

Adherence to ART Among Pregnant Women Living with HIV/AIDS in Lusaka Urban

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Abstract

Background

Adherence to ART is a challenge among pregnant women living with HIV/AIDS. This has an effect on the health of the mother and the unborn child. While studies have been done, it has shown that adherence during pregnancy is a challenge. Virological and clinical success depend critically on high adherence to ART because with low adherence. The success of expanded ART coverage in improving health outcomes depends on adherence to treatment. During pregnancy, a compromised virological response to ART also increases risk of mother-to-child transmission (MTCT) of HIV. This study was carried out to determine factors that influence adherence to antiretroviral therapy among HIV positive pregnant women in Lusaka district of Zambia.

Methodology

This was a qualitative study which used a case study approach. Data was collected through in-depth interviews. The collected data was analysed using a thematic analytical approach.

Results

17 pregnant women living with HIV/AIDS in Lusaka had challenges with adherence to ART. The study explored factors related to adherence to ART among pregnant women living with HIV/AIDS. ART adherence was found to be low. The findings call for the need to reduce social stigma. The results confirmed that there is low adherence to ART among pregnant women living with HIV/AIDS in Lusaka.

Conclusion

Adherence to ART among pregnant women living with HIV/AIDS is a challenge for Zambian pregnant women. Improved levels of adherence to ART is hampered by fear of social stigma, and fear of being blamed by partners if they disclosed their status. Stigmatisation needs to be addressed because nearly all the participants expressed this factor. There is need to address the HIV/AIDS stigma very seriously in order for society to look at HIV/AIDS like any other illness.

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Introduction

Antiretroviral therapy (ART) during pregnancy should focus on the reduction of perinatal transmission and the treatment of maternal human immunodeficiency virus (HIV) disease. ART can reduce perinatal transmission by several mechanisms, including lowering maternal antepartum viral load and pre-exposure prophylaxis of the infant. Therefore, for prevention of perinatal transmission of HIV to be achieved there is need to ensure there is adherence to prescribed ART. Adherence continues to be a major public health concern in both high-income and low-income countries. Different Studies have shown that virologic and clinical success depends critically on good adherence to ART. With poor adherence, the virus quickly develops therapy-limiting drug resistance (WHO, 2010). Studies prior to 2005 using older Combined Antiretroviral Therapy (CART) regimens suggested that sustained virological suppression is achieved only if at least 95% of prescribed doses are taken (J B Nachega 2007).

Background

Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) is a global pandemic and a major health problem in many countries. According to the World Health Organization (WHO) report it has been estimated that 1.6 million more people were receiving ART in low- and middle-income countries at the end of 2012, compared to the previous years, this was the largest annual increase ever, with the greatest contribution coming from the WHO African Region (UNAID/WHO,2008)²⁷. The 300 000 people who were receiving ART in low-and middle-income countries in 2002 increased to 9.7 million in 2012. In the WHO African Region, which continues to bear the brunt of the HIV epidemic, more than 7.5 million people were receiving treatment at the end of 2012 compared to 50 000 people a decade earlier (WHO,2010). In 2012, over 900 000 pregnant women living with HIV received Antiretroviral Therapy (ARV) prophylaxis or treatment for Prevention of Mother to Child Transmission (PMTCT) (WHO 2013).

Problem Statement

Zambia's prevalence of HIV/AIDS is at 14.3% inclusive of pregnant women living with HIV/AIDS. Sub-Saharan Africa contains over 60% of the world's

HIV infections and Zambia is among the most severely affected countries in the region. An estimated 1.1 million Zambians are HIV+ and the majority, are women. Beginning in 2004, the Ministry of Health in Zambia has offered antiretroviral therapy (ART) for free in the capital city, Lusaka. This program has expanded rapidly with over 120,000 people receiving ART at over 160 sites throughout the country by 2007. (UNAIDS/WHO, 2007)²⁵.

Zambia scaled up the PMTCT country wide since (with the focus on adherence) since there was a policy shift from PMTCT to universal access to treatment. To get maximum benefits adherence to treatment is cardinal. One of the consequences of non-adherence to treatment is developing drug resistance.

Justification

Data on factors influencing adherence is still not well documented. Little is known about factors affecting adherence to ART among pregnant women in Zambia. Implementation and prevention of new infection and PMTCT is crucial as this reduces on the virological impact. Current studies on this topic in Zambia have focused more on general ART adherence, leaving out the pregnant women. As adherence to ART during pregnancy is crucial in reducing the viral load and improving the maternal wellbeing of pregnant women living with HIV/AIDS, this study has generated evidence based information on factors that influence adherence. The generated information will inform policy makers to formulate factual based health promotion strategies that will enhance adherence. Therefore it was important to explore factors that influence adherence to ART among pregnant women.

Literature Review

In order to facilitate better outcomes for HIV-positive pregnant women there is need to examine the factors that influence adherence to ART. The process of adherence, and its impact on maternal wellbeing of the pregnant woman and her unborn child is critical and challenging (Nachega et al 2006)¹⁹. This chapter has reviewed different studies relating to factors affecting the adherence to ART among pregnant women living with HIV/AIDS. Most of the literature discussed in this study are mainly based and informed by studies conducted in Africa and various parts of the world.

Adherence to Art

Adherence

While antiretroviral therapy has improved dramatically the clinical status of many pregnant women with HIV infection, attention is increasingly focusing on the role of treatment adherence to this therapy. Evidence shows that poor adherence to antiretroviral treatment regimens has serious consequences on the health of the pregnant woman and her unborn baby. It has been estimated that if pregnant women adhere at least 95% this maximizes the benefits of ART and improves the virological, immunological and clinical outcomes (Iliyasu, 2005). According to WHO (2003), adherence to long-term therapy is defined as the extent to which a person's behaviour (taking medication, following a diet and/or executing lifestyle changes) corresponds with agreed upon recommendations from a health care provider. National Institute of Health (2008) defines adherence as how closely one follows a prescribed treatment regimen which includes the willingness to start treatment and the ability to take medications exactly as directed (Fogarty et al, 2002)¹¹. Although most studies have focused on adherence to medication, total adherence extends beyond taking prescribed drugs to include other health-related behaviours.

Community Level

A supportive community or interpersonal environment is critical for People Living with HIV (PLWH). High levels of stigma within the community due to lack of education and awareness of HIV has led to reduced levels of adherence to treatment. For example, community members from resource-limited settings in Asia and Africa reported fear and disgust of PLWH in their communities who were at the end stages of the disease, as well as social isolation and public shaming of patients and their families (Maman et al. 2009; Watt et al. 2009) and negative beliefs concerning ART (Kakimoto et al 2009)

Social Stigma

AIDS related stigma has a profound effect on the epidemic's course. World Health Organization (2003) cites fear of stigma and discrimination as the main reason why people are reluctant to adhere to ART treatment. One study found that participants who

reported high levels of stigma were more than four times more likely to report poor access and adherence to ART (Boyce, 2009). Patients reported that perceptions of stigma and fear of discrimination prevented them from taking their medication correctly and at the right time and they could not disclose their status to colleagues, friends, and others. This non-disclosure leads to pregnant women taking their ART medicines secretly and irregularly because of inadequate social support and encouragement (Golin et al, 2002). This wide spread fear of stigma has been held accountable for the relatively low up take of ART and seeking treatment under PMTCT programs in Zambia where treatment is free. In the case of Botswana, for example, despite the fact that the services are available at every antenatal centre in the country only 26% of pregnant women availed themselves of the opportunity to protect their unborn children. Over half refused to take a test, and if they did, nearly half of those who tested positive did not adhere to ART 90%, the required percentage of adherence to ART (Wolfe, W.R et al. 2008).

Environmental Factors

Long distances to ART clinics

In her study in Mumbwa, Zambia, Boyce (2009) noted that distances to ART centres were a challenge and this led to many women failing to adhere to ART. The cost of transport and walking long distance to the clinic was consistently noted as barriers to adherence. Pregnant women living with HIV/AIDS expressed difficulties in balancing their need for transportation to the clinic and any medication costs against the need to pay for food, and other necessities for themselves and their families and as a result, they missed pharmacy pick-ups and other follow-up appointments (Crane et al. 2006; Hardon et al. 2007¹⁰; Mills et al. 2006; Tuller et al. 2009). This study discovered that the majority of women came from far areas, not from the same community of Kalingalinga and surrounding areas of UTH. This was because of fear of stigma and so they preferred to go to areas where they were not known.

Long waiting hours

Many public facilities in sub-Saharan Africa and Zambia being one of the countries, have scaled up ART without a comparable increase in personnel to accommodate the larger number of patients

(Barnighausen et al. 2007; Van Damme, Kober, and Kegels 2008). As a result, health workers are overworked, leading to longer waiting times and deteriorated patient interaction. Long waiting times have been cited as a major challenge to adherence to visits in a Botswana study, where most of the respondents reported that they spent four hours or more at the clinic. Having to take a half or full day off from work to attend clinic visits was challenging for those patients who had not disclosed their status to their employer (Hardon et al. 2007)¹⁰. A study in South Africa found that pregnant women who had to take leave or time off work or lost income as a result of having to visit the clinic were four times more likely to miss a visit (Booyesen and De Wet 2009). This study found that staffing at the two institutions involved in the study was a challenge when it came to staffing levels. For example, the staffing levels at Kalingalinga Clinic were not enough to give adequate attention needed by these women. Pregnant women waited for more than 4 hours and came very early in the morning.

Methodology

Study Design

The study was qualitative by design and therefore a case study approach was used to investigate the contemporary phenomenon within its real-life context (Yin, 1994). A qualitative research aims at describing social phenomena and behaviour using rich contextual data that emphasises the subjective experience of society. In-depth interviews provide a flexible tool to collect narration data, describing interviewer's perspectives. In this case study focus on developing an in-depth description and analysis of this case was done so as to provide an in-depth understanding of this case through studying the event of more than one individual

Study Site

The study was carried out in Lusaka, which is the capital city of Zambia. It has an estimated population of 1.748 million with an annual growth rate of 3.8 per cent and a population density of 65; 4 persons per square kilometres. The University Teaching Hospital and Kalinga Linga Clinic were selected for data collection. UTH being a referral centre with a bed capacity of 1,846. The hospital is an entry point as well

as a referral hospital where complicated cases are referred to. Pregnant women with conditions such as Cardiac conditions and Preeclampsia are referred to UTH from the local clinics. Kalinga Linga Clinic was chosen for its social demographic location. The health Centre is located in a high densely populated area with both low and middle class and an average level of education and income.

Study Population

The study population comprised of pregnant women living with HIV/AIDS on ART for more than six months and whose pregnancy has been confirmed by ultra sound machine and Positive Gravindex Test. These were purposively recruited from the two health facilities of Lusaka (UTH BO2 Clinic and Kalinga Linga Clinic) using PMTCT Register and pharmacy records. Pharmacist and Nurse Midwives directly involved in the provision of ANC care as well as drug dispensing to HIV pregnant women in the selected clinics were also interviewed to get their views of pregnant women's experience on adherence to ART.

Data Collection

Data Collection Procedures

Data collection was done by the researcher who had an understanding of qualitative data collection. Face-to-face in-depth interviews were conducted with eligible research participants using an in-depth interview guide and a key informant interview guide. Key informant interviews were conducted in English while interviews with pregnant women were conducted in English and Nyanja. Interviews were conducted in a location which was considered neutral and conducive to participants. The interviews and discussions took place in a private room located within the health facility. Detailed handwritten interview notes were taken and written in an interview notebook.

Data Collection methods

In-depth interviews (IDIs) and Key informants Interviews are the methods that were used to collect qualitative data in this study. Key informant interviews of pharmacist/ nurse midwives was carried out in their health facilities on potential determinants of ART adherence, utilization of the facilities among pregnant women in accessing ART treatment service, An exploration was done on their experience of attending

to the pregnant women on ART.

Data analysis

All interview transcripts constituted unit of analysis. Unit of analysis refers to all words and phrases of the interview transcripts. Interview notes were read and re-read in order to gain understanding of their content. The interview transcripts were then coded, and the codes were compared for similarities and differences by conducting within-and across-case analysis (Ayres *et al.*, 2003). Similar codes were then grouped together to form categories and then themes were developed by interpreting the categories for their underlying meaning. Data was then analysed using a thematic analysis approach; it was coded manually and organized into themes. Data was then categorized and coded using themes, description of categories and subcategories of data was done and this was followed by identification of major themes which was used in the final analysis of the contents. By using this analytical strategy, we were able to generate experiences among pregnant women living with HIV/AIDS. Interview excerpts were then used to illustrate the themes.

Study Finding

Social Demographic Characteristics (Table 1-3)

This study explored factors related to Adherence to ART among pregnant women living with HIV/AIDS. In my study it was observed that adherence to ART was a challenge that needs to be addressed. Zambia like other countries have scaled up the programmes of providing free ART to pregnant women in order to reduce on maternal child transmission of HIV to the unborn child. It has also embarked on the program of option B+. The scale up of prevention of mother to child transmission of HIV programme are expected to reduce the rate of infants contracting HIV, but this can only be achieved if there is good adherence to ART at least women should adhere to 95% to the drugs if this has to be achieved. Zambia will continue spending a colossal amount of money in treating the pandemic and the HIV rate going up.

The challenges faced by pregnant women on adherence to ART included; economic factors (lack of food), Physical factors (side effects of the drugs) Environmental factors (long waiting hours with long queues) and Community factors (social stigma). The challenges faced by pregnant women on ART included; economic factors (lack of

food), Physical factors (side effects of the drugs) Environmental factors,(long waiting hours with long queues) and Community factors (social stigma). The findings call for the need to improve on food programs, improve on drug regimens, and improve on staffing levels at the health facility in order to reduce on long waiting hours and queues. Social Stigma needs to be addressed because nearly all the participants in this study expressed this factor as a challenge. There is need to address the HIV/AIDS stigma. There should be continued sensitization among communities against stigma and discrimination in order to improve on the full benefit of ART adherence among pregnant women (Simoni, *et al.*, 2006). These issues should be addressed so as to allow society to look at HIV/AIDS like any other illness that affects the human population.

Community factors

Lack of social support and Social stigma

This highlights how various aspects of stigma negatively impact on health outcomes of the pregnant women. This factor emerged as a significant challenge to ART adherence in this study and it was described in many ways by respondents including fear of being laughed at by friends, fear of being talked about by different people, and fear of being accused as someone who has infected the partner. Because of social stigma, most of the women could not disclose that they were taking ART to their partners. Due to lack of social support they took their drugs secretly. This did not guarantee adherence because when they had no chance of taking the drugs secretly they missed the dosages. This may not only preclude HIV-related social support and its attendant benefits but may also have direct negative effects on disease progression for HIV positive pregnant women. However, a lot of women felt that disclosure of their treatment contributed to stigma. This made it difficult to adhere to ART because the women could not take the ART when other family members were around. This attributed to self-stigma as the women feared being rejected if their husbands discovered they were on ART

The findings show women failing to access ART from their community covering long distances fear of being seen access the ART by community members, when they had no transport money drugs were not

Table 1. Age and Parity of the pregnant women

Respondent	Respondent Age (Years)	NUMBER OF CHILDREN	Age of Children (Range)
1	18	0	-
2	19	1	2
3	20	1	2
4	22	0	-
5	23	2	1 - 4
6	26	1	6
7	26	2	4 - 6
8	28	5	2 - 15
9	33	6	4 - 16
10	36	5	5- 18
11	39	4	2 - 15
12	40	4	3 - 23
13	40	7	3 - 20
14	42	8	2 - 20
15	43	6	4 - 17
16	45	8	4 - 21
17	45	4	8 - 23

Age range e.g. (3-8), with 3 indicating youngest child of age 3 years and 8 indicating oldest child of age 8 years. Age range e.g. (5), indicates one child only of age 5 years.

Table 2. Respondents default to ART adherence

Respondent	Art Start Date (Year)	Art Default Date (Month, Year)	Duration of Default
1	2012	June, 2014	1 month
2	2014	March, 2014	3 weeks
3	2013	January, 2014	1 month
4	2011	February, 2015	3 weeks
5	2014	January, 2015	4 weeks
6	2010	December, 2014	2 months
7	2013	January, 2014	3 weeks
8	2008	February, 2015	2 weeks
9	2013	June, 2014	3 weeks
10	2014	December, 2014	2 weeks
11	2010	January, 2015	1 month
12	2012	February, 2015	2 weeks
13	2010	December, 2015	3 weeks
14	2013	October, 2014	2 months
15	2011	January, 2015	2 weeks
16	2009	November, 2014	1 month
17	2012	December, 2014	2 weeks

shows the women who defaulted. They all had different reasons. This table illustrates different levels of drug compliance. Hence the need to address the challenges women face when they are taking ART

Table 3. Length of time since the pregnant women started taking ART

YEARS SINCE ON ART	NUMBER OF PREGNANT WOMEN
6 Months > 1 year	12
1 year > 5 years	3
≥ 5 years	2

shows the length of time the women have been on ART. This study revealed that challenges to adherence were mostly experienced by women who were on ART for less than one year.

collected and adherence was a challenge.

Social Stigma

Findings reviewed women did not access ART from their community; they preferred to cover long distances fearing being seen by community members. Social stigma was expressed in different ways by the respondents. This was a big challenge in accessing the ART in their community. They covered long distances which was a cost in terms of transportation. When they had no transport money they could not go to get their drugs and this contributed to poor adherence.

Long Distance

The women covered long distance to access the ART, they feared being spotted going to get the ART by their family members because a lot of them had not disclosed that they were taking ART. When they had no income for transportation they did not go to get their supply and could not adhere to the treatment.

Discussion

The study explored factors affecting adherence to ART among HIV positive pregnant women. In particular the study sought to understand the preposition of pregnant women's adherence to ART. The women gave reasons to their challenges to adherence. The study has confirmed that adherence to ART among pregnant women living with HIV/AIDS is a challenge despite the free supply of ART to pregnant women. Collecting the drugs every month does not signify taking the drugs accordingly as prescribed. It is therefore understood that the challenge to adherence to ART among pregnant women leads to development of viral resistance and risk of MTCT. Therefore control strategies in improving adherence to ART among pregnant women in Lusaka district and Zambia in general, requires commitment to drugs and high knowledge of factors affecting adherence.

Social Stigma

The majority of the respondents did not disclose that they were on ART even to their partners. They feared social stigma. Women were forced to keep it a secret because if their friends and family knew about their HIV status or that they were on ART, they would face discrimination and isolation. The women in this study preferred not to disclose their HIV status and to

rather access the health facilities that are far from their homes. Others even preferred to go to areas as far as Kafue which is another town. This has challenges in terms of adherence because if they fell ill no one will know where they keep the ART, and this will interrupt adherence. It was discovered that women most of the women who accessed the drugs in these two facilities came from far places. They could not get drugs from their nearest clinics because they feared to be seen. The women had low adherence because when they had no money for transport they were not able to come for their drug refill. When they had collected their drugs they were not able to take them correctly because at home they had not disclosed their status and they feared to be seen that they were taking ART. Some women due to non-disclosure when they were not home and run out drugs they could not ask for any member of the family to collect the drugs for them. If this stigma has to be addressed there is needed to involve men, fathers and partners in the care of the pregnant women at community level. This has been supported by a study done by (Mushana *et al.*, 2006; Handson *et al.*, 2007)

Limitation of Study

This study is limited by its use of a self-report adherence measure which, while shown to be associated with virological response, is likely to over-estimate actual levels of adherence. The women because of fear if they will be looked after well could not give the correct figures of adherence. This study was done in two settings which could not reflect the true picture of adherence.

Conclusion

The study explored the factors influencing adherence to ART among pregnant women living with HIV/AIDS. Qualitative studies are useful in general as they in-depth insights into such health problems. The findings suggest that adherence to ART among pregnant women living with HIV/AIDS is low and it is mostly influenced by social stigma among the community and family members. However, an improved level of adherence to ART among pregnant women living with HIV/AIDS is hampered by fear of social stigma, side effects of the drugs, economic challenges leading to lack of food and fear of being blamed by partners if they disclosed their status. These findings highlight the need

for an in-depth understanding of the challenges to adherence to ART among pregnant women. The study findings call for the need to improve on food programs, improve on drug regimens, improve on staffing levels at the health facility in order to reduce on long waiting hours and queues and reduce on social stigma. Stigmatisation needs to be addressed because nearly all the participants expressed this factor. There is need to address the HIV/AIDS stigma very seriously in order for society to look at HIV/AIDS like any other illness. These factors were found to be common among pregnant women's challenges to adherence to ART. It will be considered as the basis for future intervention in improving adherence to ART among pregnant women. Meanwhile the method used in this study proved useful in bringing out local and potentially important factors affecting adherence to ART, and this should be investigated using more robust study design. Since low adherence to ART in pregnant women leads to increased risk of virologic failure, disease progression, development of drug resistance and risk of vertical transmission of the HIV virus to the unborn baby, there is need to scale up programs that will improve adherence.

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