Stigma and Discrimination as Barriers to PMTCT and HIV Care and Treatment for Maternal, Neonatal, and Child Health

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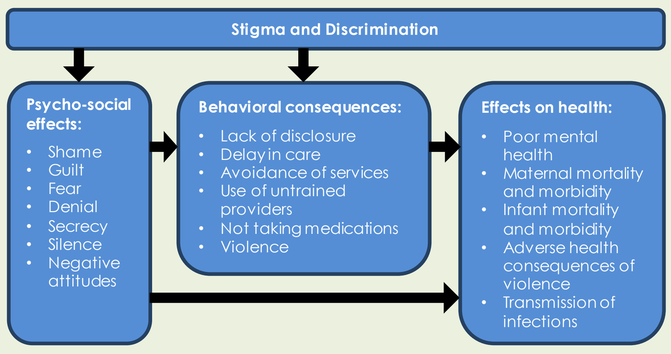
Introduction

- Global goals have been set of virtual elimination of vertical transmission of HIV and 50 percent reduction in HIV-related maternal mortality by the year 2015.
- Substantial progress has been made in expanding prevention of mother-to-child transmission (PMTCT) services, yet uptake and utilization of these effective interventions are still very low in many settings.
- There is mounting evidence demonstrating an urgent need to examine and respond to demand-side barriers in women's lives that affect initiation and retention in PMTCT programs.
- **Key among these barriers are stigma and discrimination (S&D)—specifically, fears around disclosure of HIV status; fears around confidentiality; and fears of being discriminated against by the community, family, and male partners.**

Figure 1: A Framework for the Effects of Stigma on Maternal, Neonatal, and Child Health

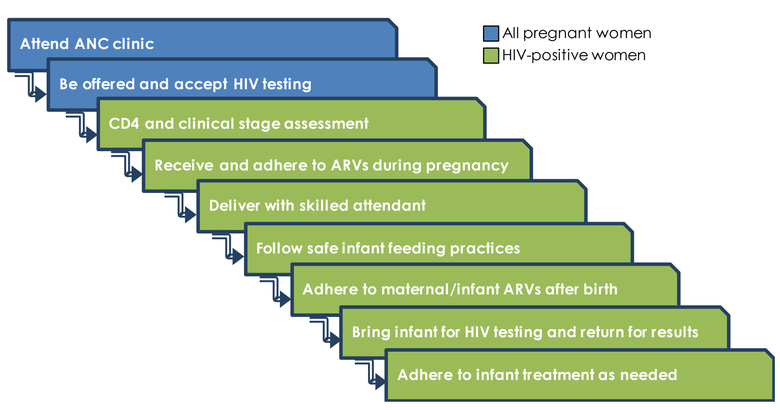


Adapted from Kumar et al., *Culture, Health, and Sexuality,* 2009.

Methods

- Strategic review of the existing academic and programmatic literature to examine the current evidence on stigma, discrimination, and their negative impacts on PMTCT and family health to examine
  - How stigma and discrimination act as barriers at each step in the complex series of interventions that women and infants must complete for successful PMTCT (characterized as "the PMTCT cascade").
  - How and whether the integration of PMTCT and antenatal care (ANC) and maternal, neonatal, and child health (MNCH) services may mitigate the negative effects of stigma and discrimination.
- Search engines: PubMed, Scopus and Google Scholar, focusing in the three key areas of stigma and discrimination as a barrier to PMTCT; integration of PMTCT with ANC/MNCH services and stigma and discrimination; and interventions to reduce stigma and discrimination.
- Data were used to develop recommendations for programmatic actions to integrate the reduction of stigma and discrimination into PMTCT/ANC/MNCH services.

Figure 2: The PMTCT Cascade



Results

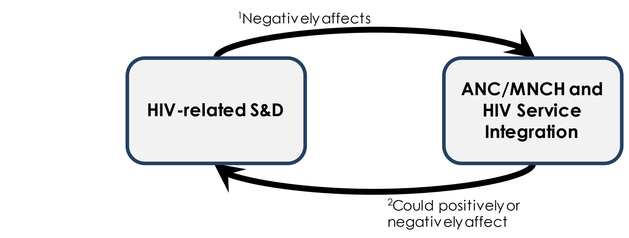
A. Stigma, Discrimination, and the PMTCT Cascade: Substantial evidence from research conducted in a variety of country contexts indicates that stigma and discrimination from the community, family, and health workers are among the most important barriers to completing the PMTCT cascade. We found that stigma and discrimination affected every step of the cascade (Table 1).

Effects of HIV-related Stigma at Every Step of the PMTCT Cascade

Step in the Cascade	How Stigma and Discrimination Affect the Cascade Step	Illustrative Finding
1. Initiating use of ANC	As routine opt-out HIV testing becomes standard and well-known in ANC clinics, women may avoid ANC services if they fear HIV testing and lack of confidentiality of HIV test results.	In South Africa, HIV-positive mothers described delayed ANC attendance due to apprehension around HIV testing (Laher et al., 2011).
2. Being offered an HIV test	There is the potential for health workers' stigmatizing attitudes and stereotypes about who is at risk of HIV to affect who is offered HIV testing, resulting in some types of pregnant women not even being offered the test or others being tested without their consent.	In Vietnam, healthcare workers described offering HIV testing earlier in pregnancy to "suspicious cases," such as women who look like drug users or have certain jobs, such as "hotel work" (Oosterhoff et al., 2008).
3. Accepting an HIV test	Pregnant women may decline an HIV test for fear of being HIV positive, unwanted disclosure if found to be positive, and the S&D that may follow.	In Kenya, pregnant women who anticipated male partner stigma were more than two times more likely to refuse HIV testing during the ANC visit than other women, after adjusting for other factors (Turan et al., 2011a).
4. Enrolling in PMTCT and/or HIV treatment services	Women may defer enrollment in these services at the time of HIV testing, often citing a need to go home and confer with their husband, and then never return to the health facility due to fears of HIV-related stigma. Women may also avoid enrollment in HIV care programs if they lack the support of their partner and live in a high-stigma setting.	In a study in Nairobi, stigma was the most commonly cited barrier for HIV-positive pregnant women's failure to enroll in HIV care (77%)(Otieno et al., 2010).
5. Adhering to ART and follow-up visits during pregnancy	Even if women do enroll in PMTCT programs and/or HIV care, fears of unwanted disclosure, stigma, and discrimination may make it difficult for them to adhere to ART prophylaxis and/or highly active retroviral therapy during pregnancy.	In South Africa, women who felt their HIV status was kept confidential at the health facility were significantly more likely to report adherence to single-dose nevirapine during pregnancy (Peltzer et al., 2010b).
6. Giving birth with a skilled attendant	Fears about lack of confidentiality, unwanted disclosure, and HIV-related stigma may cause some women to avoid childbirth in a health facility.	In rural Kenya, HIV-positive women who had disclosed their HIV status to anyone were 6.5 times more likely to deliver in a health facility than HIV-positive women who had not disclosed to anyone, even after controlling for other factors associated with childbirth in a health facility (Turan et al., 2011b).
7. Adhering to recommen-ded infant feeding practices	Women may fear that following an infant feeding regime that is not the cultural norm/standard (e.g., exclusive breastfeeding or formula feeding) will lead to disclosure of HIV status. As recommended infant feeding practices for positive mothers become more widely known, exclusive breastfeeding may become a marker for HIV infection.	In Burkina Faso, Cambodia, and Cameroon, HIV-positive women made infant feeding decisions based on their perceptions of the risk of being stigmatized as a ''bad mother'' or as HIV positive (Desclaux and Alfieri, 2009).
8. Bringing infant in for HIV testing	Similar factors related to HIV-related stigma have been shown to come into play in parents' utilization of infant HIV testing services.	In South Africa, women who had shared their HIV test result with someone were 2.5 times more likely to have had their infant tested for HIV than those who had not shared with anyone (Peltzer and Mlambo, 2010).
9. Adhering to maternal and infant follow-up visits and ART after the birth	After the birth, fears of stigma and discrimination can again be barriers to adherence to ART for infant and/or self, due to the need to hide visits and/or medications from others.	In Rwanda, infants of women who had not disclosed their HIV status to someone other than a partner were less likely to have received infant nevirapine at the recommended time (Delvaux et al., 2009).

B. Integration of ANC/MNCH and HIV Services: will it remove S&D as a barrier to PMTCT and cause of loss to follow-up?

Figure 3: Potential Relationships of HIV-related S&D and Service Integration



[1] Effects of HIV-related S&D on ANC/MNCH Service Integration

Potential Negatives
- Women who fear stigma still less likely to use
- ANC/MNCH providers with less HIV-related experience and training may be reluctant to provide services for women living with HIV

Potential Positives
- None

[2] Effects of ANC/MNCH Service Integration on HIV-related S&D

Potential Positives
- Less unwanted disclosure at health facilities since women don't need to visit a separate HIV clinic

Potential Positive Outcomes
- More uptake of and retention in PMTCT and MNCH services
- Better MNCH and family health outcomes

Potential Negatives
- HIV positive women have longer appointments, resulting in unwanted disclosure
- Less disclosure to partners?

Potential Negative Outcomes
- Continued low utilization and retention
- Continued infant infections and maternal deaths

Conclusions

It will be impossible to reach global goals to virtually eliminate vertical transmission and reduce HIV-related maternal mortality without addressing the real context of women's lives. In particular, it is necessary to lower the barriers of stigma and discrimination. Integrating maternal health and HIV services may not be enough to overcome social barriers that keep women, partners, and infants from fully accessing health services. Alongside important modifications to make clinical services more effective, convenient, and accessible for pregnant women and families; PMTCT, maternal, neonatal, and child health services must address HIV-related stigma.

Existing stigma and discrimination reduction tools and intervention models, as well as measures to evaluate progress, that can be easily integrated into these services include:

- Measurement tools to identify, address, and monitor stigma in ANC/MNCH and labor and delivery service settings (including meeting the needs of service providers)
- Programs, such as support groups, that directly address the expressed needs of women of reproductive age
- Involvement of women living with HIV in service delivery
- Positive engagement of the communities and male partners of pregnant women living with HIV
- Design of any PMTCT media campaigns with the participation and input of advocacy groups and pregnant women living with HIV
- Development and implementation of national and regional policies that protect the rights of persons living with HIV and that mandate humane and non-discriminatory treatment

For more information, please see

Turan, J., L. Nyblade, and P. Monfiston. 2012. *Stigma and Discrimination: Key Barriers to Achieving Global PMTCT and Maternal Health Goals*. Washington, DC: Futures Group, Health Policy Project.

Available at

www.healthpolicyproject.com

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