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Development and assessment of an innovative video to introduce concepts of adherence in Soweto, South Africa

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The Development & Assessment of an Innovative Video to Introduce Concepts of Adherence in Soweto, South Africa

A Thesis Submitted to the
Yale University School of Medicine
in Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

by
Ilene Yi-Zhen Wong
Yale School of Medicine 2004
ISSUES: The widening availability of antiretroviral therapy but dearth of medication taking experience among rural South Africans has raised concerns about adequate adherence to these medications. Interventions to improve adherence have been limited in development and evaluation and are often not culturally appropriate to patients in resource poor settings. It is hypothesized that a culturally-sensitive audio-visual patient education program may be of significant use in increasing patient understanding of concepts of resistance and medication taking skills, particularly in areas with low literacy rates.

METHODS: After focus groups with health care providers and HIV-positive adherence counselors, a 15 minute educational video was created in which basic drug-taking concepts, as well as practical advice on how to improve adherence, were presented. After taking a 24-point Likert-style baseline survey of drug-taking knowledge, 34 HIV-positive patients (including 11 ARV naïve patients and 23 ARV experienced patients) were shown the completed educational video. Immediately post-video, they were given a second questionnaire to assess their knowledge.

RESULTS: Overall, patients showed a statistically improvement in their baseline knowledge score, with an average improvement of 2.2 points out of 24 (p=0.028). ARV naïve patients had an average improvement of 3.0 points, with most significant gains in understanding of medication taking strategies and side effects.

CONCLUSIONS: With the help of focus groups with providers and HIV positive individuals, complex information and concepts can be reduced to comprehensible and learnable messages using creative film techniques and culturally-specific metaphors. A key element of the video’s success was the utilization of a three-pronged approach including 1) a mock doctor-patient encounter, 2) a narrative sketch (in which actors depict correct and incorrect medication taking procedures), and 3) a documentary portion including practical advice from adherence counselors.
ACKNOWLEDGEMENTS

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INTRODUCTION

**AIDS in Africa**

Out of the approximately 25 million people living with HIV/AIDS (PLWHAs) in Sub-Saharan Africa, less than one tenth of one percent currently receive life-prolonging antiretroviral treatment (ART) (1). Until now, due primarily to economic barriers, most of these individuals have lived without hope of ever receiving ART, with sobering consequences: the average life span has dropped in some African countries by almost 20 years (2, 3).

Recent reductions in the price of ART may make the widespread use of the therapy more feasible, though even the reduced prices ($300US for a year’s supply) represent a significant financial burden on a continent where per capita income can be as low as $310US. Pricing, however, is not the only barrier to the successful administration of ART therapy. In the past, some pharmaceutical companies have argued that the medical infrastructures in developing countries may be insufficient to effectively administer complex drug regimens, with reduced access to standard laboratory tests such as CD4 counts and viral loads. Additionally, some believe that the risk for the emergence of drug-resistant strains of HIV due to non-adherence may counterbalance the obvious health benefits of ART.

**The Importance of Adherence**

Certainly, the issue of adherence has surfaced as one of the fundamental challenges to AIDS clinical care. Non-adherence drastically reduces the effectiveness of ARTs by selecting for drug resistant strains of the HIV virus, which Ho *et al* (4) have shown is particularly
susceptible to errors in replication, producing $10.3 \times 10^9$ virons each day. As Friedland and Williams noted (5), “long-term and perfect or near-perfect adherence is critical, since drug holidays or missed doses permit viral replication and the selection of drug-resistant viruses.”

Strong adherence can also be a key component to HIV prevention strategies, as good adherence drastically reduces viral load in semen and vaginal fluid, thus lowering transmission rates.

Perfect or even near-perfect adherence, however, is no mean task. Estimated adherence rates for chronic disease medications in the US range from a dismal 20% to an adequate 80% (6,7). One study of epileptics showed an adherence average of 76%, with adherence decreasing from 87% to 39% as the number of required daily doses increased from one to four pills per day. Such a correlation between poor adherence and regimen complexity is, of course, particularly worrisome for ART takers given the nature of highly active antiretroviral therapy, which requires the consumption of three or more pills, often several times a day, and often on specific schedules for food and water intake.

The typical range of total self-reported adherence to ART is from 46% to 88% in the United States (8). In another study of patients interviewed for an adherence trial, 50% of patients admitted to skipping at least one dose, indicating a pervasive widespread inability to adhere perfectly, based on the multifactorial process of medication taking (9).

Risk factors to non-adherence are myriad. Adherence theorists have generally utilized a number of models to understand the reasons for noncompliance with medication regimens. Some divide adherence factors into 1) patient factors (e.g. physical/mental health, resources, cultural beliefs and social support), 2) clinician factors (e.g. accessibility, interpersonal style and communication skills), 3) regimen factors (side effects, cost and number, size, taste, and
administration of pills), and 4) disease/illness factors (symptoms, duration, severity and stigma) (10-16).

Research has shown that some resource-poor populations have difficulty adhering to even once-a-day therapy (17), though other early studies link non-adherence more closely to working outside the home than to income. A more recent study by Kalichman, et al showed that even after controlling for income, ethnicity and social support, persons of low health literacy (as measured by an adapted Test of Health Literacy in Adults) are significantly more likely to miss treatment doses due to confusion and depression (18). Studies such as these are of particular interest when contemplating adherence levels in resource-poor countries with less extensive healthcare and education infrastructures.

**Improving Adherence: A Multidisciplinary Task**

By its nature, adherence is a multifactorial notion, and methods of improving adherence are best when used in conjunction with each other. In general, strategies fall into one of six categories: 1) patient education, 2) reminder strategies, 3) management of side effects, 4) reduction of regimen complexity, 5) enhancement of communication between patient-provider and 6) optimization of the patient’s psychosocial functioning. It is important, however, to be cognizant that improving adherence should not be approached with a “one size fits all” strategy (19-24).

While it seems intuitively evident that an individual who is more well-informed and educated would be more likely to be compliant with life-saving medication, health care providers in all realms of medicine have long found difficulty in translating increased knowledge into behavior change (25). For example, when Solomon et al (26) showed that an
educational videotape proved to have a significant increase in patient knowledge of gonorrhea treatment, it produced a much smaller effect size (0.39, Z=7.9, P<0.001) with regard to increase in compliance with tetracycline.

A 2000 Cochrane Systematic Review assessing the effectiveness of patient support and education interventions for improving adherence to HAART identified a paucity of studies in the area, and stated an urgent need for controlled trials (27).

More recently, there has been mixed evidence to support the use of educational interventions (though not specifically educational videos) to improve patient adherence. One 2003 trial by Rawlings et al, in which 195 HIV-positive individuals from sectors underrepresented in research were given an intensive HIV education (consisting of four modules from the Tools for Health and Empowerment HIV intervention), failed to demonstrate a difference in mean adherence rates after six months, as measured by a rigorous Medication Event Monitoring System (MEMS) protocol (28). Of note, however, is that the control group for this study did undergo routine counseling regarding medication.

A recent study by Goujard et al (29), however, was successful in demonstrating a statistically significant increase in adherence based on a personalized educational intervention utilizing pillboxes, stickers, and at least three one hour educational sessions. This impact in adherence was measurable at six months, 12 months and 18 months. It should be noted, however, that this study measured adherence using a global adherence score based on two questionnaires, rather than a more rigid MEMS protocol. Several other studies also support the role of education in improving adherence (30), including a French study of 244 patients. Those patients who underwent three counseling sessions, versus a single standard of
care session, showed a significant improvement in adherence at six months (75% vs. 61%, p = .04) (31).

Further complicating the study of educational interventions on adherence is a well known rebound phenomenon, by which the effect of adherence interventions decreases as time from intervention increases (32). Long-term studies on the need for repeat education are needed to understand the optimal use and form of educational interventions.

Adherence in South Africa

Widespread availability to ARVs has only recently become a possibility. In addition to the financial barriers to wide antiretroviral dissemination, political obstacles have limited access to AIDS drugs. Over the years – denying Medical Research Council evidence that 40% of deaths between ages 15 and 49 are related to AIDS – South African leaders have insisted that poverty and violence are more valid targets for government intervention, while questioning the safety of AIDS drugs and calling in to doubt the relationship between HIV and AIDS (33). It was not until August of 2003 that South African president Thabo Mbeki changed national policy and announced the government’s intent to provide ARVs to 1.5 million of its AIDS stricken citizens over the next five years. Even supporters of this policy, however, acknowledge that antiretroviral roll-out has its difficulties (34). Particularly in South Africa, where the tide of the epidemic has not been stemmed, proper adherence to antiretrovirals is imperative not only to justify the government’s expense, but also to theoretically prevent further transmission of the HIV virus.

Intuitively, the question of how to improve adherence to antiretrovirals in South Africa hinges upon many factors, including 1) the unique method of health care delivery –
including the language barrier often separating doctor from patient; 2) the unique economic and social stressors placed on patients; 3) patient experience with medication taking and 4) the cultural perception of the value and necessity of ART.

In terms of the available literature on this subject, the lack of access to ART in Africa precluded the wide availability of any assessment of ART adherence at the start of my project in 2001. Though one abstract of a pilot Senegalese HAART study stated that “the majority of patients reported having taken 83% adherence”, the abstract did not go into detail regarding the method of determining adherence (35). More recently, studies of adherence in centers of excellence in South Africa point to high adherence rates, though a significant number of patients still report adherence levels below 80%. For example, one study at the Perinatal HIV Research Unit (PHRU) at Baragwanath Hospital in Soweto, South Africa reports that 72% of patients had adherence rates of greater than 95% (36). This may be due to a number of factors: centers such as the PHRU offer extensive educational benefits, income generation projects, and even transport fees. Moreover, it is hypothesized by PHRU physicians that the very scarcity of ARVs in South Africa is a motivating factor to patients, who perceive their medications as a precious and rare gift that cannot be wasted.

Perhaps the most interesting data to emerge from this small body of African adherence literature indicates that low socioeconomic status may not be a barrier to successful antiretroviral administration. One Cape Town study of 242 patients on HAART showed a mean adherence of 88.5%, with a median of 94.5%, with no statistically significant correlation between poor social circumstances and adherence <80% (37).

More generally, literature points to an anecdotal history of poor adherence to tuberculosis treatment regimens in sub-Saharan Africa (38). One South African study
compared non-compliance rates for self-medication of over the counter drugs, finding that 46% of randomly sampled blacks in Orange Free State ‘always’ completed their course of treatment, compared to 67% of whites. An additional 47% of blacks reported ‘often’ or ‘sometimes’ completing their courses, with the non-compliance most closely associated with a long traveling time to the source of formal health care (39).

It is believed that adherence to therapy in the African setting is complicated by difficulties in communication and lack of medical resources (40). However, preliminary interviews performed by myself in rural South Africa in 2001 suggest that non-adherence may also be due to lack of medication taking experience. Of the small group of patients interviewed, most had experience with as-needed analgesics only, for which compliance is a smaller issue. It is a very rare patient who has had experience taking medication for more than three weeks in succession. As one would expect, their knowledge of certain medication-taking concepts was limited. While 11 out of 11 of patients understood that medications could sometimes cause physical side effects, only one half of the patients interviewed were familiar with the concept of drug resistance. Clearly, room exists for patient education regarding basic pharmacology and medication-taking habits.

In recent years, a small body of literature does indicate that several innovative educational programs in Africa have been effective in improving patient adherence to medication for non-AIDS related illnesses. Patient empowerment, information provision, social networking support, and educational activities such as photonovels have all proven to be effective and may be useful in the promotion of antiretroviral adherence (40-1). For instance, a 1991 randomized controlled trial of compliance improving strategies in hypertensive patients in Soweto, South Africa, showed that reminder letters and patient
retained medication letters significantly increased the number of patients who took 80% or more of their medication (15% control compliance vs. 31% in study group) (42).

*The Use of Video in Health Education*

The use of video as a means to improve patient adherence is a relatively new notion, though a significant body of literature touts the efficacy (and cost-effectiveness) of video as a means to influence patient knowledge and attitudes, particularly in resource-poor areas. In 1998 Dunn *et al* concluded that videotape can convey complicated information more effectively than written materials, regardless of race or education level (43). In a recent study on the effectiveness of an educational video to educate Russian schoolchildren on HIV/AIDS, Torabi *et al* (44) astutely commented that “health educators should consider video education as an effective and efficient tool to present facts to a young audience when they face constraints of shortage of funds, lack of trained teachers, and scarcity of related information.” A growing literature attests to the widespread use of video HIV-education programs in resource-limited countries (45).

The literature on the effect of video on adherence is somewhat smaller, and a 1988 literature review on the efficacy of video in patient education concluded that while video is as good as and often more effective than traditional methods of education in increasing knowledge, it offers no advantage in promoting long-term adherence (46). More recently, however, a study by Solomon *et al* noted that a video intervention had a significant effect (0.39 effect size) on drug compliance to gonorrhea treatment (25). Video education has also been shown by Janda *et al* (48) to improve the behavioral compliance with basic health maintenance, with a significant (p=0.02) increase in the frequency of breast self-exams.
One very relevant study of the developing world by Denis (49) showed a significant, albeit modest increase in the compliance of a group of Cambodians after watching a 9 minute video which discussed side effects and benefits of completing therapy.

This study hypothesizes that the use of video education programs will be uniquely suited to the South African environment because they are 1) cost-effective and 2) a standardized education program, which obviates the operator dependency of face-to-face counseling. Currently, a significant number of South African hospitals, including Baragwanath, rely primarily on written materials to educate patients. This may be a limitation of current education programs, as at least one meta-survey of English-language cancer education materials suggested that written patient-education materials often outstripped patients' abilities (50). Educational videos circumvent the problem of illiteracy in South Africa, which has been estimated to range from 27% in metropolitan areas to 50% in rural areas.

An additional component of the study is the ease of dissemination of digital educational material. Digital video production is both easily replicable and easily portable. Should this intervention ever be expanded to more rural areas of South Africa, where televisions (not to mention video cassette recorders) are scarce, a video that can be viewed on a battery-powered laptop with CD-ROM will allow access to a significantly larger viewing audience than traditional video tape.
Methodological Issues in the Production of a Culturally Sensitive Educational Video

A number of studies articulate the desire of underrepresented minorities to have educational materials specific to their culture. In well controlled study by Herek et al (51), a culturally specific video was rated by African Americans as more credible, attractive and of higher quality than an identical video with a multicultural cast and message. Cultural specificity was defined by Herek as a function of source, message and receiver; in other words, the source (communicator) should be perceived as credible and attractive to the specific audience member, while the message should have a content and presentation that is keyed toward the need of the viewer.

More importantly for educational interventions, culturally sensitive videos are not only well received, they also result in greater retention of knowledge, as proven by Stevenson and Davis, who showed an increase in the amount of HIV information retained by African American adolescents 2 weeks after a culturally sensitive video intervention. Similarly, Kalichman et al showed an increase in the number of black females who reported to HIV-testing after watching a video presented by an African American as opposed to a white announcer (51).

Substantial literature details the successful use of focus groups to obtain data on underserved populations whose needs have not been clearly identified through the wider literature. The focus group method also allows researchers to better assess the language, values and style of thinking of the surveyed groups, all factors which are essential in the development of a culturally-sensitive video. Furthermore, focus groups have been described as being flexible and inexpensive data collection tools that do not discriminate against the illiterate (53), both of which characteristics would serve well in a South African setting.
STATEMENT OF PURPOSE

1) to gain a better understanding of South African patients’ baseline knowledge of drug-taking concepts including the importance of adherence, notions of resistance, side effect profiles and dietary restrictions

2) to understand in greater detail the barriers to patient adherence to HAART

3) to develop an innovative, culturally-sensitive educational video specific to the adherence needs of South African HIV patients

4) to assess the effect of aforementioned educational video on South African’s knowledge of medication taking strategies

I hypothesize that patients who watch a 15 minute educational video will improve their score on a drug-taking concept quiz compared to baseline. Additionally, I hypothesize that this enhanced awareness of the importance of maintaining their drug regimen will increase patient adherence to HAART, as evidenced by pill count and three day recall of medication adherence.
METHODS

Project Setting

The study was performed at the Perinatal HIV Research Unit (PHRU) of Baragwanath Hospital in Soweto, South Africa. Established in 1996 as an offshoot of the Baragwanath Perinatal HIV Clinic, the PHRU is involved in several large trials of antiretroviral therapy to all populations of AIDS patients. As of 2002, over 200 patients were enrolled in ARV treatment studies, providing one of the largest cohorts of such patients in an African setting. As part of their provision of ARVs, the PHRU initiated in 2000 a therapeutic counselor program, in which HIV positive individuals act as adherence counselors to impart medication taking techniques to patients who are determined by pharmacists to be non-adherent based on refill pill-count. Though total adherence data is not currently available, a pilot study of 43 patients in an operational trial showed that 72% of patients had adherence of 95% or greater, based on pill count (36). NOTE: the author of this study actively initiated and carried out portions of all aspects of this study except when noted otherwise.

Part I: Script Production

In preparation for determining the structure of the educational video, the study author critically reviewed three sets of HIV educational videos available at the time. Two of these, “Introduction to Anti-retroviral Therapy” from the Beat It!: HIV/AIDS Treatment Literacy Series, and the “Inmate Adherence Video Series” produced by Albany Medical Center, directly addressed matters of adherence (54). The videos were evaluated for their ability to engage the audience, their pacing, and their use of narrative techniques. Particularly effective portions of these videos were earmarked as models for video education.
Production of the Soweto-specific video began after individual interviews with health care providers at the PHRU. Additionally, the PHRU’s six current adherence counselors were interviewed individually and in focus groups. They were reimbursed 100 South African Rand for their time and were provided with beverages and snacks. After short introductions in which they spoke about their personal experiences with disclosing their HIV status, the adherence counselors were interviewed using the set of questions shown in Figure 1.

The discussion of the types of metaphors used to demonstrate resistance was particularly important because of the editorial decision to include within the video an arresting visual depiction of HIV replication and resistance. It was felt that the concept of resistance as often depicted in literature and video was a difficult and abstract one that could benefit from a concrete, visual manifestation.

**Figure 1: Focus group questions**

1. Before you took ARVs, did you know what the concept of resistance was? If not, how did your doctors explain to you what resistance was? When you speak with your clients about the importance of resistance, how do you explain to them what resistance is? Do you ever use any metaphors or examples where you compare HIV to an army, or an animal, or other object?
2. Tell us about your clients who have had trouble taking ARVs.
3. Do you use any devices (pillboxes, timers, reminders from family) to help you remember to take your drugs? Do you recommend any of these to your clients?
4. When your clients are not adherent, what reasons do they give for not being adherent?
5. What kind of advice do you give your clients when they are not adherent?
6. What do you think are the top three barriers to adherence?
In addition to the data collected through interviews and focus groups, data from PHRU adherence surveys conducted in 2001 were utilized to identify barriers to adherence in the specific PHRU population which should be specifically addressed in the video script.

A draft script was produced by the study author in conjunction with an experienced screenwriter after the decision to utilize a number of narrative techniques that are seldom used in educational video. After review of the existing video products, it was determined that it would be most effective to use a three-pronged approach to video production, including 1) a skit-like role play between doctor and patient in which standard patient questions about adherence and side effects were broached, 2) a voice-over narration of the lives of an adherent patient versus a non-adherent patient, and 3) a documentary-like section including adherence counselors giving practical advice on medication taking strategies. As a pacing/transition element, two short humorous “commercial” segments were included between the three sections. The documentary portion of the video was given a preliminary “guide” script based on the topics that were chosen as advice for adherence; however it was determined that the adherence counselors would be allowed to speak without the constraints of a word-for-word script in order for their role to be as natural as possible.

After the preliminary script was produced, it was distributed to the adherence counselors for edits and reviews. After a day’s allotment for reading, the author, screenwriter and adherence counselors met in a focus group. The counselors were asked to identify any segments that seemed confusing, poorly worded, or culturally inappropriate. They were specifically asked to comment on the appropriateness of the snake-egg metaphor that was eventually utilized to represent resistance. The counselors were also asked to participate in a
reading of the script that identified areas of the script which were awkward or difficult to verbalize. The final script is attached in Appendix 2.

**Part II: Video Production**

After the script was finalized, a casting call was made. The determination was made to utilize professional actors, rather than PHRU staff, as doing so would circumvent any concerns in regard to confidentiality of HIV positive individuals, and also assure smooth filming. The cast was assembled from students at the University of Witwatersrand School of Drama, with the intention that the demographics of the cast would be the approximate equivalent of the demographics of the Soweto area, namely black South Africans. Attention was also made to the clarity of the actors’ speech, as diction is extremely important to the ability of drama to convey complex ideas. For the role of the doctor, it was attempted to identify an actor who would feel comfortable with medical terminology, and who seemed mature enough to invoke confidence in an experienced physician.

On-location sets were secured at Baragwanath Hospital and in nearby townships, including PHRU clinic rooms, exterior hospital shots, and township-house interiors. The documentary section was filmed in offices at the PHRU research unit, against a wall of HIV-awareness photographs. For the snake metaphor, tame snakes were provided by ReptiPet of Johannesburg for a small fee. The snakes were handled for filming by the author. Costumes were provided by the University of Witwatersrand School of Drama.

The video was filmed over the course of four days using a Canon GL-1 digital camera and tripod, with a boom mike used for the dialogue and documentary style sections. Attention was paid to filming at secure locations to ensure safety of actors and equipment.
More importantly, attention was paid to creative filming, using point-of-view shots, close-ups and traveling shots to make the video a dynamic film rather than a static documentary.

The score to the film was created from a combination of sources. A short one hour recording session with the HIV-positive chorus at the PHRU provided South African spiritual music which was used in the opening sequences of each section. Additional background music and snake sounds were provided by the University of Witwatersrand School of Film’s digital music library.

After filming, the digital images were downloaded onto a Fujitsu P2110 laptop (Crusoe 900mHz processor, 256 RAM, 20GB hard drive, CD-RW/DVD drive). Editing was performed using Adobe Premiere 6.5. During the editing process, goals included 1) making the video seem as cinematic as possible, 2) using layers of background music and sounds to place an emphasis on certain concepts, 3) ensuring clarity of sound through boosting and digitally altering unclear dialogue and 4) keeping the video to under 15 minutes to avoid losing the attention of viewers. Selected screen shots from the video are depicted in Appendix 1.

**Part III: Video Assessment**

A 12-question Likert-style questionnaire was developed to assess patient’s knowledge of medication taking strategies, including basic knowledge of HIV science, management of side effects, and concepts of resistance and adherence. The questionnaire was modeled after the Likert-style questions developed by Walker, *et al* to assess the knowledge obtained by their educational video for New York State HIV-positive inmates [54]. One modification to this questionnaire was made to address the Soweto patients’ lower incomes. Responses to
these questions were on a 5-point scale ranging from definitely no to definitely yes, with the midpoint defined as maybe. A sixth option for “Don’t Know” was also present.

Additionally, a short 12-point multiple choice section assessed patient knowledge of the existence of specific side effects and medication strategies that were addressed in the video. Two side effects which were not mentioned in the video, namely jaundice and nightmares, were added to this multiple choice section to act as a gauge to assess the patients’ pre-existing knowledge of side effects, as a number of the interviewed patients had had extensive education from adherence counselors and health care professionals.

A final question to gauge the amount HIV education already received by the patient asked whether they had attended general support group meetings, watched a general educational video, or met with adherence counselors. The completed questionnaire, which was pilot tested on five patients to identify ambiguously worded or misleading question, can be found in Appendix 3.

General demographic data was obtained from all patients, including their gender, age, the length of time they had been taking ARVs, and the highest level of education they had received.

The post-video questionnaire is essentially identical to the pre-video questionnaire, save for a question asking if the video was clear, and a final open-ended question asking what the patients would learn from the video, and how it would change their medication taking strategies. The post-video questionnaire is included in Appendix 4.

Eligibility criteria for this video study includes HIV positivity, age between 18 and 50 years of age (alternatively, the interviewer could be the parent/primary caretaker of an HIV positive minor taking ARVs), and a command of English that would allow for understanding
of the video, as determined by a multilingual South African research assistant. Exclusion criteria include unwillingness to watch an educational video, evidence of dementia, and inability to comprehend English, Zulu or Sesotho. ARV experienced patients were recruited in a sequential order by the research assistant after being identified through PHRU records as being on an ARV trial, while ARV naïve patients were approached randomly. All patients were approached for enrollment in the PHRU waiting room while awaiting routine care and were offered full informed consent.

The patients were then taken to a private room to undertake the pre-video questionnaire under the supervision of the research assistant, who was present to assist with interpretation of the questionnaire as needed. The participants were then shown the adherence video on the screen of a Fujitsu laptop with a 10-inch screen, using private headphones. After watching their video, the post-test questionnaire was administered and the patients and were given a 5 lb bag of corn meal, as well as a box of soy mince to compensate for their time and effort. Their questionnaires were labeled with their study participation number only, with the key to these numbers being kept in a separate location to ensure confidentiality.

Test scoring was based on a 24 point scale, with one point given for each correct answer on the 12 Likert-style questions, and one point given for each correctly identified side effect and medication taking strategy in questions 14 and 15 respectively. Question 13 requires three correct answers, and full credit was only given if the patient identified all three correct components. Finally, one point was added to patients’ score if they correctly left the two poor adherence strategies in question 15 blank.
All scored questionnaires were tabulated using Microsoft Excel, and statistical analysis, including paired student t-tests, Chi squares and regression analysis, was performed using SAS software at the Yale Prevention Research Center.

**Part IV: Measuring the effect of the video on patient adherence**

Baseline adherence data for all patients (based on refill pill counts) is available through the PHRU pharmacy records, and will be compared to their adherence at one month and six months time after the administration of the video to assess the effect of the intervention on their medication taking habits.
RESULTS

A total of 34 HIV-positive patients were shown the video and given pre- and post-test assessments. Twenty-three patients were enrolled who had previous experience with ARVs (including four mothers who were administering ARVs to their children); eleven patients who were not taking ARVs were enrolled.

The demographic characteristics of the included patients are shown in Table 1. Due to the perinatal nature of the PHRU’s focus, the majority of the interviewed patients (82.3%) were women. The average age of all participants was 31.2 years old, with a range from 13 to 48 years old. Their average education level was the completion of 8.8 standards (or grades) of high school, with a range from 1 standard to matriculation and college. Seven of the

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<th>Table 1: Demographic characteristics of study patients</th>
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<td>All patients</td>
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<td>Length on ARVs (months)</td>
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patients had education levels of standard/grade 6 or lower. The average age of the 11 ARV naïve patients was 28.5 years old and their mean education level was 8.45 standards of high school. Analysis of these age and mean education demographics through Chi-square and Fisher’s Exact tests indicate that they do not correlate with statistically significant change in performance on the knowledge questionnaires (p=>0.05).

The 23 ARV experienced patients had been taking ARVs for an average of 19 months, with a range from 1 to 48 months in duration.

Of the total patients, 17 (50%) had watched an HIV educational video, 24 (70.6%) had been to a support group, 14 (41.1%) had been to an adherence support group, and 19 (55.9%) had met with an adherence counselor.
Part I: Results of focus groups with adherence counselors

A. Explaining the concept of resistance: When asked how they explain concepts of adherence to their patients, the counselors noted that they often utilize a Zulu metaphor, amaso tsha omzimba, meaning soldiers of the body, to explain what the HIV virus does to the immune system. They describe the virus as a “naughty” virus that can hide and hurt the soldiers of the body. They often emphasize that the virus is very clever, and can wear camouflage, or dress up as soldiers to deceive the body’s army. Additionally, they describe how the virus can “learn” to defeat the soldiers of the body if you do not take your medications correctly, so that “the drugs no longer work in your body.” One counselor uses the metaphor of a door, saying that with medications you put “the handle on the door up so that the virus cannot get in.”

Frequently, the adherence counselors utilize visual aids such as posters that show that different kinds of immune cells are different members of a kind of army. They also frequently depict the HIV virus as a kind of monster. When asked about what kind of animals were considered to be particularly frightening in their culture, the counselors mentioned snakes as a potentially strong metaphor for Africans.

B. Reasons for non-adherence: The adherence counselors identified a myriad of reasons why their clients in Soweto were not able to be adherent to their medication regimens.

1) Attitude – Again and again, the counselors emphasized that non-adherent clients are more likely to be characterized by “depression and loss of hope”. Successfully adherent clients were more likely to have a positive outlook about their ability to “take control of their life”, and to realize that taking ARVs is a “once in a lifetime opportunity” given the rarity of
ARV treatment in South Africa. They were also more likely to have come to terms with their disease, whereas non-compliant patients were more likely to be “in denial” that they were ill and needed to be treated.

2) Lack of education, including understanding of the importance of taking ARVs correctly – The counselors expressed their concern that many of their non-adherent clients were not fully educated on many of the key elements of drug-taking knowledge, namely the dosages, medication names, and major and minor side effects. Related to this was a lack of understanding regarding the consequences of non-adherence; one counselor commented that her patients often say they “feel so good they don’t need it [medications],” not understanding that they feel good because of their medications. At times, lack of education also impacted patients’ trust of health care professionals. One counselor described how one patient, not understanding the latent nature of the HIV virus, stopped taking ARVs because he thought, “I’m not sick. They’re lying [about my HIV status].”

3) Lack of family support – Due to the taboo associated with HIV/AIDS in African society, a large number of the clients served by the adherence counselors had not disclosed their status to their family members. As a result, it was observed by the counselors that clients often felt that they had to hide their drugs from their families in order to avoid being “chased out.” This lack of disclosure forced many to keep their ARVs in special containers that were often not readily available. One counselor noted that she had had a client who had even taken the labels off of her medication bottles, a dangerous practice because it could impair the patients’ understanding of what drugs she was taking.

4) Side effects – the counselors noted that several of their clients became non-adherent because of their lack of tolerance for minor side effects, staying that “they want to
rest a bit.” They stated that their clients were seldom aware that even one missed dose gives the virus a chance to replicate. They also noted that their non-adherent clients often did not know that many side effects can be treated, and that they should return to the clinic if they have side effects.

5) Lack of food and money – Adherence counselors identified low economic status as one of the most significant barriers to adherence. Lack of food can contribute to exacerbation of side effects, and low income can substantially impact access to care when patients are unable to afford transportation fees to attend routine clinic visits or support groups. One counselor noted how low income often contributes to a generalized depression, where the patient thinks “oh, I don’t even have enough money for food and for my children, why should I take my ARVs?”

6) Lifestyle – Counselors noted that a number of patients seemed to be non-compliant due to their “lifestyle.” Patients who regularly consumed alcohol and who were “party animals” were more likely to forget doses and be nonadherent. Physicians at the PHRU also indicated during interviews that the lifestyle of many Sowetans, including the lack of scheduled daily activities and routine, does not allow for a very good sense of the passage of time. Such a lack of routine often contributes to non-adherence because patients lack mental memory cues to remember to take their medication.
C. Medication-taking strategies/Advice for non-adherent clients:

1) Education – The adherence counselors uniformly agreed that it is imperative to fully educate patients about all aspects of their disease and treatment. Patients must be aware of the kind of medication they are taking, their specific dosage, and the kind of side effects that they can have. Most of the counselors believed that the patients should have a baseline understanding of viral replication, as the counselors often invoke CD4 counts and viral loads to explain to patients the pressing need for complete adherence. To improve patient medication, the counselors currently use a series of basic HIV awareness educational videos produced in South Africa, and follow these viewings with support group discussions. The PHRU also has a substantial number of pamphlets in both English and Zulu which offer detailed educational material on HIV transmission, ARV treatment, side effects and adherence.

2) Disclosure – All adherence counselors noted that disclosure to one’s family and close friends is a vital means to promote adherence. Family members who are aware of the patients’ HIV status and ARV regimen can act as in-home reminders, and help organize the family routine around medication administration. Family members and friends can also provide vital moral support for patients.

3) Memory aids – The PHRU adherence counselors advocated the use of a number of memory aids to enhance adherence to ARVs. These include the use of pillboxes near commonly accessed places such as toothbrush holders and bedsides, and the use of calendars in which daily doses are checked off as taken. Alarm clocks can also be used to alert that it is time to take medication. Patients are encouraged to synchronize their medication taking with daily routines, such as watching the TV show Generations, which is shown daily. One
innovative program that the PHRU counselors are hoping to implement is the use of a free SMS text messaging computer program to send daily reminders to patients’ cell phones; this is of particularly good use in South Africa, where the dearth of land lines in townships renders cell phones extremely common.

4) *Income generation and financial aid* – The PHRU offered a number of income generation projects to patients, including jewelry making and food gardening. They are also extremely supportive of patients’ efforts to secure disability grant funding. In addition, the PHRU provides travel stipends and lunches for patients who attend their support group meetings.

5) *Detailed discussion of the patients’ habits* – The counselors agreed that it was of great benefit to the patient to go through a detailed schedule of the persons’ day to identify times where the patient is very likely to miss a medication dose. Such an hour-by-hour examination of the patients’ lifestyle also identifies times and places that would be most amenable to placement of memory devices, and would also allow the patient to identify habits such as drinking or socializing which can be controlled to make a schedule optimal for adherence.

6) *Counseling and support groups* – Finally, all counselors strongly recommended that patients taking ARVs attend support group meetings. They noted that, due to the intense stigma which is still attached to HIV disease in South Africa, patients who attended such meetings were generally more optimistic about their illness after speaking to other HIV positive patients. Attending support group meetings also gave patients the opportunity to exchange medication taking strategies.
Part II: Subjective reaction to the video

All 34 participants to the video responded that they felt that the video was clear in its educational purpose. Primary observation of participants as they viewed the video showed that they rapidly engaged in the video’s content, often reacting with a sharp breath or gasp when the snakes were shown, and reacting with outward sympathy when the character Joseph lies ill after being non-adherent to his drugs.

More specifically, patients were given an opportunity during the post-movie questionnaire to comment on how the video might change their medication taking behavior. Figure 2 summarizes the post-video responses by patients when they were asked what they learned from the video, and how the video would change their medication taking habits. A majority of patients noted specific changes they would make to their medication taking strategies, with disclosure being the intervention most frequently mentioned; others commented on the knowledge they had gained about the way the HIV virus works in their body. Only one patient commented that she was already implementing most of the strategies in the video.

It should be noted, however, that due to faults in the administration of the questionnaires (namely that nine patients completed the questionnaire and left after ignoring or not noticing the final question), only 25 of the study patients commented on the knowledge that they had gained. Additionally, one of the 25 respondents’ comments was uninterpretable due to written language difficulties on the part of the patient.

Observation of patients’ comments as related to their improvement on the pre and post test questionnaire showed no clear trends; even patients with perfect scores prior to the video administration commented that they may utilize strategies offered by the video.
Figure 2: Summary of post-video answers to Question 16
(How will this video change your medication taking habits?)
*numbers in parentheses are the change in client’s pre- and post- test scores

- “By looking at it now and then to remind myself about some of the important aspects that I might turn to forget along the way.” (+3)
- “Stopping ARVs is worse than not taking them at all. You must stick to the right way [to take your medications].” (+0)
- “Now I understand what happens to my immune system if I do not take her medication correctly.” (+0)
- “The video has improved my knowledge of HIV.” (+3)
- “I learned how the virus works in my body.” (+2)
- “I will use a calendar now.” (+0)
- “I must use a clock and a calendar.” (+2)
- “Now I know about pillboxes and grants.” (+4)
- “It teach me to tell my family that I’m taking ARVs, and to not miss my ARV [doses].” (+4)
- “This video change my medication to drink every day at time.” (+2)
- “It will help to be more open about me taking the ARVs.” (+0)
- “It will change it completely.” (+1)
- “The video taught me I can use an alarm, and that I should disclose to my family and start a food garden.” (+1)
- “I learned that disclosure is important.” (+1)
- “You must place your pills where you can see them everytime, and put them under your pillow or where your toothbrush stays, or take them when I wash my babyboy in the morning.” (+3)
- “I should disclose to my family members and keep [my pills] in my handbag at all times.” (+0)
- “I learned that I mustn’t be secretive with my status.” (+5)
- “I will try to disclose to my family.” (+1)
- “Even if the ARVs are making side effects I should try to take my ARVs every day so that the immune system cannot be destroyed by the virus. And keep myself health, eat well, or tell my family that I’m taking the ARV so that they can remind me to take medication.” (+5)
- “I must take my ARV every day and the right time. If I don’t take the tablets every day I will becoming ill. If the ARV affects me I must go back to the doctor and check me. He can change the pill and give me another one.” (+4)
- “This video changes my medication [taking] to know about ARVs to help my life and to keep regular appointments with my health care provider.” (+6)
- “To me it is the same because I also use the alarm clock to remember my pills.” (+0)
Part III: Results of pre- and post-test knowledge questionnaires

Table 2 shows the mean pre- and post- test scores for all patients, as well as the mean scores for the ARV naïve and ARV experienced patients. The overall increase in score for all patients was shown by a standard t-test to be statistically significant (p=0.0214).

Additionally, analysis of the two patients subgroups using SAS (paired student t-test) shows a statistically significant increase in knowledge after the intervention for both ARV naïve (p=0.0028) and ARV experienced (p=0.001) patients.

Pre-video, the average score of all participants was 17.8 out of 24 points (74.2%; SD = ±4.02 points). The average score of the 11 patients who were ARV naïve was 15.6 out of 24 points (65%; SD = ±4.5 points), compared to 19.0 out of 24 points (79.1%; SD = ±3.4 points) scored by patients who had experience with ARVs.

Table 2: Pre- and Post-test knowledge scores

<table>
<thead>
<tr>
<th></th>
<th>All patients (n=34)</th>
<th>ARV experienced patients (n=23)</th>
<th>ARV naïve patients (n=11)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pre-test raw score</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% correct</td>
<td>17.8 (±4.0)</td>
<td>18.9 (±3.4)</td>
<td>15.6 (±4.5)</td>
</tr>
<tr>
<td></td>
<td>74.2%</td>
<td>78.8%</td>
<td>65%</td>
</tr>
<tr>
<td><strong>Post-test raw score</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% correct</td>
<td>20.1 (±4.0)</td>
<td>20.8 (±2.9)</td>
<td>18.6 (±3.4)</td>
</tr>
<tr>
<td></td>
<td>83.8%</td>
<td>86.6%</td>
<td>77.5%</td>
</tr>
<tr>
<td><strong>Change in score</strong></td>
<td>2.29 (±1.9)</td>
<td>1.9 (±1.5)</td>
<td>3.0 (±2.5)</td>
</tr>
<tr>
<td><strong>Significance</strong></td>
<td>p=0.021*</td>
<td>p=0.001**</td>
<td>p=0.0028**</td>
</tr>
</tbody>
</table>

*using standard t-test **using paired student t-test and SAS model
Overall, 28 out of the 34 patients (82.3%) showed improvement after watching the video. Post-video, the average score of all participants was 20.1 out of 24 points (83.8%; SD = ± 4.03 points) with an average improvement of 2.2 points out of 24 (9.2%; SD = ± 1.9 points). Subset analysis shows that the 11 ARV naïve patients had an average increase of 3.0 points out of 24 (12.5% improvement, SD = ± 2.5 points), while the 26 patients who had prior experience taking ARVs averaged an increase of 1.8 points out of 24 (7.6% improvement, SD = ± 1.5 points). While the difference between the ARV naïve and ARV experienced groups was not significant (p=.3482), this measurement was likely hampered by the lack of power of the study; a larger sample size (n>65) is needed to show a difference between inter group improvement. Figure 3 graphically depicts the improvement shown by each patient cohort.

Figure 3: Graphical comparison of performance on knowledge questionnaires pre- and post-video

![Bar chart showing performance comparison](chart.png)
A full graphical representation of the pre- and post-video questionnaire results, sorted by type of question, is shown in Figure 4. The most significant gains in knowledge were seen in the areas of basic adherence concepts, side effects and medication taking strategies, with the questions garnering the greatest increase in correct answers being as follows:

- Sometimes ARVs make people feel sick
- HIV causes my immune system (my body’s army) to work poorly, making it easier for me to get infections
- Side effects cannot be treated
- It doesn’t matter what time of the day I take my ARVs
- What can I do to improve my adherence to ARVs – pillbox

**Improvement in scores of Likert-style concept questions**

Separate analysis of the 12 Likert-style questions, which test essential medication taking concepts shows, that 37% of the patients surveyed received full marks prior to video, compared with 54% post-video. The ARV naïve patients had an average pre-video score of 8.64 (72%), compared to a post-video score of 10.8 (90%), showing a 2.1 question (18%) improvement in score after watching the video. Nine out of the 11 ARV naïve patients (81.8%) showed an improvement in score, ranging from +1 to +4 questions. In comparison, ARV experienced patients had an average pre-video score of 10.6 (88%) and a post video score of 11.4 (95%) with an average increase of 0.8 questions (8%). A total of 12 of the ARV experienced patients (52%) showed an improvement in score, ranging from +1 to +2 questions.
Figure 4: Question-by-question comparison of correct answers pre- and post-video

Key: Adherence=questions regarding concepts of resistance and the importance of adhering to ARV regimens; funds=question regarding alternative sources of income; HIV=questions regarding HIV virus science; SE=questions regarding side effects; strategies=questions regarding medication taking strategies;
The most frequently missed Likert-style questions pre-video were as follows:

- Side effects cannot be treated
- If I forget to take my ARVs sometimes, it will not affect my health
- Sometimes ARVs make people feel sick (side effects)
- It doesn’t matter what time during the day I take my ARVs
- Most side effects will go away after a few weeks
- If I forget a pill, I should not tell my doctor about it.
- HIV causes my immune system (my body’s army) to work poorly, making it easier for me to get infections.

**Improvement in non-Likert questions on side effect and medication taking strategies**

The 12 non-Likert questions (questions #13-24) were intended to assess specific side effects and medication taking strategies. Overall, the average score on this section of the questionnaire was 7.9 (65.8%) pre-video compared to 8.91 (74.3%) post video, showing an average increase in score of 1 question (8.5%). Of the 34 patients, 18 showed improvement on the test, with the change in score ranging from +1 question to +3 questions. Two patients showed a decrease in score. The remaining 14 patients showed no change in their score.

Subset analysis of the non-Likert questions shows that the ARV experienced group showed a 12% post-video improvement from 8.39 (69.9%) to 9.4 (78.3%), while the ARV naïve group showed a 17% improvement from 7.0 (58.3%) to 8.2 (68.3%).

The most frequently missed non-Likert questions involved side effects. As expected, a majority of patients (27, or 79.4%) failed to identify jaundice (“face turning yellow”) as a potential side effect of ARVs. Other frequently missed questions are noted below:

- How can I improve my adherence to ARVs? – Get a pill-box
- How can I improve my adherence to ARVs? – Use an alarm clock
- Which of the following may be side effects of ARVs? – Rash
- How can I improve my adherence to ARVs? – Keep regular appointments with my health care provider
DISCUSSION

This project demonstrates that it is feasible in South Africa to utilize focus groups to develop culturally-sensitive educational materials using familiar metaphors, which can be shown to have a statistically significant effect on patients’ baseline knowledge of medication taking concepts. Indeed, focus groups were a key element in creating culturally sensitive materials because their open-ended question format allowed the counselors to express in detail the specific barriers to adherence experienced by the Sowetan patients under their care. For instance, no previously viewed adherence video has discussed the importance of disclosure in ARV administration, while it was clear from discussions with adherence counselors as well as from the literature that family involvement can be key to successful adherence to antiretrovirals (24).

At this preliminary stage of the assessment of our video (ie: before the collection of adherence data), it is promising that analysis shows a statistically significant increase in post-knowledge after the intervention for both ARV naïve and ARV experienced patients. Even more heartening is the increase shown in patients who were naïve to ARV therapy. Though a larger sample size (greater than 65) is necessary to demonstrate that ARV naïve patients demonstrate a statistically significant increase in comparison to ARV experienced patients, current data does suggest that the video intervention might be particularly helpful for patients initiating ARV therapy who are less familiar with medication taking strategies.

One conclusion that can be gathered from this study is that even ARV experienced patients who have had the extensive PHRU educational interventions can gain a beneficial increase in knowledge of medication taking skills from watching the video. How this
additional knowledge translates into adherence, however, is another question: Given the already high adherence rate at PHRU, it may be difficult to show a statistically significant improvement in ARV experienced adherence rates, as there may be minimal room for improvement in adherence rate. An interesting follow-up study would be to show the effect of the video intervention on patients whose baseline adherence rates were below 90%.

**Video Production**

Discussions with adherence counselors, patients, and health care professionals identified a core set of strategies that led to the success of the video as an intervention:

1) *Dramatization of concepts* – it was agreed by the filmmakers and watchers alike that educational videos often fall into the trap of telling rather than showing. Monologues are less effective at generating thought than dialogues, which are less effective than full-scale real life depictions. Rather than delivering a speech to patients in video format, it was decided to create a dynamic plot to dramatize the necessity of adherence – namely that severe illness and even death can result from non-adherence. By “bringing to life” the stories of adherent and non-adherent patients, the viewers could begin assessing how they could utilize strategies such as pillboxes and alarms in their own lives.

2) *Question/answer format* – When stimulating thought about concepts of adherence, it was imperative that the fictional patient ask questions of the doctor, both to demonstrate that it is imperative that the doctor-patient relationship be a two-way process, and to make patients feel comfortable that they can ask basic questions, as
they would elucidate important concepts that may not be transparent in their physicians’ explanations.

3) **Culture-specific metaphors** – The wisdom of using a snake-soldier metaphor to describe the replication of the HIV virus was illuminated when one of the pharmacist viewers noted, “It was very smart of you to use the snakes; Africans do not like snakes.” Indeed, the cultural significance of snakes clearly made a visceral impact on many of the patient viewers, grabbing their interest and giving the abstract concept of an unseen virus a concrete manifestation that could be “fought against” by the “soldiers of the body” (immune system).

4) **Use of local actors/locales** – A key component in creating a culturally-sensitive video was to utilize actors that looked and spoke like the patients who would be viewing the video. This is important not because it increases the likelihood of viewer comprehension of the characters’ spoken English, but also to create a feeling that the characters on the screen are realistic and plausible patients who have lives and live similar to the viewers’. Similarly, it was vital to film in locations that looked familiar to the patients’ surroundings. For example, the narrative sequence where the character Joseph is attempting to hide his disclosure from his mother was most effective when filmed in a small township home that depicted the cramped living situation experienced by many Sowetans.

5) **Utilization of cinematographic motifs** – The director and editor of the video made an effort to include creative cinematic effects to make the story more interesting and attention-grabbing to viewers. These included the use of point of view shots, montage
sequences, and sequences in which snake images were overlaid to create the effective and somewhat frightening illusion that the snakes were multiplying in huge numbers.

6) **Humor** – It was attempted to use humor as much as possible throughout the video. This ranged from using humor to poke fun at the pun inherent in the word “adherent”, to slapstick humor used to depict side-effects, to the more sophisticated irony used in the video’s “commercials”, in which tense, action-filled situations are interrupted by clock alarms, after which the participants cease their actions and take their ARVs. Time after time, viewers of the video noted that the most memorable portions of the video were the segments that made them laugh.

7) **Music** – Music is a key component in South African culture; it is a kind of *lingua franca* for emotion and communication of ideas. Thus, two South African inspirational songs, as sung by the PHRU HIV-positive choir, were used. The first song, which opens the video, is about surviving illness, and the second is about spiritual hope.

8) **Use of repetition** – In an effort to reinforce certain key ideas regarding resistance, it was decided to use as many repetitive images and catch phrases as possible. For instance, during the narrative section it the phrase “every day, in the morning and night” was used frequently to reinforce the need to take ARVs every day at the same time. Visual repetition also occurred, as the snake replication sequence occurred first in the doctor-patient skit and then recurred several times during the Joseph and Hope narrative sequence to illustrate viral replication when Joseph neglected to take his medications. Finally, silent excerpts from the Joseph and Hope sequence reappeared
at appropriate times in the documentary section (i.e. when counselors spoke about pillboxes and placing ARVs by toothbrushes).

9) *Keeping it simple* – After watching a number of HIV educational videos, and speaking with health care professionals and adherence counselors, a decision was made to try to keep the video under 20 minutes long in order to maximize the attention spans of the patients. Twenty minutes is also the approximate amount of waiting time that PHRU patients must wait to obtain an appointment, meaning that they could conceivably watch the entire content of the video in the course of a routine visit. To keep the video under 20 minutes, and to maximize the retention of the most important drug-taking concepts, editorial decisions were made regarding the breadth of material to cover. For instance, only some of the most common side effects to ARVs (diarrhea, nausea/vomiting and dizziness) were mentioned. Details of specific drug administration were also not addressed, as regimens differ from clinic to clinic.

10) *Depicting actionable strategies* – It was felt that this video was most effective because it not only increased general knowledge regarding medication taking concepts, but it also offered actionable steps (through the documentary portion) that patients could take within their own communities and social structures to improve their adherence. In this way, the video offered not only knowledge, but tangible advice.

It is suggested that future educational interventions could benefit from utilizing these strategies to ensure a culturally-sensitive product.

A number of lessons were learned concerning the logistics of video production and questionnaire administration. First, it is recommended that documentary sections involving
interviews be structured as a question and answer session in which the interviewed individual repeats the question stem in his answer. In this way, their answers can be taken in context without needing to involve the second role of an interviewer. This is also a more focused method of conversation than ad-lib talking, which can fail to cover certain key points.

Second, it must be mentioned that for confidentiality reasons, as the video was to be shown in their local area, the adherence counselors (with one voluntary exception) did not disclose their HIV status, and were identified simply as adherence counselors.

In regards to the video assessment and questionnaire, it was noted that the knowledge questionnaire most effective if given orally, to minimize the impact of relative illiteracy or carelessness on the part of the test-takers (on more than one occasion a patient admitted to reading the question incorrectly when the test was reviewed post-video).

The project has several limitations: First, the study may not be fully generalizable because of the study site. The Perinatal HIV Research Unit (PHRU) at Baragwanath hospital is indisputably a center of excellence in South Africa, offering extensive baseline education interventions that are lacking at most other South African health centers, such as those in rural areas. The human resources offered by PHRU, in particular the presence of a full-time staff of HIV counselors who run daily support group meetings, were invaluable resources in development of the educational video. Undoubtedly, however, the presence of these resources may have affected the outcomes data that we procured regarding patients’ knowledge of medication taking strategies. It is possible that patients presented the video in health care environments with fewer baseline educational interventions, and without any experience with ARVs may demonstrate an even greater increase in baseline score than the studied patient population, many of whom had perfect scores on core medication taking
concepts. Alternately, it is possible that patients without the support offered by the PHRU may score lower based on lack of basic health literacy.

Additionally, most participants were women who spoke English. While the data obtained in this study may be reproducible in a similar urban environment, it must be noted that the majority of participants spoke basic English and had education levels above elementary school, factors which would be unlikely to exist in more rural areas. Based on the disparity in English-speaking ability in South Africa, it is recommended that the educational video be dubbed into the native Zulu, Sesotho and Xhosa languages for rural distribution.

There are several other limitations to the study, including small sample size, under-representation of men, and lack of clinical correlations between education and adherence. The logical next step in the evaluation of the educational video is a randomized controlled trial comparing the adherence of ARV-naïve patients who are not shown the video to patients who are shown the video prior to initiating ARV therapy. As prior studies have shown a decay effect of educational interventions on behavior, it would be helpful to measure the adherence at one month, three months, six months and one year after the intervention. CD4 counts and viral load assessments at these intervals would also provide valuable information. Additionally, further studies evaluating the efficacy of the dubbed video in rural areas with much fewer educational interventions would be vital in proving the effect of video educational initiatives on populations with low health literacy.

In conclusion, the production of a culturally-sensitive video to address local barriers to adherence to antiretrovirals is a feasible undertaking, and one which has a measurable and significant impact on patient knowledge of basic medication taking concepts and strategies. A controlled and randomized study to determine the effect of the intervention on patient adherence is warranted.
REFERENCES


antiretroviral therapy for HIV/AIDS. *Cochrane Database of Systematic Reviews.* (3):CD001442.


Appendix 1: Sample Screen Shots from the Completed Video

1. Title Screen

2. Opening doctor-patient dialogue
3. **Snake metaphor:** This is a representation of the “soldiers of the body”, who have badges labeling them as CD4 soldiers

4. **Snake metaphor:** The portion of the metaphor in which the snake sneaks up on the CD4 soldiers

5. **Snake metaphor:** Depiction of the soldiers using ARVs to kill the snake eggs before they hatch
6. **Snake metaphor:** Depiction of the soldiers pouring ARVs over the snake eggs to kill the snakes before they hatch.

7. **Snake metaphor:** Depiction of the “thick shelled” ARV-resistant snake eggs hatching.

8. **Side effects:** Demonstration of one kind of ARV side effect (nausea and vomiting).
9. Commercial: Gunfight scene setup

10. Commercial: During the gunfight, one assailant gets a SMS message reminder to take his ARVS…

11. Commercial: …and takes his ARVS in the middle of the gunfight
11. Commercial tagline

Adherence: Don't Forget

12. Commercial: …while his opponents look at each other quizzically

13. Joseph and Hope Narrative:
Hope walks into the hospital
14. Joseph and Hope Narrative:
Hope discloses her HIV status and her ARVs to her brother

15. Joseph and Hope Narrative:
Joseph looks in to see if his mother is home so he can hide his drugs

16. Joseph and Hope Narrative:
Hope puts her pills into a pillbox before going to a party
17. Joseph and Hope Narrative:
Joseph goes to a party, forgetting to take his ARVs

18. Joseph and Hope Narrative:
Joseph feels side effects, and again does not take his ARVs

19. Joseph and Hope Narrative:
Hope takes her ARVs after having placed them by her toothbrush so she would remember them.
20. Joseph and Hope Narrative: Joseph lies in bed, dying, wishing that he had taken his ARVs properly.

21. Documentary: An adherence counselor demonstrates how to use a pill box.
Appendix 2: Adherence to ARVs: A Life Choice (Screenplay)

N.B.: Everything in **bold** lettering will be emphasized on the screen by pull-out captions

FADE IN (to the sound of African inspirational singing)

**Title: Adherence to ARVs: A Life Choice – Why Adherence?**

FADE OUT/IN

*Setting: Doctor’s office. Dr. LAWRENCE is sitting in his chair, reading a patient’s chart. There is a knock on the door and Tumi, a patient, enters.*

**DR LAWRENCE**

Hello, Tumi. My name is Dr. Lawrence. We are happy that you will be able to receive antiretroviral therapy to treat HIV/AIDS. Antiretroviral therapy, also known as ARV or ART, will help your body defend against AIDS. While ARVs are not a cure, they make it possible to live a long and healthy life while infected with HIV—but only when you take them correctly. We want to teach you about adherence to ARV drugs.

**TUMI**

*(confused) But doctor, what is adherence? Does this mean that the pills stick to my body?*

**DR LAWRENCE**

No, you’re right, it’s a funny word, but in this case, **adherence means taking your drugs**

1) every single day  
2) at the right time  
3) according to your doctor’s instructions.

**TUMI**

But, excuse me, doctor… Why is adherence so important?

**DR LAWRENCE**

Good question. Let’s go into the body and see what happens with HIV and ARVs.

*(the following portion will be brought to life by actors)*

**DR LAWRENCE (off screen)**
As you may know, your body’s immune system – or amaso tsha amzimba – is an army of soldier cells that guard your body from sicknesses like HIV. But HIV is a particularly bad sickness because it not only fights your body, it fights CD4 soldier cells. HIV is like a poisonous snake, sneaking up to the CD4 soldiers while they are sleeping and killing them. These snakes are small and wily, hiding, so the soldiers cannot find them to fight them. The snakes also breed very quickly, multiplying and multiplying until they overwhelm the CD4 soldiers and the body becomes very sick.

This is where ARVs come in. ARVs can prevent the multiplication of the HIV virus. It is as if the body’s soldiers could find the HIV snake nests, and pour poison on the snake eggs to keep the eggs from hatching.

However, ARVs are a kind poison that only works for a limited amount of time. They must be taken every day, in the morning and evening, or else the HIV virus can start reproducing.

TUMI (off screen)

Why is this? Why do I have to take the drugs every day? What if I forget?

DR LAWRENCE

Every day you forget your ARVs means that the HIV virus has a chance to multiply. The HIV virus, though, is a very smart virus. It is constantly thinking of ways to defeat the ARV poison, a thing that is caused drug resistance.

TUMI

Huh? What is drug resistance?

DR LAWRENCE

Good question.

- Resistance means the HIV virus has changed so that the ARVs you are taking can no longer fight it

- If you develop resistance, HIV is much more likely to kill you, since ARVs cannot fight it

- Resistance can develop any time you don’t take your ARVs properly

Let’s say one day you don’t take your ARVs. Now the soldiers have no poison to pour on the snake eggs. The HIV virus begins to multiply -- the snake eggs hatch, and many more snakes come to attack the soldiers.
If you now take your ARVs, the soldiers will again be able to poison the HIV snake eggs. But the problem is that some of the new snakes that hatched will be different than their mothers. One snake might have spots. Another might be longer. And another might lay eggs with a thicker shell.

Now the soldiers go to pour ARV poison on these eggs, but the thick shell keeps it from killing the baby snake. The eggs hatch, and the new snakes begin to lay more eggs, which also have thicker shells. Soon, the ARV poison is useless against the HIV snake eggs.

This is what we call *resistance*. It means that the HIV virus has changed, like the snake that lays thick-shelled eggs, so that it cannot be controlled by ARV drugs.

Every time you forget your ARVs, the HIV virus has a chance to multiply. Some of the new HIV viruses might be able to resist ARVs, like the snake with thick-shelled eggs. This is why you must take your drugs every day, at the same times, even if you feel well. ARVs can control HIV only until the virus develops resistance, which can happen any time you don’t take your drugs. So you must make sure you never let this happen.

**TUMI**

Sheah, you can say this, but I hear that ARVs can sometimes make you feel bad. And what if I feel fine? Do I need to take them?

**DR LAWRENCE**

You’re right. Taking ARVs properly is not easy. They have *side effects*, which means that sometimes your body can feel unpleasant in the first few weeks after taking the ARVs because your body is getting used to the medications. Sometimes people have problems taking drugs because they make them feel sick to their stomach, or dizzy, or constipated. *(show action shots of people throwing up, fainting and sitting on a toilet)*. But most of the time these side effects go away as your body gets used to the medication.

**TUMI**

Hmmm… If I feel healthy, does that mean that I don’t need to take the drugs?

**DR LAWRENCE**

No way! Some people say, “Oh, if I feel good one day, I don’t need to take it.” This is not true, because in fact, it is the drugs that are making them feel good in the first place! And besides, as we just discussed, ARVs are not like Panado – you don’t just stop taking it when you feel better. Remember, the HIV virus is very smart and needs to be defended against every day.

**FADE OUT TO COMMERCIAL A**
EXT. ABANDONED BUILDING – OR CAN BE ANY HALLWAY, ETC

One GUY is being chased by two THUGS. They both carry guns, exchanging gunfire.

The guy’s cell phone rings in alarm. He picks it up and looks at it: an SMS message reads: REMEMBER YOUR ARVS.

The guy smiles. Calmly, he lowers his gun. Bullets continue to whiz by him.

He takes out a bottle of ARV drugs. He pops one in his mouth.

SPLASH SCREEN

Adherence: Don’t Forget

BACK TO SCENE

The thugs share a look, confused.

FADE OUT

TITLE SCREEN

Title: Adherence in Action – The Story of Joseph and Hope

FADE IN: EXTERIOR OF BARAGWANATH HOSPITAL

(the following portion will be brought to life by actors)

NARRATOR
This is the story of two people – Joseph and Hope. Joseph is a construction worker. Hope is a domestic servant. They both live in Soweto. Both are HIV positive.

One day, Hope walks into Baragwanath Hospital to meet with her doctor. He tells her that her CD4 count has dropped below 200, and she can begin receiving ARV drugs to combat HIV. He gives her a prescription and explains which drugs to take when. One thing is particularly important, he says. She must always remember to take the drugs. If she forgets, the virus can develop resistance, and the drugs will not work. She listens carefully. Once the meeting is over, she picks up her drugs at the pharmacy.

As she walks out of the hospital, Joseph walks in. He meets with the same doctor. He learns that his CD4 count is also below 200. He listens to the same speech about adherence, and goes to the same pharmacist to pick up his drugs.
Hope gets back to her house. She tells her mother about her new drugs. She sets them next to her bed, where she will see them when she wakes up in the morning.

Joseph is about to walk into his house, when he realizes that his mother will see his drugs and ask about them. Instead, he walks to the store and buys some drinks. He hides the drugs in the bag with the drinks. Then he goes home, and hides the drugs in a box, so no one will see them.

The next morning, Hope asks her mother for a glass of water and takes her first dose at 7:00. Joseph takes his drugs out of his box, makes sure his mother isn’t nearby, and takes his first dose at 8:00. They both take their drugs that evening, twelve hours later.

The next morning, Hope is in a rush to get to work. She is about to head out the door, but her mother reminds her to take her drugs. She does.

Two days later, Joseph is also in a rush. He walks past his mother and out the door, forgetting his drugs. Inside his blood, the HIV virus is now able to reproduce rapidly, and it does. It kills many of his CD4 cells. It doesn’t stop until Joseph takes his drugs that evening.

That weekend, Hope is invited to a party. Before she leaves the house in the afternoon, she picks up a dose of her drugs and puts it into a special container, because she knows she won’t come back again until late at night.

When Joseph’s friends come by to pick him up, he doesn’t bother with the drugs. After all, he’ll probably be back in time to take them, right? Wrong! The HIV virus multiplies again, and doesn’t stop until the next morning, when he takes his pills.

Two days later, Hope takes her drugs at 7:00. Soon afterwards, she feels very sick in her stomach. The drugs are causing side-effects. She arranges to meet her doctor the next day, and continues to take her medication. She meets with him, and he switches her to a new drug. That evening at 7:00, she takes the new drugs. She feels better.

The same day, Joseph takes his drugs, and feels very sick. The next morning, when it’s time to take them, he doesn’t. He doesn’t want to feel sick, and missing one dose can’t hurt, right? Inside his body, the HIV virus begins multiplying. This time, one of the new viruses is different than the others. It is resistant to ARVs. That night, Joseph decides to take his pills. Inside his body, most of the HIV viruses stop multiplying, Except for the resistant strain. It keeps multiplying.

Over the next few weeks, Joseph takes his pills. But the resistant strain of the virus continues to multiply. Soon most viruses in his body are resistant.

He becomes sick with a common illness. Since the resistant strain of HIV has killed most of his CD4 cells, his body cannot fight the sickness. He takes his pills, but it makes no difference.
A few months later, he is sicker. He must stay in bed all day. Hope, on the other hand, remains healthy. She takes her pills every day, twice a day. She continues to work, go to the cinema, and play with her children. The HIV virus never has a chance to reproduce and develop resistance.

In the meantime, Joseph lies on his bed, dying. He wonders what would have happened if he had been able to take the drugs every time.

FADE OUT

FADE IN to Commercial B

INT. BEDROOM – Night

CLOSE UP: A condom wrapper is ripped in two and the condom is taken out.

Under the covers of a bed, a MAN and WOMAN make love.

Their cries of passion approach a climax.

An alarm clock goes off.

The man looks over at the alarm. Unperturbed, he turns off the alarm and pulls out a bottle of ARV pills. He takes one.

SPLASH SCREEN

Adherence: Don’t Forget

BACK TO SCENE

The woman looks at the man, confused.

FADE OUT

Title: Strategies for Adherence

Strategy #1: Disclosure

ADHERENCE COUNSELOR (LAWRENCE)

(this section ad-libbed by adherence counselor)
(flashback to Joseph hiding the pills in the bag)

(flashback to Helen’s mother reminding her to use her meds)

**Strategy #2: Support groups and literature at Baragwanath**

**ADHERENCE COUNSELOR (PRISCILLA)**

(this section ad-libbed by adherence counselor)

(show pictures of Priscilla, Joan and Lucky leading support groups; show picture of patient reading pamphlet on side effects)

**Strategy #3: Memory aids**

**ADHERENCE COUNSELOR (LUCKY)**

(this section ad-libbed by adherence counselor)

(show shot of Lucky crossing dates off a calendar and using a pillbox)

**ADHERENCE COUNSELOR (ANNIE)**

(this section ad-libbed by adherence counselor)

(show shot of putting pills/pillboxes by toothbrush, under a pillow, as well as a picture of Annie reaching into her pocket for an alarm/SMS message)

**Strategy #4: Financial aid**

**ADHERENCE COUNSELOR (GHADI)**

(this section ad-libbed by adherence counselor)

(show picture of people filling out grant application, working in a community garden)

FADE OUT to sound of African spiritual music
Appendix 3: Pre-Video Questionnaire
## Pre-video questionnaire (page 1 of 2)

<table>
<thead>
<tr>
<th>Study number</th>
<th>Gender: Male</th>
<th>Female</th>
<th>Age</th>
<th>Highest grade completed</th>
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<tbody>
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</table>

Are you currently taking ARVs?  
Yes  No  
When did you start them?  

Please read each question below carefully. Mark whether you agree (1), somewhat agree (2), somewhat disagree (3), or disagree(4).

**ARVs = antiretroviral therapy (HIV medications)**

| 1. HIV causes my immune system (my body’s army) to work poorly, making it easier for me to get infections | 1 | 2 | 3 | 4 | 5 |
| 2. It is important to take my ARVs every day | 1 | 2 | 3 | 4 | 5 |
| 3. If I forget to take my ARVs sometimes, it will **not** affect my health | 1 | 2 | 3 | 4 | 5 |
| 4. Sometimes ARVs make people feel sick (side effects) | 1 | 2 | 3 | 4 | 5 |
| 5. Most side effects will go away after a few weeks | 1 | 2 | 3 | 4 | 5 |
| 6. Side effects **cannot** be treated | 1 | 2 | 3 | 4 | 5 |
| 7. If I have side effects I should talk to my doctor | 1 | 2 | 3 | 4 | 5 |
| 8. If I feel better, I can stop taking my ARVs | 1 | 2 | 3 | 4 | 5 |
| 9. If I have no food or money, I can build a food garden or apply for a social grant | 1 | 2 | 3 | 4 | 5 |
| 10. If I forget a pill, I should **not** tell my doctor about it | 1 | 2 | 3 | 4 | 5 |
| 11. If I don’t take my ARVs as prescribed, I am giving the virus a chance to multiply and my medications could stop working | 1 | 2 | 3 | 4 | 5 |
| 12. It **does**n’t matter what time during the day I take my ARVs | 1 | 2 | 3 | 4 | 5 |
13) To take my drugs correctly, I must take them:

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>Every day</td>
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<tr>
<td>At the right time</td>
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<td>According to my doctor’s instructions</td>
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</tbody>
</table>

14) Which of the following may be side effects of ARVs (you may circle more than one)?

   a. Vomiting
   b. Diarrhea
   c. Dizziness
   d. Face turning yellow
   e. Rash
   f. Bad dreams

15) What can I do to improve my adherence to ARVs (you may circle more than one)?

   a. Tell my family that I’m taking ARVs
   b. Hide my pills
   c. Get a pill box
   d. Use an alarm clock
   e. Don’t tell anyone about my HIV/AIDS
   f. Put my pills next to my toothbrush or under my pillow
   g. Keep regular appointments with my health care provider

16) Please tick below if you have:

   - [ ] Watched HIV an educational video
   - [ ] Been to a general support group meeting
   - [ ] Been to an adherence support group meeting
   - [ ] Met with an adherence counselor
Appendix 4: Post-Video Questionnaire
Post-video questionnaire  (page 1 of 2)

Study number______________    Was the video clear?     ___entirely clear   ___mostly clear   ___not very clear

Please read each question below carefully. Mark whether you agree (1), somewhat agree (2), somewhat disagree (3), or disagree(4).

ARVs = antiretroviral therapy (HIV medications)  

<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
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<tbody>
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<td>12. It doesn’t matter what time during the day I take my ARVs</td>
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</table>
16) To take my drugs correctly, I must take them:

- Every day
- At the right time
- According to my doctor’s instructions

17) Which of the following may be side effects of ARVs (you may circle more than one)?

- a. Vomiting
- b. Diarrhea
- c. Dizziness
- d. Face turning yellow
- e. Rash
- f. Bad dreams

18) What can I do to improve my adherence to ARVs (you may circle more than one)?

- a. Tell my family that I’m taking ARVs
- b. Hide my pills
- c. Get a pill box
- d. Use an alarm clock
- e. Don’t tell anyone about my HIV/AIDS
- f. Put my pills next to my toothbrush or under my pillow
- g. Keep regular appointments with my health care provider

16) What did you learn from the video that you did not know before?