Strategies for Living with the Challenges of HIV and Antiretroviral Use in Zambia

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Abstract

This study sought to identify strategies for living with the challenges of HIV and antiretroviral (ARV) use among new medication users in urban Zambia. Participants (n = 160) were recruited from urban Lusaka, Zambia. Qualitative Data was drawn from monthly ARV treatment education intervention groups addressing HIV and antiretroviral use. Themes included community stigma, nutrition, social support and HIV/ARV knowledge, concerns and beliefs. Strategies for adherence included family, friends, and community organizations that provided emotional and financial support regarding medication, feelings of depression, help with household duties, transportation and companionship at clinic visits and assistance during illness. Social support was the most frequent strategy in coping with ARV use. Challenges included learning to take medications regularly (51%), remembering information about medication (29%), clinic wait times (24%), timing of doses (28%), transportation (23%), food (23%) and lack of social support (23%). Results highlight needed programs to support nutritional supplementation and reduce stigma and the utility of support groups targeting new ARV users to enhance health and encourage sharing of challenges and solutions for consistent ARV use. Strategies for the establishment of health behaviors supporting medication use early in ARV prescription are presented as an important element in long term adherence.

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Key words: *Zambia, HIV, Intervention, Drug Therapy, Qualitative Analyses*.

Introduction

Recent health surveys indicate HIV prevalence is 19.7% in urban areas in Zambia.[1] The progression of disease in persons living with HIV/AIDS has dramatically altered with the advent of ARV medications; in Zambia, the aim of HIV/AIDS management has shifted from palliative care to strategies to promote access to antiretroviral (ARV) medication and provide support for long-term adherence to medication and treatment.[2] Zambia has been cited for significant increases in antiretroviral treatment access[3]; as of September 2007, 122,700 people were receiving no-cost ARVs[4] and high rates of HIV medication adherence in resource limited settings have been documented.[5] However, while controlled clinical trials of ARV therapy have demonstrated viral suppression below detectable limits when adherence reaches 95% or greater,[6] studies of long term use in clinical settings in the US report that adherence rates may be as low as 50%.[7] Viral resistance to ARVs is the most significant limiting factor in the long-term efficacy of HIV pharmacotherapy and is a predictable consequence of substantial but imperfect adherence[8] and may also be associated with ethnicity.[9] Growing concerns about the potential for the development of resistant virus has lead to increased resistance testing across sub-Saharan Africa during 2008 (personal communication CDC, 2008). At present, only 2 lines of variable generic ARV combinations are available in Zambia for low income patients. Thus, it is essential to establish adherence health behaviors at the time of introduction of ARV medication.

Challenges to ARV medication adherence in sub-Saharan Africa include stigma, lack of confidentiality, gastric side effects in already undernourished, weakened patients[10-12] and travel or migration for work which may interfere with access to medication and adherence.[13] In the US, individual characteristics, aspects of the provider and patient provider relationship, factors related to illness or regimen, and contextual/environmental factors have also been related to non-adherence to ARVs.[14] These individual factors may facilitate or reduce adherence;[15-18] e.g., beliefs about medication toxicity or effectiveness,[5,19] provision of care to HIV seropositive family members and neglect of personal health. In Africa, stigma and negative attitudes in community and health care settings, both perceived and enacted, may serve as challenges to HIV medication adherence,[5,20] e.g., healthcare may be perceived as supportive or stigmatizing and inaccessible, family members may blame and ostracize members with HIV.[21] Contextual factors such as poverty and food shortages, experienced by 68% of Zambia's population, may also contribute to ARV non-adherence.[22] While a healthy diet rich in vitamins and nutrients maximizes the benefits of anti-HIV drugs, inhibits disease progression, maintains CD4 T-cells, and decreases viral load,[23,24] in Africa, the effects of lack of food in combination with ARVs may outweigh, or even reverse their benefit.[22] However, social support can improve the quality of life of people living with HIV/AIDS and has been associated with HIV support group attendance, taking vitamins, and receiving counseling.[25]

Cultural and social context may influence interventions and assessment of factors associated with adherence. Qualitative reports play an important role in validating culturally appropriate health education interventions.[26] Factors such as medication concerns and beliefs, healthcare and community stigma, poor access to nutrition and lack of social support can be challenges to adherence and treatment,[27] and developing health education interventions to respond to these issues can be a strategy for ensuring the establishment of long term medication adherence behaviors early in medication prescription.[28] This study sought to assess experiences with HIV and antiretroviral use in new medication users in Zambia. Using preliminary data drawn from baseline assessments and qualitative reports drawn from treatment education intervention groups, this study sought to identify challenges and successful strategies for living with HIV and medication use in the Zambian community.

Method

Participant Recruitment

The Adherence Project was a randomized clinical trial that recruited 160 HIV positive Zambians 18 years of age or older between September 2006 and June 2008. Participants were on ARV medication < 24 months. Men and women were drawn from the Lusaka metropolitan area and primarily recruited from the University Teaching Hospital Immunology Clinic at the University of Zambia School of Medicine. Prior to participant recruitment, Institutional Review Board and Ethics Committee approvals were obtained in accordance with the provisions of the US Department of Health and Human Services and the University of Zambia regarding the conduct of research. Potential recruits were assessed for medical eligibility, i.e., HIV seropositive, ARV use duration between 6 and 24 consecutive months, no previous use of ARVs and provided informed consent prior to study enrollment. Literacy was not required for study participation and all assessments were administered at baseline by multilingual study staff in a primary local language (Bemba, Nyanja or English) as requested by the participants. All participants received monetary compensation (Kwacha 20,000) for their travel expenses, which was the cost of transportation to and from the hospital clinic.

Cultural Adaptation of Assessments and Intervention Materials

The team used focus group data to adapt the assessments and intervention content, addressing cultural and linguistic issues to enable speakers of local languages to participate fully. All assessment instruments and intervention elements were translated and back translated and reviewed for cultural appropriateness and comprehension. Intervention materials were subject to rigorous review prior to implementation and ongoing cultural review to ensure conveyance of intended meaning. Recruiters, assessors, and interventionists were multilingual and communicated in participant's dialect/language (e.g., Bemba, Nyanja, English). Intervention groups conducted intervention sessions using a combination of Bemba, Nyanja and English, due to the mixture of audience language (73 local and 3 primary regional languages in Zambia).

Baseline Quantitative Assessments

All assessments were administered by study staff and each measure was 5 minutes in duration.

Demographics. This questionnaire included data collection on age, religion, nationality, ethnicity, educational level, employment status, residential status, approximate date of HIV diagnosis, mode of infection, marital status/current partner and children's serostatus, living situation, number of children, substance use.

Adherence to anti-retroviral medication. Self-reported adherence was measured by 4-day self-report using the ACTG (AIDS Clinical Trials Group) Questionnaire for Adherence to Anti-HIV Medications (4 days). [29] The mean number of pills per day was divided by the prescribed number using information regarding the medication regimen provided by the participant, to calculate an average adherence percentage

Beliefs about medicines questionnaire (BMQ). Participants' beliefs about ARVs were measured using the BMQ, [30] two five-item scales assessing general beliefs about medication (scale scores ranging from 12 – 60), beliefs regarding the necessity of taking medication (scale scores ranging from 8 – 40 and concerns about its potential negative consequences (scale scores ranging from 8 – 40 (scale scores ranging from 11 – 55). Participants rated their level of agreement with statements about medication using a Likert-like scale (5 = Strongly agree to 1 = strongly disagree). "Concerns" assessed actual experiences with medication as well as abstract beliefs about potential future problems. Scores were summed to constitute scale scores and means obtained to create a range of 1 – 5 for both beliefs and concerns, and split into three scales: beliefs about medications in general, beliefs about the necessity of the ART medications, and concerns about the side effects of ARVs.

Adherence Attitude Inventory (AAI). The AAI is a 28-item Likert-like scale that measures attitudes associated with problems with adherence.[31] The scale consisted of four subscales (cognitive functioning, patient-provider communication, self-efficacy, and commitment to adherence). The Commitment to Adherence Subscale is 7 items with a 7-point scale ranging from “none of the time” to “all of the time “and addresses determination to overcome obstacles to adherence (scale scores ranging from 7 - 49). Food problems were measured using the AAI (scale scores ranging from 2 - 14) in which high scores indicate high access to food.

Stigma Indicators Questionnaire (SIQ). Participants experiences of stigma were tested in four key domains: avoidance of contact with people living with HIV and fear of casual transmission; values and attitudes, perceived and enacted stigma (discrimination); and disclosure using the Stigma Indicators measure.[32] Perceived community stigma (scale scores ranging 0-17), enacted stigma (scale scores ranging 0-18) and enacted health care settings stigma (scale scores ranging 0-14) are reported.

The Barriers to Adherence Checklist (BAC). The BAC is a 56 item checklist which includes general barriers to HIV treatment, as well as barriers specific to medication-taking and has excellent internal consistency with an alpha of 0.92.[16] Participants rated the degree to which each item reflected their own experiences and beliefs using a four-point rating from “definitely true” to “definitely false.”

Social Support Questionnaire (SSQ). The SSQ[33] was designed to assess the perceived availability, desirability, usefulness and experience of social support among persons living with HIV. There are 8 sets of questions in the SSQ which asks the respondent to use a Likert-like to rate each type of social support (scale scores ranging from 12 - 60). The measure asks participants to describe the extent to which others (including peers) assist them with their HIV illness, health care behaviors and areas of more general assistance. Areas of support cover emotional, socializing, practical assistance, financial assistance, and advice/guidance.

Qualitative Assessment

Intervention. Participants attended 3 group sessions over 3 months with maximum of 10 participants per group; each session was 90 minutes in duration. The sessions addressed knowledge about HIV and HIV-related medication, barriers and concerns about ARVs, adherence, and problems and solutions, utilizing a group format to share and problem solve with peers and the facilitators. Sessions were audiotaped, transcribed and translated into English and results were reviewed by team members for translation accuracy. All qualitative data were collected from transcripts of the intervention sessions.

Coding. Session transcriptions of the intervention were reviewed for content and coded for frequently arising themes related to barriers and facilitators of adherence. Transcriptions were be coded line by line using descriptive codes for common themes and patterns and grouped into broad categories (e.g. stigma, nutrition, social support, and beliefs). Multiple readers (3) met and compared categories, which were reduced through theory-based consensus. Initial session content was reviewed again on the basis of relevance to the identified themes using coding categories to categorize coded data. The remaining transcriptions were analyzed using these coding categories and the team met as needed to resolve potential category revision.

Results

The following preliminary data was drawn from baseline assessments collected prior to the onset of the Adherence Project intervention. As outlined in Table 1, participants (n = 160) were men (n = 78) and women (n = 82) with a mean age of 37 and had been on ARV medications for a mean of 15 months. Participants were predominantly of low socioeconomic status; 82% were extremely low income (earning under $5000 per year), 40% were unemployed, and secondary school was the highest education attained by 60% of participants. Most participants (84%) reported eating three or more meals per day. The majority of participants were married (53%); 19% were single and 18% were widowed. Only 31% had disclosed their serostatus to more than 10 people, while 41% had disclosed to three persons or less.

Baseline Analyses

Self-reported adherence was high at baseline (99% of participants reported perfect adherence to medication over a 4 day period); 76% of participants reported consistent adherence over the last 3 months and were taking 2-8 pills (mean = 4) per day. Length of time on ARVs ranged from 6 – 24 months, with 51% of the sample on medication 6-12 months and 49% between 12 and 24 months. Measures of self reported adherence, pill count, CD4, education and time since diagnosis were not associated with each other, indicating at least one of the measures had limited validity. CD4 count was derived from medical chart review and did not accurately reflect fluctuations in adherence. Challenges associated with HIV and ARVs included learning to take medications regularly (51%), remembering information about medication (29%), clinic wait times (24%), timing of doses (28%), transportation (23%), food (23%) and lack of social support (23%). Participants (53%) reported devoting 2 – 4 hours to clinic appointments (1 – 2 hours for appointments, 24%).

As illustrated in Table 2, baseline scores indicated a high commitment to adherence among participants, with an average of 45 (scales scores ranged from 7 – 49 with high scores indicating high rates of commitment to adherence). General beliefs about HIV medications were moderately positive (mean = 44, scales scores ranged from 12 – 60 with high scores indicating positive beliefs). Beliefs about the necessity of ARV medication were highly positive (mean = 33, scale scores ranging from 8 – 40, with high scores indicating a high beliefs in the necessity of medication). Concerns about HIV medication were low (mean = 37, scale scores ranged from 11 - 55, with high scores indicating low levels of concern).

Most participants reported low levels of community stigma or experiences of negative community attitudes based on HIV positive serostatus (mean = 3, scale scores ranged from 0 – 17 with high scores indicating high levels of perceived negative community attitudes). Similarly, most participants reported low levels of enacted stigma (mean = .6, scale scores ranged from 0 – 18 with high scores indicating high enacted stigma); 26% reported being stigmatized. Only a modest number (12% of participants) reported actual experiences of enacted stigma in a health care environment (mean = .2, scale scores ranged from 0 – 14 with high scores indicating high levels of enacted stigma). High levels of social support were endorsed (mean = 32, scale scores ranged from 8 -40 with high scores indicating high levels of social support; see Table 2).

Pearson correlations (*r*) were used to assess association between variables (See Table 3). Community and healthcare stigma, both perceived and enacted, were inversely associated with beliefs ($r = -.283$, $p < .001$), and concerns about medication ($r = -.299$, $p < .001$), in which stigma was associated with more negative concerns and beliefs. Finally, more frequent clinic visits were associated with higher levels of side effects ($r = .204$, $p = .010$). Social support was the most frequent strategy in coping with ARV use. Beliefs about HIV medications ($r = .160$, $p = .044$) and concerns about ARVs ($r = .262$, $p = .001$) were associated with commitment to adherence.

Qualitative Analyses

The following qualitative reports were drawn from the Adherence project intervention sessions. Themes arising on HIV and ARVs discussed below included community stigma, nutrition, social support and HIV and ARV knowledge, concerns and beliefs. Strategies for adherence included family, friends, and community organizations that provided emotional and financial support regarding medication, feelings of depression, help with household duties, transportation and companionship at clinic visits and assistance during illness.

Stigma. Negative community and healthcare beliefs about HIV, both perceived and enacted, were associated with beliefs ($r = -.174$, $p = .028$) and concerns about medication ($r = -.299$, $p < .001$). Fear of being stigmatized as a result of taking ARVs also prevented some from taking ARVs in the presence of visitors who were unaware of their status. A woman commented,

> [I] fear taking medication when people are with [me], hence [I am] dashing off to the toilet and ending up taking it without water which is not good. [You] cannot take medicines around people who do not know you have HIV, [the ARV] package is known by others...[I was] feeling shy to take medication in presence of people and later postponing [it] to a later time, [I] then eventually forget to take the drug.

Local healthcare settings were sometimes avoided; a man commented "…the medical personnel at our local clinic do not know our status and we have fear that they may reveal our status to other people." One male participant described his uncle's strategy to avoid the healthcare system entirely, "My uncle in Livingstone discovered that he was HIV. He went to a friend, [a] pharmacist, he did not follow the CD4 count levels and without instructions [he] started taking drugs, so I feel he made a mistake."

Participants also developed positive strategies for avoiding disclosure and stigma; one man described, "I always move [about] with bubble gums. If there is no water to take the drugs with and there are people around me, I put the gum and the drugs at the same time in my mouth so that people think [I] am just chewing a gum."

Discrimination due to stigma occurred in the home, from partners, in the work place and in church, one woman observed that "some churches [are] preventing people from taking any kinds of treatment." Participants reported feeling isolated and avoided by others for fear of being infected as well as being gossiped about and ridiculed. One woman disclosed,

> At my work place they shun being with you. They make bad comments and …people look at [you] with disgust…by pointing fingers to show as they gossip and laugh…at church [people] do segregate; to take part one must be negative…people will not shake hands with you… [they] don't want [you] to sit closer to them…[they are] gossiping [saying] "kanayaka", meaning the light is on (local descriptor for those who are HIV positive).

Participants had varying strategies for responding to being stigmatized. While many reported feeling depressed and resorted to violence, others took legal action and alerted the authorities. Many participants described active or avoidant coping strategies for responding to stigma, including ignoring gossip, avoiding specific people, focusing on their spirituality or staying busy with church activities. A man observed, "Most of the time people feel stigmatized, but personally I do things that I want to do and forget what people think. I started concentrating more on people who showed love to me."

Nutrition. Lack of food or limited access to food containing proper nutrition was not correlated with side effects associated with medication (r = -.245, p = .004) and 83% of participants reported no problems with lack of food. However, fear of hunger appeared to be a dominant issue; one man commented,

> [I] fear to take medication on an empty stomach and fear that [I] might develop side effects like stomach pains. Some fear to take medication because they don't have enough money to buy food and because they believe that they have to eat before taking medication, so what would one do?

The Zambian practice of shared bowls, utensils and the use of hands to eat lead some participants to express distress at changes in eating arrangements, such as

> [They] don't want to eat together thinking they will be infected, sometimes they want to use separate kitchen utensils. When you are eating, then a child comes to eat from your plate; he is told not to eat with you.

Social support was an effective strategy for maintaining adequate nutrition. Twenty-five percent of the sample indicated their family and friends provided them with food as a result of HIV serostatus. A man observed, "They (family) encouraged me to eat when my appetite was bad. My wife [is] so supportive, [she] insures [I] take my medicine, [and] prepares meals." One woman had a friend who shared strategies for coping with loss of appetite, commenting "[When I] have no appetite, [a] friend told me to eat roasted groundnuts (peanuts)."

Social Support. Social support was both positive and negative; negative social support was associated with abuse and abandonment by family members. The social context of gender-based power dynamics, e.g., women's subordinate social and economic status and financial dependence, resulted in problems for some women. Most often, it was domestic violence and abandonment experienced by their sexual partners after HIV status disclosure. One woman observed, "My spouse beat me up after learning that I was positive. [He] kicked me out of the house saying I had brought a shameful disease." Another young woman noted, "When my husband knew I was positive he left me since he was tested negative."

In contrast, support groups, friends, caring family members and church members served as buffers in times of crisis and as sources of information. Strategies for maintaining adherence included family, friends, and community organizations that provided emotional and financial support regarding medication, feelings of depression, help with household duties, transportation and companionship at clinic visits and assistance during illness. Many referenced religious support, such as "[the] priest came to pray with me, church members are very caring; [I received] home based care from my church [which provided] soya, maize (honey), cooking oil, and blankets."

Many participants commented on support from family, "They support me spiritually, mentally, and [are] always there for me," and "My brother helps me in terms of school fees for children, food and rent." Participants also reported receiving support from their spouses. A woman commented, "My partner has accepted me and provides all I need…My spouse has been there for me from [the] time [I] was tested positive." Similarly, a man observed, "She (wife) has allowed me to do business at home…My partner is ever by my side." Participants commented on the importance of peer support,

> You develop bad and short tempers because of the fact of knowing that you are HIV positive, but when you accept your status you take things normally. Depression goes when you discover that you are not the only one HIV positive. I finally revealed about my status to the family, especially my first child, who now reminds me to take drugs and even to tell me to come for sessions at the Adherence Project.

Men and women commented on the value of HIV support groups, "You make friends, find buddies who call you when you are in need, learning a lot on issues of HIV/AIDS." Another commented, "[I get information] from a support group and this has worked for me." The opportunity to participate in a support group and learn from each other was seen as helpful by most participants, commented one woman, "I met someone at the clinic who told me that she is going to stop taking the medication because it kills. I told her about [the] Adherence Project how it teaches us about adhering to medication." Members expressed a desire to form small groups to go teach others in the community about what they had learned. One woman concluded, "I feel motivated to continue taking drugs because I feel even stronger and healthy and can encourage another person, stronger in such a sense that I cannot believe it is I who stands strong today."

Knowledge and Beliefs. Beliefs about medication also represented a challenge. Participants had varying degrees of knowledge about HIV/AIDS and ARVs, and held both positive and negative beliefs about ARVs. Beliefs about HIV medications ($r = .160$, $p = .044$) and concerns about ARVs ($r = .262$, $p = .001$) were associated with commitment to adherence. Many expressed concern about medication; one male participant asserted, "I heard these medicines have toxics (sic) and if one does not go for LFT (liver function test) one develops serious illness." Many participants were concerned about the continuing availability of ARVs, questioned one man, "Don't you think at one time they will stop producing these drugs and what will happen to us?" While some were skeptical, commenting "I know of an HIV positive neighbor who lives with parents, she has stroke, and they say it's because of the ARVs," most endorsed the efficacy of medication, "I have heard of people saying after taking ARVs for [a] long time they get better."

Misconceptions were frequent regarding transmission to children, most often among men, "If father's DNA is infected does it mean the son's body too will be infected?" Due to limited contact with healthcare staff at overburdened clinics, some participants sought pharmacists who provided information and support regarding ARVs. Other participants also considered traditional medicine for HIV and ARV side effects, such as, "[I have] heard that crocodile fat cures [HIV]," and "Rubbing feet with garlic helps [reduce] side effects." Others felt that ARVs represented a cure for HIV, such as one female participant, "[ARVs] render you HIV negative if you take it a long time because particles from the drug surround the virus and prevent it from [being] seen on microscope or [from] mutate." For most, fear of side effects and medication outcomes were common such as death, loss of eyesight, cancer, sickness, pain or darkening complexion.

Most participants found both treatment and medication confusing and strategies for resolving confusion centered around communication with medical providers. One male participant commented, "I had CD4 count done at different clinics in the space of two days and the results were different and that worried me. I asked the doctor why but he said because the machines are different."

Discussion and Conclusions

This study sought to assess the challenges and strategies for living with HIV and antiretroviral (ARV) use among new medication users in Zambia. Most participants reported consistent adherence, in line with previous studies.[2] Challenges to medication adherence included learning to take medications regularly, trouble understanding and remembering information about medication, clinic wait times, timing of doses, transportation to clinics, a lack of adequate nutrition or access to food and lack of social support. Primary themes arising from group qualitative data addressed community stigma, nutrition, social support and HIV and ARV medication knowledge, concerns and beliefs. Social support was the most frequently cited strategies for adherence in this sample of highly adherent patients. Participants reported challenges to living with HIV and ARV use in the form of stigma, nutritional limitations and medical confusion, and described their primary strategies as centering around social support and obtaining accurate information. In addition, participants endorsed the use of support group sessions targeting HIV and ARV use to share problems and solutions for consistent long term ARV use.

Baseline assessments supported qualitative reports across the themes of stigma, nutrition, social support, and HIV and ARV knowledge, concerns and beliefs. Community and healthcare stigma, both perceived and enacted, was associated with concerns about medication. Ongoing stigma and discrimination were perceived by participants to occur in the home, the church, the health care setting, the workplace and the wider community. The group intervention may have provided an opportunity to openly discuss concerns and solutions about HIV previously avoided due to perceived stigma in the healthcare setting. It is possible that knowledge of HIV status may lead to a reduction in denial, stigma and discrimination, but stigma remains an impediment to HIV testing and treatment as well as subsequent clinic attendance, treatment and ARV use. Zambia currently has nationwide programs encouraging Voluntary Counseling and Testing (VCT), but in a press statement on National VCT Day in 2008, Dr. Brian Chituwo, then Minister of Health[1] noted "only 15.6 percent of the population has accessed VCT services and undergone HIV/AIDS testing despite government and non-governmental organizations' efforts to make VCT services widely available". The health implications of stigma are numerous. Health education and promotion interventions are essential to decrease stigma in venues such as the religious community and health care settings.

Results suggest that some clinical issues may also contribute to challenges to taking ARVs medications. These include time spent at community clinics waiting for treatment and prescriptions, which are provided every 6 months. Overcrowded clinics and lengthy delays in receiving treatment are a continuing problem in both the developed and developing world and represent an ongoing challenge. In addition, low income Zambians with no personal transport may spend several hours to reach a hospital clinic, adding to the time burden of obtaining treatment and medication. Currently, health officials in Zambia are exploring development of more efficient patient scheduling in order to reduce prohibitive delays.

Additional challenges included becoming accustomed to regular use of medication, including timing of doses and remembering specific instructions on nutrition required when taking medication. For many Zambians, the communal activity of eating meals may also present a barrier to medication use due to lack of disclosure of HIV status. Lack of food, or limited access to food containing proper nutrition, was associated with medication side effects which may have arisen due to taking medication on an empty stomach. However, while food shortages remain a significant problem in Zambia, the majority of participants reported no food problems at baseline but rather, a *fear* of hunger associated with taking medication, in line with previous studies.[2] Many anti-HIV medications are taken with food in order to alleviate side-effects, e.g., upset stomach, diarrhea, or indigestion, thus food shortages can exacerbate HIV non-adherence.[22] However, most participants reported receiving more food and help (prepared meals and groceries from family members and friends as a result of their positive status. Although 80% of PWAs live in the developing world where food shortages are common, several studies have found high rates of adherence in resource limited settings.[34,5] The impact of limited access to food for those on ARVs cannot be underestimated and should continue to be addressed in the widespread distribution of medications through initiatives such as PEPFAR and the Global Fund. However, strategies for changing negative community responses to sharing food and utensils with HIV positive individuals should be addressed in culturally appropriate public health interventions.

Social support has been found to improve the quality of life of people living with HIV/AIDS (PWAs) and has also been associated with taking medication. In this study, more frequent clinic visits were associated with higher levels of social support, which may include transportation to clinic sites. Increased social support has also been associated with decreased perceived stigma and has facilitated disclosure. In fact, the combination of counseling and support group attendance has been the strongest predictor of health behaviors.[25,2,35] Participants in this study provided additional support for the importance of social support in coping with the challenges associated with HIV and ARVs. HIV and ARV support groups may be an effective and potentially cost-effective strategy to encourage health behaviors and behavioral change associated with medication adherence for larger numbers of PWAs. Additionally, group sessions may provide more time with health care practitioners than typically available to answer questions and discuss medical information related to HIV.

HIV and ARV misinformation and misconceptions were a challenge in this sample and remain a problem throughout the world. In Zambia, information about HIV and ARVs is available via the media (e.g., radio, television, newspaper, pamphlets, billboards) churches, and non-governmental organizations. However, similar programs in South Africa have found high levels of misconceptions (59%) regarding HIV transmission and beliefs that ARVs could cure HIV and would not cause side effects.[5] Clearly, the strategy of provision of HIV information and education should continue on a national basis and be integrated into clinical care provided during ARV administration and HIV treatment. The role of healthcare staff in provision of health education in the form of ARV-related information should be expanded as an adjunct to patient education during visits with doctors and clinic officers. Future studies should be developed to explore a health education intervention at the community level, and the integration of traditional healers to support HIV treatment prescription by allopathic practitioners.[36]

Limitations to the results of this study included the lack of validity of measures associated with adherence and CD4 count. Subsequent research in this population has included viral load assessment as an additional measure of medication compliance, and funding should be allocated for viral load assessment of treatment failure in the Zambian context. Self-reported adherence may have been inflated due to participants' desire to please the interviewer, and frequent pill count discrepancies from those prescribed were found to be the result of pill hoarding and confusion regarding prescription dosage. Pharmacists in Zambia represent an untapped resource and should be encouraged to increase health communication with patients to enhance HIV knowledge and understanding regarding the potential consequences of inadequate ARV adherence. Finally, participation in the Adherence Project clearly stimulated participants to discuss issues related to adherence and HIV, and may have increased strategies for social support due to participation in the group.

Clarifying the challenges of nutrition, stigma and medical beliefs and the strategies associated with social support among Zambians new to ARV provides a platform for the development of health education and clinical interventions to reduce barriers and enhance solutions to improve ARV use. Limitation of the development of resistance, the consequence of less than adequate adherence, remains a key element in the worldwide distribution of ARV medication. Establishing good health habits in the form of strategies to enhance facilitators to medication use and respond to barriers early in prescribed ARV are essential to increase the potential for longer term consistent use and potential adherence.

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Table 1. Sociodemographic Characteristics of Participants

Characteristics	
Gender	
Male	78 (49%)
Female	82 (51%)
Employment	
Full time	64 (40%)
Part time	31 (19.4%)
Not working	63 (39.4%)
Volunteering	2 (1%)
Income	
Less than $5,000	130 (82%)
$5,000 - $9,999	11 (7%)
$10,000 - $19,999	4 (3%)
$20,000 or greater	13 (8.2%)
Years of Education	
Primary	27 (17%)
Secondary	96 (60%)
College Level	35 (22%)
Marital Status	
Married	85 (53%)
Single	29 (19%)
Widowed	28 (17.5%)
Disclosure of Serostatus	
10 people or more	50 (31%)
3 or fewer people	65 (41%)
Number of Meals eaten per day	

2 or less meals per day	26 (16%)
3 or more meals per day	134 (84%)
Time devoted to Clinic appointments	
2-4 hours	84 (53%)
1-2 hours	38 (24%)

Table 2. Experiences and Attitudes Regarding ARV Medication and HIV

Domain	Range	Mean	SD
Adherence, self-reported			
Over the past 4 days	1 – 100%	99%	.099
Over the past 3 months	1 – 100%	76%	1.28
*(High scores indicate high adherence)			
Adherence Attitudes			
Commitment to Adherence	7-49	45	3.88
*(High scores indicate high commitment)			
Stigma			
Perceived Negative Community Attitudes	0-17	3	5.03
Enacted Stigma	0-18	.6	1.44
Enacted Healthcare Stigma	0-14	.2	.829
*(High scores indicate high stigma)			
Food Problems			
Hunger, Lack of food	2-14	13	2.11
*(High scores indicate low food problems)			
Social Support			
Always have support	8-40	32	9.62
*(High scores indicate high support)			
Beliefs about Medicines			
General beliefs (moderately positive)	12-60	44	4.97
Necessity of ARV medication (highly positive)	8-40	33	4.04

Concern (low level concerns)	11-55	37	5.57

*(High scores indicate positive beliefs)

Table 3. Pearson's Correlations

	General beliefs about meds	Beliefs about med necessity	Specific concerns about meds	Perceived negative community attitudes	Enacted stigma	Stigma health care Environment	Social support	Food Problems	Side effects	Health care use
Beliefs about med necessity	.548***									
Specific concerns about meds	.575***	.516***								
Perceived negative community attitudes	-.283***	-.174*	-.299***							
Enacted stigma	-.212***	-.087	-.106	.233**						
Stigma health care Environment	-.142	-.170*	-.105	.129	.662***					
Social support	-.052	-.064	.044	.005	-.061	-.023				
Food Problems	.196*	.218**	.277***	-.088	-.109	-.075	-.092			
Side effects	-.058	.088	-.172*	.010	.174*	.079	-.072	-.122		

Health care use	-.105	-.004	-.070	.169*	.332***	.401***	-.005	.019	.204*	
Commitment to adherence	.071	.160*	.262**	-.129	.005	.028	.132	.253**	-.068	.078

NB: Significance = * p < .05, ** p < .01, *** p < .001