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ARV Adherence vs. Cultural Compliance: HIV/AIDS Drug Therapy and Decision-Making among PLWHA in Rural Botswana

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Abstract

Background: The purpose of this study was to identify certain cultural barriers that facilitate or constrain adherence to Anti Retroviral (ARV) therapy in northern Botswana. ARV (anti-retroviral) therapy increases the overall quality of life for persons living with HIV/AIDS (PLWHA) but key to ARV effectiveness lies in rigorous adherence to therapeutic regimens. ARV therapy is both subsidized by the Botswana government and available to all who enroll in plans either through employers or local chemists (pharmacies) in the country. Despite this wide coverage and access, national data indicate that many who enroll become "non-compliant" as they fail to take the drugs as indicated.

Methods: A qualitative study, and similar to other recent work on this topic [1,2], results are from semi-structured interviews conducted with 25 patients, of whom 11 had been lost to follow-up and were non-persistent with ARV therapy over a four month period. In addition, focus group discussions were performed with 10 ARV nurses in the local hospital and 5 chemists/pharmacists in the village of Maun. All interviews and focus groups were audio-recorded, transcribed, and coded for themes and patterns in SeTswana using a grounded theory approach. The emergent concepts and categories were translated into English and while not intended to be representative of the population do provide a springboard for this important, ongoing research.

Results: Geographic location and transportation barriers, gender and intimate partner dynamics, perceived stigma and discrimination were major reasons for patients being non-adherent and lost to follow-up. Disclosure of HIV status, social support, and regular use of reminder assistance all improved health on ARV. Ongoing education and counseling emerged as facilitators of adherence to anti-retroviral therapy in this region but cultural factors remained significant barriers to compliance with prescribed drug regimens.

Conclusion: Improving adherence and retention in ARV therapy programs requires integration of enhanced treatment access with improved attention to cultural factors by health personnel.

Healthcare providers, community leaders, healers as well as those administering drug therapies such as chemists need to be supported to better equip patients to cope with the issues associated with ARV protocols. Development of social policies and cooperation between various stakeholders are necessary for improved health outcomes and lessened stigma in rural parts of Botswana.

Keywords: Adherence; Compliance; ARV/ART; Stigma; Botswana

Introduction

In 2011, Botswana had a population of almost 2.3 million people, of whom an estimated 380,000 people were living with HIV [3]. In 2002, Botswana became the first country in sub-Saharan Africa to launch a national antiretroviral therapy program in the public health sector.

ART, delays the emergence of drug-resistant strains of HIV by drawing upon a combination of three or more drugs that prevents the HIV virus from multiplying in the body. In Botswana, the ART is provided free to all citizens who are eligible for treatment, provided through employers and community clinics and chemists/pharmacies.

While ART has improved the lives of many worldwide and is not just limited to the context of southern Africa, lack of adherence to ART is still a major challenge to AIDS care and in Botswana in particular, certain cultural factors inhibit full adherence and compliance behavior. Research supports that the failure to achieve optimal adherence to ART may lead to an increase in the replication of HIV and the development of viral mutations. This can result in treatment failure and accelerate the emergence of drug-resistant strains of HIV, with severe consequences for public health [4-6].

As Botswana improves access to ART in all its health facilities, there is a critical need not only to estimate the rates of adherence but also to understand the key cultural and behavioral factors (motivators and barriers) that influence adherence, and to apply the lessons learnt in order to improve both existing and future ART programs. In order to do this, this study focused on Antiretroviral (ARV) users, health workers, policy-makers, community members and other stakeholders such as traditional healers and midwives (long considered part of essential and accepted Tswana healing practice yet consistently overlooked in global health studies and policy implementation in rural Botswana) [7,8] in an effort to identify key factors which influence adherence. Results of this study will facilitate the development of culturally appropriate tools and specific interventions to improve adherence and cultural acceptance by ARV users, community members and stakeholders, now and in the future.

Study Area

This qualitative study was carried out over a period of four months beginning in June of 2016 in Maun and Shorobe, in the northwest district of Ngamiland in Botswana. There is a large and newly renovated hospital in Disaneng ward in Maun that serves as a central point for ARV education and dissemination in these communities. There are also several health clinics in the Maun area and each pharmacy/chemist in town is responsible for refills of ARV prescriptions, part of the Electronic Health Record (EHR) system throughout the country. A pre-test of the recall measurement tool was conducted at the outset of the study in order to assure quality of participant's responses and pill-count recall.

Health Care Facilities and Role of Chemists

Participants were asked to first recall adherence to pill regimens and these were matched to EHR reports from pharmacy/chemist records. Chemists/pharmacists are essentially on the 'front line' in the dissemination of ARV therapy medications. As such they are often most aware of whether EHRs match patient adherence self-reports. Participant observation revealed for example that 'pill dumping' (the practice of emptying any unused medication from prescription bottles brought for refill) was ubiquitous in the parking lots and hidden areas around pharmacies/chemists.

Study Design

Semi-structured interviews were conducted with 25 patients, of whom 11 were eventually lost to follow-up and were non-persistent with ARV therapy over the four month period. This is similar to findings in recent work [1,2] and provides impetus for additional research into why patients are lost in the follow-up period of treatment. As a qualitative study, the project was not designed to be representative of the Tswana population but rather to add to similar studies [1,2,4,9-12] in the region and with respect to perceptions of obstacles and possible barriers to adherence at the local level in Botswana in particular [13]. In addition, focus group discussions were performed with 10 ARV nurses in the local hospital and 5 chemists/pharmacists in the village of Maun. All interviews and focus groups were audio-recorded, transcribed, and coded for themes and patterns in SeTswana using a grounded theory approach [14]. The emergent concepts and categories were translated into English.

Study Population

Adult patients (≥ 18 years old) who had been receiving ARV in the study clinics for at least a month and could provide informed consent in SeTswana were eligible for the interviews. All ARV nurses and chemists/pharmacists who had been working in the ARV clinics or providing ARV therapy for at least 6 months were invited to participate in the focus group discussions.

There was a total of 40 participants at the outset of the study. The mean age of the patients was 35 years of age. Exactly half of the participants were women, approximately one third (35%) were married or living with a long-term partner, 53% had primary or no formal education. The mean age of the providers and pharmacists was 31 years of age and approximately two thirds of these (including clinic nurses) were women. Again, while not intended to be representative of the entire population, these data are shared in order to provide the most holistic demographic overview of those involved in the study and do reflect characteristics of those most engaged with the practices surrounding ARV adherence.

Data Collection and Analysis

Data were collected from June 2016 to September 2016 using semi-structured interview and focus group discussion guides with patients and healthcare providers (including nursing staff and pharmacy chemists). The guides were designed to elicit information from the patients' and healthcare providers' points of view based on their experience with HIV medication, including factors that facilitate or constrain adherence to HIV medication and reasons for loss to follow-up.

Following an inductive approach, where value is added by constant checking and re-checking for relevance of the instrument, interview guides were updated regularly as the result of ongoing data analysis before the next interview or focus group discussion. While the tool of data collection was not changed substantially, the interview protocol language in particular could be adjusted to better elicit open-ended responses. This approach follows that of others engaged in similar research [1,2,15,16].

A trained research scientist and social worker conducted the interviews and focus groups in the local language, SeTswana. Comprehensive notes were taken throughout and after interviews and focus groups, and all sessions were audio-recorded using digital recorders. Analysis of data aimed to describe the barriers to, and facilitators of, adherence to ARV including the possible reasons of patients for missing appointments and/or being lost to follow-up at clinics or pharmacies. A grounded theory approach was used for analyzing the data and results coded and textual data were coded into themes inductively. Two coders (the research pharmacist and the main field researcher) performed the coding separately and differences were resolved with discussion. Focus groups and interviews were coded and analyzed separately, and matched for common themes and all data were uploaded and analyzed too using MAXQDA software. The key findings were illustrated by selecting representative quotes.

Participants had the autonomy to decide on where and when interviews would be conducted in order to facilitate open discussion and lessen the perceived stigma or potential stress. Participants in the focus groups were required to maintain confidentiality of all involved as well as the content of the discussion. All were given the option to end the interviews or remove themselves from discussion if they felt any undue anxiety or distress. Data were stored in a locked cabinet in locked facilities in the University of Botswana. All electronic records were stored on a secure, password-protected, server at DePauw University. Researchers were able access the data whenever required. Data will be destroyed 5 years following publication. Paper data will be securely shredded and electronic data will be erased at this time.

Results

Coded results from the interviews and focus group sessions fell into several patterns that elucidate the cultural barriers to ARV adherence. The most common explanations for and themes that were relevant to lack of adherence to ARV regimens include: lack of technology to aid compliance, transportation and other economic challenges, stigma, cultural/gender barriers and nutritional barriers.

Lack of Technology

Technology has both facilitated and hindered the accessibility and ease of adherence to ARV regimens in Botswana. In a country where mobile and smart phones are ubiquitous, it is clear that apps and reminders have helped with basic adherence on a daily basis [7]. But for those without technology enabled phones (pay-as-you-go phones or 'disposable' phones) the lack of technology can be a simple but profound barrier. As one focus group participant said: 'The most common reason for me to forget to take the pills is the lack of watch or reminder, without technology these days it is hard to remember…my phone is a simple one and does not always have the alarm enabled'.

Another, a pharmacy chemist, said, 'I'd say the biggest challenge for patients is the lack of communication and reminders…all of these things are available but people are not using them, they are not using the reminder apps or the calendar we do not know if the pill count they provide is accurate, we do not know if they are dumping the pills because they forgot to take them…maybe they are even selling them'.

The Electronic Health Record (EHR) system in Botswana too seems to have facilitated adherence at a population level. An individual can go into any pharmacy/chemist in Botswana and have their EHR called up on the computer. Ethnographic evidence suggests however that despite reported rates of high adherence to medication (pill bottles are returned empty and recorded as such when refilled), actual rates of adherence are much lower as pill dumping prior to entering the clinic or chemist is common, errors in reporting that are not being accurately captured through EHR systems alone.

Transportation and Safety Challenges

Several respondents (12 of the initial 40 total participants) talked about the challenges of transportation to refill their prescriptions and did so early in their interviews and when contacted about the project. In rural, northwest Botswana, the challenge of transport across relatively unpopulated areas is a considerable one. Transport from Maun to Gaborone (the capital city) is via bus once a day; smaller combi routes run from Maun to outer villages. It is particularly challenging for those living or working in the Okavango delta region (often as part of a tourist camp) to depend upon reliable transport to Maun aside from regularly scheduled shift changes (employees in the camps are often at the camp for two weeks at a time before a break occurs to come to town).

Even when transportation is reliable and relatively inexpensive, wait times and concerns over safety affected participant ability to adhere to drug regimens. As one young woman noted, 'you are waiting for a long time for transport but the return is the problem….for young girls they are often in a queue late at night, it is dangerous, there are young men around, older sugar daddies, this makes women at risk while trying to get their pills'.

The question of selling drugs is less of a problem in the context of Botswana than it is elsewhere. Primarily because ARV therapy is provided free of cost to all citizens, pill resale has not been a tremendous market or barrier to adherence. Increasingly however, as ARV therapy is denied to those who are not citizens (for example the growing population of Zimbabwean immigrants in the Dukwi refugee camp near Francistown on the eastern corridor of the country), demand for black market pills may likely increase. Research in this area has been limited thus far but as the rates of relationships between BaTswana and refugees has increased and efforts to protect these populations has come under scrutiny (non-Tswana are not eligible for subsidized ARV therapy) then presumably the market for pill resale will be a factor.

Stigma

Participants noted that stigma still played a significant role in decisions not to take ARV therapy on time. While many officials in Botswana have argued that Botswana has been successful at the reduction of stigma on a large scale (i.e. there have been numerous HIV/AIDS awareness campaigns over the past several decades, testing is ubiquitous and counseling routinely offered to those who present at clinics and hospitals), for individuals in more rural areas, stigma emerged as a barrier to adherence [6]. As one of several participants said, 'I was too embarrassed to take pills when I was with my friends, not everyone knew that I was taking them and so I would wait until I was alone, I knew it was going to be a problem but I did not want the bigger problem of trying to explain'.

Another explained,

'My friends and family know that I am taking pills and even know how important it is to take them on time, my boyfriend even sets his phone [alarm] so that I will, but when I go to work, that is a different story, most employers, they don't want to know that you are on ARVs, that you have to take pills in their house. I'm working in a woman's house now and if she saw me taking the pills I know she would realize and maybe ask me to leave. Many people talk about how good ARVs are for people but they don't want to see it in front of them, or in their kitchen…so yes, those are times when I cannot take the pills at the time I should, just to protect my status…I don't want to lose my job so it is easier to just wait a bit some days'.

Disclosure of status and privacy issues remains important barriers to effective ARV therapy in Botswana. Despite knowledge and education about HIV and AIDS over the years and real progress in treatment as a result of ARVs, it is clear that stigma remains an important aspect to best therapeutic practices.

Gender Barriers

Gender-based barriers were significant factors in understanding lack of adherence to holistic ARV regimens. Specifically, women were at greater risk of lack of adherence if their male partners did not know or did not support their therapy. One nurse in the study commented that 'I've seen many partners who are not concurrent be supportive of one another and help the positive one take the medications, but you see just as many partners who you know are not supportive and that the couple is not being honest with one another'. In several cases both chemists and providers suggested that women were being put at risk by partners who were engaged in Multiple Concurrent Sexual Partnerships (MCPs). As one provider said, 'If a man comes home and says he wants to have sex with his wife but she asks him to wear a condom or even get tested so he can go onto ARV therapy, there will be a problem, she will be suspicious and he will often be angry and so the wife ends up at risk if he is having sex with many other ladies…even if he is on ARV therapy, it does nothing to protect the wife in that case, it just reinforces that imbalance'.

Several female patients too commented that they were more afraid to be seen taking ARV therapy than they suspected their male friends and counterparts were. As one young woman suggested, 'on women it is more noticeable too, when you are on ARVs, you get fatter and people notice this more on women, whether that is good or bad, they will say something or suspect you and men are not getting those same comments if they are taking the pills'.

Some women too noted problems of patriarchal systems of labor, arguing that women were far more inclined to be in the more rural villages with less access to clinics and chemists than men were. With the increase in forms of public transportation and combi routes some of this has been ameliorated but several women commented on the fact that without 'walking to town, women don't have the same access to refill those pills as men do, they may not ask their husbands or boyfriends or families to pick up the pills for them if they can even do that, they will be too afraid or others will not want to get those medications for them in public'.

Gendered stereotypes too about who is at greater risk for disease persists as well. While current education and prevention messages clearly emphasize the fact that all individuals are at risk for HIV and AIDS, in some more traditional, medical explanations, women are still seen as more culpable. A nurse at the Disaneng clinic said, 'we sometimes get people in here who have been told my traditional healers, by dingaka, that the pills will actually make them sicker, so they stop taking them….mostly they are just reacting to the side effects and need to wait to see but you know if you hear a healer telling you not to take this medicine, it will be a challenge…they also tell young people that mostly women have the disease…that is a shame, most young people today no more than that but you still see small children believing that they are going to get sick from their mothers, or sisters or aunties…these are the misperceptions that we know about'.

Nutritional Barriers

Several participants noted that nutritional health and lack of food can be significant barriers to ARV adherence. While Botswana on the whole is a wealthy nation, the more rural, northern areas where this study was conducted tend to be affected by greater poverty and diversity of diet. One chemist in Maun noted that it is often only when patients came in to town that they might get a wider range of options of both perishable and non-perishable foods. A woman in one focus group noted that 'there are times when patients on ARVs are trying to decide whether they can afford the cost of certain foods or the visit to get the pills refilled, just because the pills are paid for by our government, that doesn't mean there isn't a cost there and people overlook that, they forget that there is still a cost to get your medication' [11]. Others noted that ARVs can cause hunger or upset the stomach if not taken with enough food [17,18]. Several clinic providers noted that they often heard stories of patients who only took ARV pills when they ate an evening or bigger meal, reducing the number of times that they were taking the medication drastically. For parents or caregivers who provide nutrition and/or medications to those on ARVs, finding ways to improve access to sound and consistent nutrition will be important in the future.

Social Network and Community Support

A significant number, just over half (15 of the final 29 total participants after the loss to follow-up) of respondents talked about how disclosure of their status and their participation in the nationally subsidized ARV program actually facilitated their adherence to drug therapy regimens. In Botswana, it has long been normative to see young people and couples with t-shirts that proclaim 'I know my status, do you?'. The same is true with ubiquitous billboards and public education campaigns that for decades have normalized questions about status and the need for knowledge and testing. While stigma associated with HIV remains, it is certainly true that among Tswana populations, community engagement with HIV education and prevention programs have long been a part of everyday discourse. As one young woman put it, 'I have shared with my closest friends and my family that I am PLWHA [person living with HIV and AIDS], it helps me that they know, they can make certain that I am taking my pills, there is always someone who reminds me that I am important and so taking the pills is important.'

Another suggested,

'my daughter knows that I am HIV positive and that she is not, she is only a small child, but she knows that I must take the pills in order to stay well and be able to care for her, there is no problem or feeling that she should be ashamed of her mother who is taking care of her and herself.' Caretakers and family members are often able to offer support of those on ARVs; many cited that it was part of traditional Tswana culture to care for family members in one's home village or maternal village.

Social media and several television and radio programs in Botswana have also been effective agents in the reduction of stigma and the increase of community support and awareness [10,13]. The radio program, Magkabeneng for example was often referred to by study participants as a popular serial in which HIV and AIDS was openly discussed and strategies for support explored. As one young man, who was also a youth pastor in the local community, said, 'my girlfriend and I got together because we had friends who would listen to the show all together…it is a good program, the themes are real life, they have characters who have sex and HIV and deal with it, it is a nice model for youth to see.'

Discussion

This study has shown that despite an active, ongoing awareness and prevention campaigns, cultural norms, stigma and contextual barriers exist that prevent the efficacious adherence to ARV therapy for PLWHA in Botswana. This study was conducted qualitatively in order to help identify those specific, local/individual barriers which constrain or actually facilitate adherence to drug regimens. Participants in this study identified the lack of technology as well as the lack of transportation and geographic location as some of the most significant factors in determining patient compliance to ARV protocols. Specifically, distances in northern Botswana can be great and lack of reliable (and safe) transportation was a factor that numerous participants cited as a consistent cause of lack of adherence. Beyond describing lack of adherence as a matter of 'forgetfulness' [2], study participants were also able to identify specific factors that might facilitate adherence such as the use of technologies to remind patients when to take ARV medication as well as suggestions about improved efficacy of EHRs. Specifically, providers and chemists suggested that reminders could be linked to patient mobile phones that also signaled the pharmacy as to when to expect refills for certain individuals. While many providers and chemists had administered visual pill count tests (asking patients to give a best guess as to how many pills were regularly left in a bottle or how many they took over a certain amount of time), improved technologies were singled out as one of the next, best options for overall, coordinated and improved adherence across the country.

Social stigma and fear of disclosure in certain instances remained significant constraints on ARV compliance [1,9,15,19]. Fears over employer awareness or lack of ability to leave one's place of employment to refill prescriptions in a timely fashion were cited as problems associated with adherence. Cultural assumptions about gender too emerged as particularly problematic in this northern region of Botswana [16]. Participants routinely agreed that access in various forms was a significant inhibitor to ideal ARV adherence even despite high levels of education and community awareness of the positive impact and long-term outcomes of ARV therapies [12,20].

Limitations to this study are that certain congruent behavioral factors were not controlled for or asked about in qualitative interviews. Specifically, alcohol use (which is high in Botswana overall and in this region in particular); some respondents reported that alcohol was 'sometimes' a factor in their lack of adherence to a drug regimen but data were not collected systematically yet on that potential barrier. While some older members of the study community mentioned traditional healers and medicine, beliefs about witchcraft or dingaka as primary facilitators or barriers to ARV adherence did not emerge as a significant theme but therapeutic pluralism would be an important factor to continue to consider as patients make decisions about adherence and effective treatment of HIV and AIDS.

Conclusion

Despite barriers to ARV adherence, the overall adherence (self-reported) by participants in rural Botswana remains encouraging. Moreover, those receiving treatment expressed awareness of the positive outcomes and longitudinal benefits of continuing on ARV treatment in this context.

These preliminary qualitative data suggest that participants in the ARV programs are aware of the need to be compliant, do not want to have to leave the program, but that significant cultural, geographic and potentially even economic factors create barriers to successful adherence. Despite these early and comparative data (both qualitative and quantitative) little research has been done with individuals who are labeled non-compliant. This project helps to assess the socio-cultural belief and behavioral factors that lead to non-compliance among BaTswana enrolled in national (and internationally funded) ARV therapy plans.

Ideally it will help to create better means through which compliance and adherence to drug regimens and follow up may be achieved in the future and through which prevention effectiveness models can be designed and implemented.

Acknowledgements and Conflict of Interest

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