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Prevention of mother-to-child transmission of HIV services in China: A conversation between healthcare professionals and migrant women with HIV

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Abstract

In China, the access to prevention of mother-to-child transmission (PMTCT) of HIV services is particularly low among migrant population, which remains a challenge in the fight against HIV/AIDS. The study is aimed to investigate the PMTCT continuum for migrant women with HIV (MWHIV) and to identify barriers and potential strategies to improve the service delivery. The study started with a first round of focus group discussions with 20 healthcare professionals to map out the local PMTCT service cascade, followed by in-depth interviews with 20 recently delivered MWHIV to explore their perceived barriers along each step of the cascade, and a final round of focus groups with healthcare professionals to identify potential strategies to improve the PMTCT continuum. Lack of knowledge of antenatal care, stigma and discrimination in healthcare settings, inadequate provider-patient communication were major barriers hindering the PMTCT service utilization. Potential strategies to enhance the PMTCT uptake included broaden publicity to the general population and using mobile phone application for health education. The issues of HIV designated hospital and integration of postpartum and neonatal care were also discussed. The study allowed the healthcare professionals to recognize the service gaps along the PMTCT continuum and identified potential solutions for service improvement.

Keywords

Prevention of Mother to Child Transmission; Service cascade; Migrant women; HIV/AIDS; China

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Introduction

Prevention of mother-to-child transmission (PMTCT) using antiretroviral therapy (ART) prophylaxis is proven to be efficacious in reducing vertical HIV transmission.¹ Over the last decade, China has made significant strides in the implementation of PMTCT.² Since 2003, free ART prophylaxis is provided to all pregnant women with HIV (PWHIV) and their babies.³ HIV vertical transmission was substantially reduced from 31.8% prior to the scaling up of free PMTCT program to 2.3% in 2011.²

Nonetheless, significant gap still exists between the ideal and the current situation. In China, only about 60% of PWHIV ever received ART prophylaxis.^{4,5} Approximately 33% of HIV exposed infants had not received HIV testing, and 22% had not received ART prophylaxis. A systematic review has summarized multilevel barriers to utilization of PMTCT services in China: lack of PMTCT knowledge and unawareness of HIV susceptibility among general population are major barriers at individual level; financial burdens and lack of involvement or even negative attitude/behavior of male partners are family-level barriers; the barriers from the social perspective consisted of social stigma towards HIV-infected individuals and inconvenience transportation; the barriers within the healthcare system included lack of facilities or techniques for PMTCT services, absence of policy and/or funding support, and inadequate technical and communication skills among service providers.⁶ Similar barriers were also reported in other countries.⁷⁻⁹

One of the pressing problems of the PMTCT implementation in China is the insufficient prenatal care among migrant women with HIV (MWHIV). It is estimated that there are 277 million migrants in China, accounting for nearly 20% of the total Chinese population.¹⁰ These migrants are often associated with an elevated risk of HIV acquisition and transmission.¹¹⁻¹³ No health insurance coverage, lack of maternal health care knowledge, and financial constraints all have contributed to the delay of migrant pregnant women's access to prenatal care and a missed opportunity to use ART prophylaxis for the PMTCT.^{4,14} The operational issues, which may be responsible for the gaps in PMTCT services gap among the migrant population need to be identified and addressed in order to achieve the United Nation's global plan to eliminate new HIV infections among children.¹⁵

Appropriate PMTCT service cascade includes a complex set of activities, from antenatal care attendance, HIV testing, prophylactic ART, safe delivery, infant feeding and follow-up, family planning, to long-term HIV care.^{16, 17} The process covers a long period from pregnancy to the end of breastfeeding, or even a lifetime.^{18,19} Although the Chinese government issued the implementation guideline for an integrated PMTCT efforts,²⁰ a significant gap still exists between the policy and the actual practice.²¹ The aims of this study was threefold: 1) to understand the current delivery of PMTCT services in China, this study applied process mapping strategies to visually display the sequential and discrete steps of the local PMTCT system and identify the responsible parties for each step;^{22,23} 2) to elicit the specific challenges of service seeking and service provision along each step of the PMTCT cascade: we employed a simplified Delphi techniques^{24,25} to seek views from both MWHIV and healthcare professionals' perspective; and 3) to explore potential strategies to

improve healthcare professionals' compliance to PMTCT implementation guideline and MWHIV's clinical outcomes.

Methods

Participant Recruitment

The study was conducted in Anhui, China between July 2015 and May 2016. The study participants comprised of 20 healthcare professionals (including 10 service providers and 10 health administrators and community representatives) and 20 recently delivered MWHIV. The ten service providers were recruited from local maternal and child hospitals, OB/GYN department of general hospitals; Center for Disease Control and Prevention (CDC) affiliated HIV/AIDS clinics, and HIV/AIDS designated hospitals. Health administrators and community representatives were recruited from Department of Health, Center for Women and Child Health (CWCH), local resident committees, women and youth organization, and family planning commission. Gatekeepers of these hospitals/organizations recommended persons who were familiar with local PMTCT services and HIV-related policies and systems to participate. The healthcare professionals had to: 1) be age 18 or over; and 2) be a healthcare professional in the study area.

Twenty recently delivered MWHIV were recruited from local hospitals, because nearly all women in urban and rural China give birth in hospitals.²⁶ To recruit participants, project flyers were posted in OB/GYN and pediatric departments of the local hospitals. Service providers assisted in the recruitment process by passing the project flyers to their patients. The eligibility for MWHIV included: 1) age 18 and above; 2) being HIV positive; 3) do not possess local permanent residency at the time of delivery, and 4) gave birth within the past 12 months. Sample characteristics are presented in Table 1.

When recruiting a prospective participant, project recruiters followed a standardized script to introduce the study objective and procedures, discussed potential risks/benefits, and explained confidentiality and voluntariness. Oral informed consents were obtained prior to the data collection. The study was approved by Institutional Review Boards of the collaborating institutes in China and the United States.

Data Collection

The study proceeded in three interrelated phases, and the findings from each preceding phase were used in the subsequent phase(s). In Phase 1, a first round of focus groups was conducted with healthcare professionals to analyze the local PMTCT cascade. The focus groups with service providers and healthcare administrator/community stakeholders were conducted separately in order to avoid power imbalance between the two groups. The discussions were conducted in a private conference room and lasted for approximately 90 minutes. A facilitator guided the participants to map the sequential and discrete steps that MWHIV pass through in order to receive appropriate PMTCT services. With the sequential flow diagram drawn on a white board, the participants discussed the challenges associated with each step of PMTCT continuum. After the focus groups, a final cross-functional flow chart²⁷ was developed combining the diagrams generated from the two groups.

In Phase 2, anonymous in-depth interviews were conducted with MWHIV. The one-hour long interviews were administered one-on-one by trained interviewers in private spaces. The participants first described their personal experiences of child-birth and PMTCT utilization. Then the interviewer presented the PMTCT flowchart and asked the participants to point out the steps they perceived to be most challenging and discussed the perceived barriers and facilitating factors specifically pertaining to each step of the PMTCT cascade. Each participant received 100 RMB (approximately 16 USD) for participation.

In Phase 3, a second round of focus groups with similar format and procedure was organized with healthcare professionals who participated in Phase 1. The facilitator guided the participants to revisit the PMTCT flowchart and debriefed the challenges and facilitators of each step in the cascade as reported by MWHIV. Some typical vignettes generated from Phase 2 were presented, and the participants discussed the causes of service delay and/or drop-out. The participants also brainstormed the strategies to improve the PMTCT cascade. The participants received 100 RMB (approximately 16 USD) for each round of focus groups.

Data Analysis

The focus groups and in-depth interviews were audiotaped and transcribed verbatim. The transcripts were analyzed using the Grounded theory methodology to attain understanding of the PMTCT service cascade, perceived challenges associated with service delivery and utilization, and potential strategies for improvement.²⁸ The data segments were organized into coding categories using Atlas.ti (<http://www.atlasti.com/index.html>). A set of priori codes was developed based on the in-depth interview/focus group guides before examining the data. The priori codes were applied to the transcripts. The code list was modified based on themes that emerged from the transcripts throughout the coding procedure. Themes relevant to the research questions were extracted from the data. Typical and informative answers were quoted in the results section.

Results

Figure 1 describes the cross-functional PMTCT flowchart. Pregnant women can choose any healthcare facility for the first antenatal visit, then they are referred to local CWCH for antenatal care registration. All pregnant women are universally tested for HIV, syphilis, and HBV. Rapid HIV tests are available for women in labor. For those who screened HIV positive, a second blood sample will be drawn and sent to local CDC for a confirmatory HIV testing.

Pregnant women with a confirmed HIV infection are referred to local CDC affiliated AIDS clinics for further check-up and treatment. The Chinese government has implemented the latest World Health Organization's guideline, which suggests all PWHIV to initiate lifelong ART regardless of CD4 count or clinical stage.²⁹ Baseline CD4\ viral load\ liver and kidney function testing is performed for women whose HIV status is confirmed. PWHIV can obtain free ART medications periodically (usually once every three months) from CDC affiliated AIDS clinics. CD4 and viral load testing are offered four times a year or as needed.

PWHIV usually visit antenatal clinics at the same interval as regular pregnant women unless they have other complications. Pregnant women who were properly registered in the antenatal care registration system can obtain five vouchers for free antenatal visits from local CWCH, which can be used in any healthcare facilities in the same administrative district. In general, pregnant women are encouraged to deliver at the same healthcare facility where they receive antenatal care. PWHIV can choose to have a vaginal delivery unless there are other medical reasons for a cesarean.

Local CWCH are responsible for the follow-up and care of the HIV exposed infants, who are tested for HIV at 42 days, three months, and every three months thereafter until 18 months. Breastfeeding is not recommended for HIV exposed infants. To promote formula feeding, local CWCH provide mothers with HIV a one-time 3,000 RMB (approximately 480 USD) allowance to subsidize infant formula. CWCH are responsible for delivering the oral ART regimen for HIV exposed infant within six hours of birth. The oral ART regimen is administered daily at home until the infant's HIV serostatus is confirmed. Postpartum women continue to receive HIV/AIDS treatment and care from CDC affiliated AIDS clinics. All the services described above do not require permanent local residency.

Challenges along the PMTCT Cascade

1. First antenatal visit—The most significant factor responsible for the low uptake of antenatal services among MWHIV was limited knowledge of antenatal care. The MWHIV participants indicated that their knowledge about antenatal care mainly came from their fellow migrants and friends. A significant proportion of MWHIV participants was not clear that permanent residency (“*Hukou*”) is not necessarily required for antenatal care until late pregnancy. Most MWHIV lacked sufficient information on their entitlements (such as vouchers for free antenatal visits) and thus could not take advantage of the preferential treatment and amenities available to them.

“My husband had a little conflict with the doctor at that time, because the doctor told us to register in the pregnancy registration database to receive free check-ups. But my husband believed that was a scam just to hook us up.” (26 years old, junior high graduate)

2. HIV testing—Provider participants reported that some private hospitals do not routinely perform HIV testing as an integral part of antenatal care services. Some hospitals bundled free HIV testing with other antenatal check-ups and charge approximately 200 RMB (approximately 32 USD), which could be a financial burden for some MWHIV.

HIV-related stigma and discrimination significantly hindered the MWHIV's service seeking and interrupted their communication with service providers. MWHIV were hesitant to discuss their serostatus with providers because they perceived lack of confidentiality protection in hospital.

“I also blame myself for not telling the doctor about my infection, but at that time there were so many people in the room. There were patients and their family members, men and women. I was scared and did not know how to bring this up.” (27 years old, junior college graduate)

3. ART for MWHIV—Although the national regulation stipulates that HIV-positive status should only be revealed to the patient him/herself,³⁰ in one case the provider only informed the husband of the wife's HIV status. Not knowing one's HIV status acts as a barrier to ART treatment adherence.

“The doctor first told my husband about my HIV infection, but my husband did not tell me about it. One day he brought back some medicine and told me that it was dietary supplements. He asked me to take it regularly but I did not take it seriously. I did not know my HIV until I gave birth to my son, and I already breastfed him for a while.” (40 year old, elementary school graduate)

Some MWHIV participants expressed confusion about perinatal ART use. Some had concerns that ART drugs would cause birth defects and/or miscarriages. As a result, they chose to reduce dosage or even stop taking the medication without consulting a doctor. Cultural beliefs could also impact ART use. For example, an ethnic minority woman believed that in their cultural traditions, taking medication is not allowed during the first month of delivery.

4. Antenatal and intrapartum care—Perceived stigma and break-down in provider-patient communication led to poor retention in antenatal care. Some MWHIV participants experienced a number of negative encounters and had become more distrustful of their providers. Some reported avoiding antenatal visits because of the fear of discriminations from service providers.

“After delivery I found that my hospital bill was almost twice as high as other HIV-negative mothers'. The doctors explained that the stuff I have used needed special sterilization, which I need to pay for.” (28 year old, elementary school graduate)

Some MWHIV chose to deliver in a different hospital than the one they received antenatal care, hoping that they would not be treated differently if the providers did not know of their HIV status. The National Health and Family Planning Commission (2013)³¹ has demanded that healthcare facilities with inadequate capacity should refer patients with HIV to local designated AIDS hospitals. The regulation resulted in more MWHIV being “pushed away” to the designated AIDS hospitals for perinatal services, which was an undesirable option from the patients' perspective since receiving care from these hospitals often labelled them as HIV-positive.

Antenatal care is especially challenging for MWHIV who had unplanned pregnancy. They often struggle with the decision whether to terminate the pregnancy or not, which delay the antenatal care and PMTCT services.

“I was told that the medicine I was taking could potentially cause birth defects, so I struggled for quite a while if I should keep the baby. I decided to get an abortion when I was six-month pregnant, but I was told that I would need approval from my hometown to get an induced labor. That was impossible for me because my hometown was thousands of miles away. So I had to keep the baby and I did not receive any proper check-ups throughout the whole pregnancy.” (40 year old, elementary school graduate)

5. Postpartum care for infant and mother—Two MWHIV participants indicated that they had no knowledge about the formula allowances or did not know where to obtain the allowance. Most MWHIV in the study reported no difficulty obtaining or administering ART regimen for their newborns. Very few MWHIV reported ever missing dose of infant ART, as the protection of the baby is their utmost concern. However, their own health issues had taken less of a priority. Several MWHIV participants recalled that they had forgotten to take their own ART medications or missed medical appointments because baby-caring consumed most of their time and energy.

There is a lack of a networked information system to follow-up with MWHIV. The providers would not be able to track a relocated MWHIV if she did not actively update the contact information with CWCH or CDC. MWHIV and their children often fall out of care not knowing where to seek healthcare services outside of their home region.

Potential Strategies to Improve PMTCT Cascade

The healthcare professionals admitted that although multiple strategies, such as distributing information brochures, service hotlines, and community bulletin board, have been used to promote antenatal care, the information failed to penetrate into the migrant population. A CHCW provider suggested that community-based health education should be strengthened to improve the knowledge of antenatal care services. The education and communication activities should target not only the pregnant women but also reproductive-aged women and their husbands/partners. Some healthcare administrators indicated that they would consider involving major employers of migrant populations (such as factories, restaurants, and construction sites) in the advocacy efforts.

Several MWHIV reported that mobile phone applications were preferred and most-used channel of seeking health-related information. Healthcare professionals agreed that mobile-based publicity platform, such as WeChat (www.wechat.com), is a popular way to exchange information among the younger generation. It would be a feasible and effective channel to reach out and engage the reproductive-aged migrant populations in perinatal care.

The healthcare professionals acknowledged that lack of privacy protection resulted in patients concealing their HIV serostatus and inefficient provider-patient communication. However, they perceived that currently it was challenging to guarantee a private room for every patient due to the limited resources in the healthcare settings. The healthcare professionals agreed that hospital management and service provider training need to be strengthened to ensure the privacy protection of patients.

The issue of HIV/AIDS designated hospital was debated among healthcare professionals. A significant proportion of healthcare professional participants supported the idea of separated treatment for patients with HIV, as they argued that designated AIDS hospitals would have better patient management, infection control, and staff preparedness. The two providers from general hospitals indicated that they had limited knowledge and experiences treating PWHIV, and they would like to receive more training and guidance from specialized doctors. They also indicated that if they were informed of the low risk of occupational HIV infection, they would be more willing to provide care for patients with HIV. The possibility

of integrating postpartum care with neonatal check-up was also discussed, and the healthcare professionals considered it difficult to achieve since postpartum care and neonatal care require different areas of expertise.

Discussion

This cascade mapping in the study served as a starting point to further investigate the performance along each step of the PMTCT service continuum and to identify solutions for service improvement.^{32,33} The challenges identified in the study, such as patients' limited understanding of PMTCT, societal stigma, poor provider-patient communication, and inadequate collaboration between health sectors, echoed the reports of previous studies using different methodologies.^{6,9} The involvement of both healthcare professionals and MWHIV in a multi-round discussion prompted (indirect) opinion exchange between the two groups and simulated problem solving endeavor.²⁰ Healthcare professionals are recommended to perform this exercise on a regular basis as it allows them to self-examine their compliance with the PMTCT national guideline and recognize their service gaps. In this study, the exercise has brought force several strategies to improve the PMTCT services, which are discussed below.

The first antenatal visit serves as an entry point to the PMTCT cascade, because it is usually when the HIV testing and/or linkage to ART takes place,³⁴ yet it presents a major constraint to the service uptake in China. Despite the continued advocacy, the message failed to diffuse into the target population. The MWHIV participants indicated that they were unclear with when, where, and how to start appropriate PMTCT services. Due to the lack of knowledge, MWHIV could not benefit from the favorable policies that are staged for the promotion of PMTCT services. As proposed by a healthcare professional participant, health education and promotion effort should go beyond pregnant women and involve the general public, especially all women at reproductive age and their husbands/partners, to improve their understanding of family planning and gynecological services. The mobile technologies should be utilized to promote services utilization and retention. In addition, since the MWHIV in the study indicated that their antenatal knowledge was mainly obtained from their fellow and friends, peer education and support among migrant women could potentially be an effective strategy to extend current HIV educational efforts.³⁵

The healthcare professionals in the study expressed their favorable attitude towards HIV designated hospital. However, it should be noted that the single-disease treatment model is not the patients' preference as it might result in stereotyping and segregation, stigma and discrimination, loss of freedom of choice, and suboptimal healthcare.³⁶ As opposed to HIV designated hospitals, WHO recommended decentralization of HIV care because it may ease the burden of health system, improve access to care, and reduce service attrition.³⁷ To ensure the quality of decentralized healthcare services, it requires providers in general hospitals to receive appropriate and sufficient training, which should emphasize the patients' right to equal treatment and protection of patient's confidentiality. Reinforcement of universal precaution in medical settings could reduce the providers' avoidance to treat HIV patients and should be incorporated into providers' routine in-service training.³⁸

PMTCT continuum should not stop at birth, as continued ART of mothers, proper infant feeding, and neonatal prophylaxes are critical to reduce the risk of new pediatric infection.³⁹ To follow-up with postpartum MWHIV and their infants in two distinct healthcare systems may present a challenge for patients and could potentially contribute to service incompleteness or termination. Integrated postpartum and neonatal services could improve the user's engagement to the care continuum.⁴⁰ However, as pointed out by the healthcare professional participants, provision of multiple services during a single point of contact is challenging as it requires service providers to have expertise in all aspects of concern. Injudicious service integration could potentially lead to undesirable consequences such as increased provider workload, long waiting time, and reduced consultation time.⁴¹ Policy makers and hospital stakeholders should carefully consider the pros and cons of integrated services. Improving communication and collaboration among different health sectors are suggested as a key strategy to enhance service access, efficiency, and patient satisfaction.^{40,41}

There are several limitations in this study. First, the study was conducted in one province of China and the findings may not be generalizable to other areas in which the economic situation and PMTCT implementations are different. Second, the focus group participants may not have expressed their honest opinions due to the influence of other participants. Third, the MWHIV participants were recruited from hospitals and their perception of healthcare services may be overrated as compared to those who could not have been reached through this recruitment strategy.

In conclusion, the study demonstrated an exercise, which aroused the awareness of service gaps among healthcare professionals, and resulted in strategies to improve the service continuum. The findings suggested that, in order to reduce the missed opportunities for PMTCT services for MWHIV, education effort should target the general public, especially reproductive-aged men and women. There is a need to reduce HIV-related stigma in healthcare settings, to improve HIV-related service quality in general hospitals, and to promote collaboration among different healthcare sectors.

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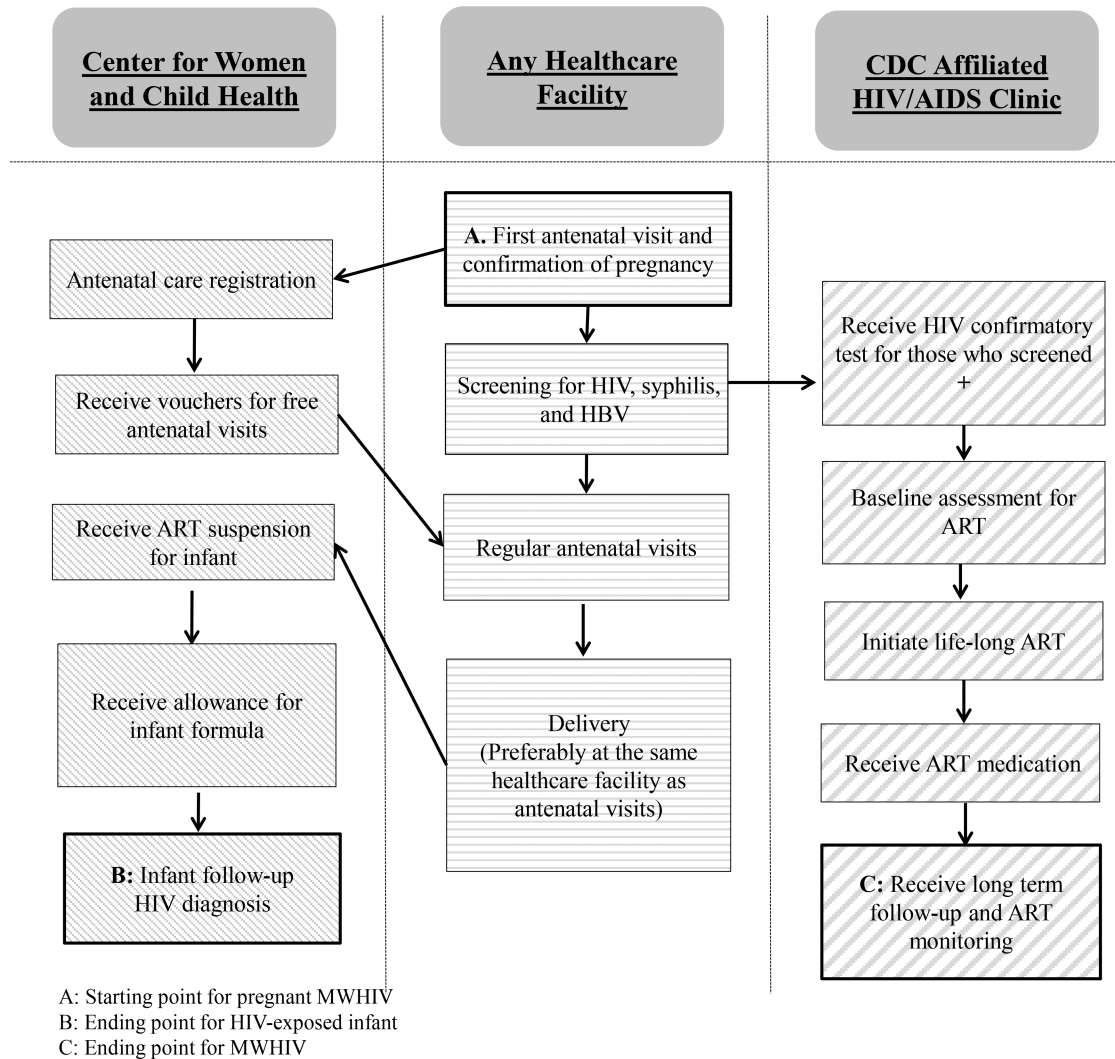


Figure 1 :
Prevention of Mother to Child Transmission of HIV Service Cross-functional Flow chart

Table 1.

Sample characteristics

Service provider Characteristics		
Gender		
Male	4	40.0%
Female	6	60.0%
Affiliation		
Maternal and Child hospital	2	20.0%
OB/GYN Department of general hospital	2	20.0%
CDC affiliated HIV/AIDS clinics	3	30.0%
HIV/AIDS designated hospitals	3	30.0%
Healthcare Administrator/Community Representative Characteristics		
Gender		
Male	6	60.0%
Female	4	40.0%
Affiliation		
Department of Health	1	10.0%
Center for Women and Child Health	3	30.0%
Local Resident Committees	3	30.0%
Women and Youth Organization	1	10.0%
Family Planning Commission	2	20.0%
MWHIV Characteristics		
Age (mean=27.8, range: 22–40)		
25 years or younger	5	25.0%
26–30 years	11	55.0%
31 years or older	4	20.0%
Education		
Elementary school or below	7	35.0%
Junior high	6	30.0%
Senior high	3	15.0%
Junior college or above	4	20.0%
Transmission Route		
Blood infusion	3	15.0%
Sexual transmission	9	45.0%
Unclear	8	40.0%