infant testing and diagnosis within PMTCT-related VCT, make on-going counseling and support services available in the post-partum period, and ensure that issues concerning infant testing are highlighted in public health education campaigns focused on preventing vertical HIV transmission. Specifically, such programmatic components should include emphasis on sero-discordance (what it is and what it means, its implications for maternal-child health care and support, and its potential implications for maternal HIV (non)disclosure), and psychosocial needs of mothers with HIV-infected children. There is also a need for the development of strategies to involve spouses, household and family members in PMTCT-related education, care and support activities both during pregnancy and in the post-partum period. In this respect, recent research elsewhere in South Africa revealed the importance of partner, household and community involvement in ensuring the effectiveness and sustainability of clinic-based PMTCT programs (Varga, 2002a, 2003a, Brookes et al. 2004). Finally, while early infant HIV testing may be advisable for both psychosocial and medical reasons, by incorporating infant testing and diagnosis issues into counseling and support services PMTCT programs will be more able to ensure that mothers are adequately prepared psychologically and emotionally for an infant's test result irrespective of its timing.

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