Factors Influencing HIV-positive Expectant Mothers’ Adherence to ARV Prophylaxis (PMTCT) in a Healthcare Facility in the Hhohho Region, Swaziland

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Abstract - The availability of antiretroviral therapy [ART] prophylactic medication through the Prevention of Mother-to-Child Transmission [PMTCT] of HIV program has transformed lives, but success depends upon optimum adherence to guidelines. The purpose of this study was to determine and describe factors influencing HIV-positive expectant mothers’ adherence to ART prophylaxis. Using descriptive design, 30 HIV-positive mothers 19 – 44 years old were selected by simple random sampling to complete a medication adherence questionnaire.

Findings revealed that better sense of health, familiarity with therapy, and good patient-healthcare provider relationships promoted adherence to ART prophylaxis. Adherence improved with increase in participants’ education level. Forgetting to take medication, lack of disclosure, limited social support, and self-perceived stigma contributed to poor adherence. HIV-positive expectant mothers need to be advised on strategies to disclose and effectively cope with self-perceived stigma. Minimization of staff turnover helps clients maintain rapport with health care providers.

Key words: HIV, prevention of mother-to-child transmission [PMTCT], adherence, antiretroviral therapy (ART), expectant mothers

Introduction and Background

The epidemic of the Human Immunodeficiency virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) in Swaziland continues to soar as evidenced by the high prevalence indicated by the 2006-07 Swaziland Demographic Health Survey; 26% of Swazis between the ages of 15–49 were infected with HIV; of these, the prevalence between the group aged 20–24 compared to those aged 25–29 was 26.5% and 39.3%, respectively (Swaziland Central Statistical Office, 2008). However, the prevalence among females was much higher than among males (31% and 20%, respectively). Between 1992 and 2010, there has been an alarming increase in the prevalence of HIV among expectant mothers, with the rates rising from 3.9% to
41.1% during that time span (Swaziland Ministry of Health [SMoH], 2010, November). The prevalence of HIV in 2010 was highest (53.8%) among those aged 30–34 years and lowest (20.4%) among those aged 15–19 years (SMoH, 2010, November).

HIV prevalence is high in Swaziland, and, without antiretroviral therapy (ART), expectant mothers have a 15–45% chance that their child will also become infected with HIV (WHO, 2010b). Pregnant mothers could transmit HIV to the baby by several routes: trans-placental, during delivery and during the breastfeeding process (Hampanda, 2013). Mother-to-child transmission (MTCT) accounted for 18.4% and 15.4% of newborn HIV infection in 2010 and 2011, respectively (Kingdom of Swaziland, 2012). However, the introduction of ART during pregnancy and continuing through breastfeeding among women who are HIV-positive may decrease the risk of MTCT by 42% (WHO 2010a).

The rate of HIV infection in children is reversing gains made in reduction of child mortality, and has significantly lowered the overall life expectancy in the worst-hit countries (WHO, 2010a), such as Swaziland. According to WHO (2010a), about half of the children who are infected with HIV through vertical transmission develop AIDS symptoms and die within the first two years of life. A child who is infected through MTCT is also at-risk of being orphaned; and the father is also likely to be infected with HIV. In the absence of efficient life-prolonging interventions, the likelihood of the parent(s) dying within 8–10 years after acquiring HIV infection is high. Recent estimates suggest that there are nearly 14 million children who have been orphaned in Africa, and this number was projected to rise to a staggering 25 million by the year 2010 (WHO, 2010a).

The crude death rate has more than doubled from 13.1 deaths per 1000 in 1997 to 31.1 deaths per 1000 population in 2007. Furthermore, by 2015, annual AIDS deaths are projected to increase from 7,114 in 2009 to 8,389 per 100,000 (UNAIDS, 2010). Mortality related to HIV and AIDS has lowered life the expectancy in Swaziland by 18 years: from 56 to 38 years between the years 1997–2000 (SMoH, 2000).

In 2002, ART began to be rolled out in Swaziland, following which there has been an encouraging increase in life expectancy. According to WHO (2014), the life expectancy in Swaziland was 52 and 55 years for females and males, respectively, in 2012. This loss of life expectancy prevents individuals from contributing fully to the economic development, and will have long lasting implications for the social fabric and the structure of families. Reduced life expectancy affects the survival of communities and the social capital within them, and erodes the financial capital of individual households and the country as a whole (Whiteside et al., 2006).

In 2003, the government of Swaziland launched the Prevention of Mother-to-Child (PMTCT) program to reduce the probability of transmitting HIV from the expectant mother to her baby. This program utilizes a four-pronged approach to the prevention of HIV infection in women and infants: prevention of HIV infection among young women; prevention of
unintended pregnancies among HIV-positive women; reduction of MTCT of HIV; and the provision of treatment, care, and support for HIV-positive women and their families (WHO, 2002). In 2012, Swaziland committed to the elimination of new HIV infections in children and keeping their mothers alive through the comprehensive up-scaling of PMTCT (Panos Institute, 2012). Currently, approximately 150 (out of 172) health facilities provide PMTCT services (Panos Institute, 2012). As a result of the high priority given to this program, significant progress has been made.

It is recommended that pregnant mothers report for antenatal care (ANC) before 14 weeks gestation (SMoH, 2010). This allows the mothers to be tested for HIV; those eligible begin taking ART that will prevent or reduce the probability of transmitting HIV to the unborn baby. To ensure that there are reduced losses due to seroconversion after the initial test, HIV-negative expectant mothers are retested every eight weeks. Again they are tested at 36 weeks gestation, and throughout the breastfeeding period to identify any emergence of HIV infection as soon as possible. This practice has resulted into tremendous gains in the reduction of MTCT (SMoH, 2010).

In 2011, 94.5% (10,641) of all HIV-positive expectant mothers were provided with ART prophylaxis to reduce MTCT. This represents a substantial increase in the provision of ART prophylaxis among pregnant women, from 69% reported in 2009 up to 77% in 2010 (Kingdom of Swaziland, 2012). In order for ART prophylaxis to be effective and efficient, the mothers’ adherence to treatment is required; lack of commitment by clients could render the program ineffective (SMoH, 2010).

Research has revealed that there is a challenge with adherence to ART prophylaxis among HIV-positive expectant mothers (Igwebde, Ugboaja, & Nwajiaku, 2010; Mepham, Zondi, Mbuyazi, Mkhwanazi & Newell, 2011; Peltzer, Sikwanr, & Majaja, 2011). Poor adherence to ART prophylaxis among HIV-positive expectant mothers is directly linked to the high rate of MTCT of HIV. However, in Swaziland there is limited documentation on HIV-positive expectant mothers’ adherence to ART prophylaxis, hence, this study.

The estimated pediatric HIV infection in children aged 0–14 years in Swaziland is 14 per 1,000 infants (SMoH, 2010). Infants who are HIV infected have serious life problems requiring more of the family’s resources. In addition, the infants are more likely to die from HIV-related complications. Not only are sick babies a physical burden, they affect their families psychologically, financially, and emotionally. The presence of a sick infant in the family could strain the family relations. Mothers of sick babies have to pay more attention to the baby and their own health may become neglected. The purpose of this study was to determine and describe factors influencing HIV-positive expectant mothers’ adherence to ART prophylaxis.

The objectives of the study were to:

1. Describe the socio-demographic variables of expectant HIV-positive mothers enrolled in ART prophylaxis.
2. Identify factors influencing HIV-positive expectant mothers’ adherence to ART prophylaxis.

3. Determine relationships among the identified factors that influenced expectant mothers’ adherence to ART prophylaxis.

Methodology
Design, Setting, and Sample
The study was conducted in the Hhohho Region utilizing a descriptive design. The population consisted of all HIV-positive pregnant women on ARV prophylaxis attending ANC at the Mbabane Public Health Unit. The participants, all Swazis between 19–44 years of age, were selected using the random sampling method. Other nationalities were excluded because they may have had practices related to adherence to medication that may differ from those of Swazis. Based on Lipsey (1990), an effect size of 0.50, power of 0.80, and an alpha ≤ 0.05 were used to determine the sample size. The sample comprised n = 30 participants who were interviewed.

Data Collection Tool, Validity and Reliability, and Data Analysis
The Patient Medication Adherence Questionnaire (PMAQ V_1.0; DeMasi et al., 2001) was adapted and used to collect data from the participants. The tool was translated into Swazi, the language spoken by the women in the villages.

According to DeMasi et al. (2001), the psychometric evaluation of the PMAQ-V1.0 used Cronbach’s alpha and item-scale Pearson correlation and the reliability total score was 0.76. Although mean Cronbach’s alpha for each dimension were lower than had been hypothesized, the reliability was considered adequate (DeMasi et al., 2001).

Data were analyzed utilizing the Statistical Package of Social Sciences (SPSS, version 17.0). Descriptive statistics and Pearson’s Correlation Coefficient were applied.

Ethical Considerations
The study was performed in compliance with the Ministry of Health Scientific and Ethics Committee guidelines. Permission to conduct the study was sought and received from the Ministry of Health Scientific and Ethics Committee.

Results
The study findings are presented according to the research objectives.

Research Objective 1: Describe the socio-demographic variables of expectant HIV-positive mothers on ARV prophylaxis.

The sample had a mean age of 28.0 and a standard deviation of 5.5 years (see Table 1). Most (70%, n = 21) participants reported that they were single, and 26.7% (n = 8) reported that they were married. Less than half (46.7%, n = 14) of the participants reported that they were not employed. Forty percent (n = 12) were employed, and 13.3% (n = 4) were self-employed. Sixty percent (n = 18) of the participants revealed that they had secondary education, followed by 23.3% (n = 7) who had primary education, and only 10% (n = 3) who had tertiary education.

Forty-three percent (43.3%, n = 13) of the participants reported that they lived at a distance of about five (5) to 10 kilometers from the health care facility, and 40% (n = 12) lived within a distance of less than five (5) kilometers from the facility. The majority
(70.0%, n = 21) of the participants reported that they were Christian.

Thirty-seven percent (36.7%, n = 11) of the participants reported that they lived with families of five (5) or more members, whereas 33.3% (n = 10) reported their family to include 1–2 people. Most (90%, n = 27) of the participants reported that they had disclosed their HIV status to at least one person. Seventy percent (n = 21) of the participants reported that they received social support from other people, while 30% (n = 9) reported that they had not received social support from anybody. Of the participants who had received social support, most (71.4%, n = 15) reported that support had been provided by their partners, while 14.3% (n = 3) of the participants reported that social support came from siblings. The participants reported to have taken ART prophylaxis for a mean period of 12.8 months. This means that some participants were already on ART prior to conception.
Table 1
*Swazi expectant mothers’ socio-demographics (N = 30)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
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<tr>
<td>Age (yrs.)</td>
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<tr>
<td>Married</td>
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<td>26.7</td>
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<tr>
<td>Widowed</td>
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<tr>
<td>Self employed</td>
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<td>13.3</td>
</tr>
<tr>
<td>Unemployed</td>
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<td>3.3</td>
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<tr>
<td><em>Sebenta</em> (adult literacy)</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td>Primary school</td>
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<td>23.3</td>
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<tr>
<td>Secondary school</td>
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<td>60.0</td>
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<tr>
<td>Tertiary education</td>
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<td>10.0</td>
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<td>70.0</td>
</tr>
<tr>
<td>Other</td>
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<table>
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<tr>
<th>Family size</th>
<th>Number</th>
<th>%</th>
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<tbody>
<tr>
<td>1–2 members</td>
<td>10</td>
<td>33.3</td>
</tr>
<tr>
<td>3–4 members</td>
<td>9</td>
<td>30.0</td>
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<tr>
<td>≥5 members</td>
<td>11</td>
<td>36.7</td>
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<table>
<thead>
<tr>
<th>Disclosed HIV status</th>
<th>Number</th>
<th>%</th>
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<tr>
<td>Had disclosed HIV status</td>
<td>27</td>
<td>90.0</td>
</tr>
<tr>
<td>Had not disclosed HIV status</td>
<td>3</td>
<td>10.0</td>
</tr>
<tr>
<td>Period on ARV prophylaxis in months</td>
<td>12.8</td>
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</table>
Research Objective 2: Identify factors influencing HIV-positive expectant mothers’ adherence to ART prophylaxis.

Intra-personal related factor: Remembering. Ninety-seven percent (96.7%, n = 29) of the participants reported that they did not have trouble remembering to get ART refill. However, half (50%, n = 15) of the participants reported that they had not taken ART as prescribed during the past week. Eighty percent (80%, n = 24) of the participants reported that they did not have any difficulty remembering to take ART whenever they left their place of residence. A slight majority (53.3%, n = 16) of the participants reported that they did not miss ART doses when they had more medication to take.

Sixty-seven percent (66.7%, n = 20) of the participants reported that they took ART on time. All (100%, n = 30) of the participants reported that they took ART as prescribed. Most (90%, n = 27) of the participants reported that they took ART whenever they were away from home. Ninety percent (n = 27) of the participants reported that they took ART even when they felt tired.

Intra-personal related factor: Sense of health. Eighty percent (n = 24) of the participants reported that taking ART resulted in a better sense of health. Ninety-three percent (93.3%, n = 28) of the participants reported that they did not discontinue taking ART when their health had improved. Many (43.3%, n = 13) of the participants reported that they took ART even when they did not have food.

Intra-personal related factor: Familiarity with medication. Ninety percent (n = 27) of the participants reported that they were familiar with their prescribed ART regimen. All (100%, n = 30) of the participants reported that they did not take more medication than was prescribed. Eighty-seven percent (86.7%, n = 26) of the participants reported that they did not have difficulty taking ART even when they were too busy. Most (83.3%, n = 25) of the participants reported that they did not have any difficulty in taking ART because of its unpalatable taste.

A majority (76.7%, n = 23) of the participants reported that they took ART when they experienced side effects. Most (93.3%, n = 28) of the participants reported that they did not have difficulties in swallowing their medication.

Patient-provider relationship factor: Client involvement in decision-making. A majority (90%, n = 27) of the participants reported that they had a good relationship with the health care providers, which facilitated discussion about ART. Most (86.7%, n = 26) of the participants reported that health care providers ensured that the participant had a plan fitting her medication dosing into their personal routine. Furthermore, 93.3% (n = 28) of the participants reported that the health care providers allowed participants to take part in decision-making about their ART regimen.

Patient-provider relationship factor: Empathy. Fifty-seven percent (56.7%, n = 17) of the participants reported that health care providers understood how difficult it was to follow the ART regimen. A majority (86.7%, n = 26) of the participants reported that health care providers wanted to know problems that participants had that made it hard to take medication. Ninety-seven percent (96.7%, n = 29) of the participants reported that health care providers made time for clients to get information they (clients) needed to know about ART.

Social factor: Social support. Most (83.3%, n = 25) of the participants reported that their family and friends encouraged the use of ART to control HIV. Eighty-three percent (83.3%, n = 25) of the participants
reported that they had family and friends who really understood them.

**Social factor: Self-perceived stigma.** The majority (63.3%, n = 19,) of the participants reported that they had difficulty taking ART when privacy was compromised. A significant number (70%, n = 21) of the participants reported that they felt uncomfortable with people knowing they were taking ART.

Research Objective 3: Determine relationships among the identified factors that influenced expectant mothers’ adherence to ART prophylaxis.

There was a negative ($r = -0.822, p = 0.01$) correlation between familiarity with ART and difficulty swallowing medication. This means that with an increase in familiarity with prescribed ART regimen there was a decrease in difficulty swallowing ART.

A negative ($r = -0.422, p = 0.05$) correlation between education and ART resulting in better sense of health was found. This revealed that an increase in education level was accompanied by a decrease in the belief that ART did not result in a better sense of health.

Finally, there was a positive ($r = 0.392, p \leq 0.032$) correlation between education and taking ART when tired. This means that with an increase in educational level, there was an increase in taking medication even when tired.

**Discussion**

The purpose of this study was to determine and describe factors influencing HIV-positive expectant mothers’ adherence to ART prophylaxis. Similar to the research of Kuonza, Tshuma, Shambira and Tshimanga (2010), in our study we found that education had a positive impact on adherence to ART prophylaxis. Kuonza, Tshuma, Shambira and Tshimanga, (2010), in a study conducted in Zimbabwe, revealed that mothers who had no secondary education were twice as likely to have poor adherence to the maternal dose of nevirapine (an ART prophylactic drug) when compared to those who had secondary education. Education enhances communication between the mother and healthcare providers and also improves retention of information provided, leading to better implementation of recommended interventions. Education also enlightens and empowers women to become autonomous in making important decisions without relying on other people (Abu-Rabia-Queder, 2008) including close family members.

In harmony with previous research (Deribe, Woldemichael, Wondafresh, Haile, & Amberbir, 2008; Negese et al., 2012), we found that most participants had disclosed their HIV status. Disclosure plays a major role in curbing the spread of HIV and in promoting adherence to ART. Disclosure can be accompanied by several benefits. These include enhanced acceptance of HIV status; reduced stress of coping in isolation; improved access to health services, care and support; and increased protection for oneself and others from contracting HIV or reinfection with HIV (Negese et al., 2012). Openness about HIV status could help the expectant mother to negotiate for safer sex practices. Disclosure could assist in the reduction of stigma, discrimination, and denial surrounding HIV and AIDS. It could facilitate the promotion of responsibility. Furthermore, disclosure could enable the expectant mother and her loved ones to plan for the future.

Similar to previous research (Igwegbe, Ugboaja, & Nwajiaku, 2010), some participants revealed that they had forgotten to take their ART prophylaxis. Forgetting to take medication could increase the likelihood of HIV transmission to the baby, partner infection or reinfection, development of drug resistance, and continued viral replication accompanied by...
increased morbidity and mortality (Igwegbe et al., 2010).

Consistent with Pratt (2003), good patient-healthcare provider relationships promoted adherence to PMTCT. According to Pratt (2003), the collaborative nature of treatment decisions in HIV care is essential in promoting adherence. In order to achieve engagement with the client, the health care provider needs to use a range of interpersonal and clinical skills. These include good communication skills, being sensitive to the needs and limitations of the client, and developing an understanding of the client’s situation (Pratt, 2003). However, it was beyond the scope of this study to determine the health care providers’ skills which facilitated the expectant mothers’ adherence.

Comparable to the findings of the National Multi-Sectoral Strategic Framework for HIV and AIDS 2009-2014 (National Emergency Response Council on HIV and AIDS [NERCHA], 2009), we found that self-perceived stigma contributed to poor adherence to PMTCT. It is reported that women may hide their medication from their husbands / partners in fear of being ostracized, resulting in poor adherence to medication schedules. Self-perceived stigma has been reported as the main reason most clients fail to adhere to ART in Swaziland (Makoae et al., 2009).

Adherence to PMTCT was reported by the expectant mothers in spite of poverty, side effects, and improved sense of wellbeing. According to Root and Whiteside (2013), women are willing to take ART so that they might live longer and be able to take care of their children. Furthermore, it is likely that the expectant mothers adhere to ART prophylaxis in order to increase the possibility of giving birth to healthy HIV-negative babies.

Consistent with previous research (Komter, Voorpostel, & Pels, 2011; Voorpostel, van der Lippe, & Flap, 2012), participants reported limited sibling support. This finding could be related to stigma associated with HIV. However, the siblings may also have fears that their unknown HIV status may be positive too. Limited sibling social support needs to be explored further.

The participants reported that they took ART even when they did not have food. Moreover, 40.7% of the participants were unemployed. According to NERCHA (2010), ART is better tolerated by adequately nourished clients, and, as with many other medications, ART need to be consumed with food. While ART should not be delayed for clients whose health is deteriorating, the ART regime is harder for the food-insecure clients. The availability of food serves as a determinant of patients’ adherence to ART prophylactic treatment among pregnant women.

Based on the study findings several recommendations are made for practice, education, and research:

**Practice**

Health care workers need to

1. Develop an individualized adherence tool that will be kept in the clients health care records. This will ensure meticulously follow-up of clients with adherence problems.
2. Teach clients strategies for coping with self-perceived stigma.
3. Monitor the client through telephone on a weekly basis with reminders on how to take medication. This is important, considering that some clients have a low educational level.
4. Maintain good patient-healthcare provider relationships for sustained adherence to PMTCT, consequently improving client
quality of life and prolonging life expectancy.
5. Encourage expectant mothers to engage in income-generating projects so as to overcome poverty.
6. Encourage couple counselling so as to overcome challenges related to disclosure to partner.
7. Advocate for policy that will compel active partner involvement in maternal and child services.
8. Reinforce peer education, whereby clients who have successfully gone through the PMTCT program are equipped to advise other clients.

Education
There is need to reinforce the importance of adherence to ART prophylaxis in the pre-service and Continuing Professional Development (CPD) curriculum, because of the detrimental consequences related to poor adherence.

Research
There is need to replicate this study on a larger scale for inference to HIV-positive pregnant women beyond the Hhohho Region of Swaziland.

Summary and Conclusion
The study findings need to be considered within its limitations. This was a cross-sectional study which obtained self-reported data from a sample in one (1) health facility. Self-reported data from participants might have resulted in under / over-reporting adherence to ART. The single setting for data collection limits inference of the study results. However, the study revealed important findings on factors that influence expectant mothers’ adherence to ART. Better awareness of health, familiarity with therapy, and good patient-healthcare provider relationships promoted adherence to ART prophylactic treatment among HIV-positive expectant mothers. Furthermore, there was improved adherence with increase in the participants’ education level. On the contrary, forgetting to take medication, lack of disclosure, limited social support, and self-perceived social stigma contributed to poor adherence to ART prophylaxis. Expectant mothers need to be advised on strategies to disclose HIV-positive status and effectively cope with self-perceived stigma. Minimization of staff turnover helps clients maintain rapport with health care providers.
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