

Antiretroviral Adherence Perspectives of Pregnant and Postpartum Women in Guyana: Barriers and Facilitators

Journal of the International Association of Providers of AIDS Care
2017, Vol. 16(2) 180–188
© The Author(s) 2016
Reprints and permission:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/2325957416680297
journals.sagepub.com/home/jia



Deborah Vitalis, PhD¹, and Zelee Hill, PhD²

Abstract

The Caribbean region has the second highest HIV prevalence after Sub-Saharan Africa. Guyana's adult HIV prevalence is 1.9% among pregnant women, with women accounting for an estimated 58% of all persons living with HIV. However, there are few studies on ART adherence in the Caribbean, none from Guyana, and none focusing on adherence in pregnancy and the postpartum period. The objective of this study was to explore the perspectives of HIV-infected pregnant and postpartum women and healthcare providers in Guyana about barriers and facilitators to ART adherence. Data was collected using semi-structured interviews with 24 HIV-infected pregnant and postpartum women and nine healthcare professionals at five clinics between February and April 2012. The Framework Method for analysing qualitative data identified facilitators and barriers related to five core themes: (i) Concern for wellbeing of children; (ii) ART-related factors; (iii) Disclosure; (iv) Socio-economic issues; and (v) Religious and cultural beliefs. Non-disclosure did not adversely affect adherence, contrary to other studies in the literature. Two broad categories emerged from the lived experiences of women in Guyana. The first is related to the act of actually taking their medication where their tenacity is displayed in efforts made to ensure ART is taken. The second relates to the significance of ART to them in terms of reduced risk of MTCT, and the possibility of better health for themselves to enable them to care for their children. However, issues related to poverty, food insecurity and side effects reduced adherence need to be adequately addressed.

Keywords

Guyana, ART, adherence, pregnancy, postpartum

Introduction

Advances in antiretroviral therapy (ART) for HIV-positive pregnant and postpartum women have resulted in delayed disease progression, improved maternal health, and significant reductions in mother-to-child transmission (MTCT) of HIV. To sustain these gains, high levels of ART adherence are needed, yet a recent systematic review reported that only 74% of pregnant women achieved optimal adherence.¹

Recently updated ART treatment guidelines from the World Health Organization recommend lifelong ART for all pregnant and breast-feeding women irrespective of the CD4 count or clinical stage,² meaning that women will now have to adhere to ART for a longer period compared to the previous regimens, making sustained adherence difficult. Adherence to ART is complex, as a variety of factors can influence the outcomes. These factors can be grouped into 3 categories: treatment—antiretroviral (ARV) regimen and its effects^{3,4}; patient—socio-economic and psychosocial factors^{4–7}; and the health care system—access to health care, support from health care staff, and drug availability.^{4,7,8}

Given the multiplicity of factors that can affect adherence, the need to customize interventions for the individual is

recognized as the need is to start interventions prior to ART initiation to offset misinformation, fears, stress, and depression.⁹ Among pregnant women, there may be little time for this preparation or customization prior to initiating ART. In addition, women may have to grapple with issues surrounding their newly diagnosed status and the impending pregnancy.

The Caribbean region has an estimated adult HIV prevalence of 1.1%,¹⁰ the second highest after sub-Saharan Africa. Guyana's adult HIV prevalence is 1.4% in the general population¹¹ and 1.9% among pregnant women,¹¹ with women accounting for an estimated 58.1% of all persons living with HIV.¹⁰

Guyana, the only English-speaking country in South America, has a population¹² of 767 100 and an estimated 9300 persons living with HIV,¹⁰ with 85.2% of eligible patients

¹ Infection and Population Health, University College London, London, United Kingdom

² Global Institute of Child Health, University College London, London, United Kingdom

Corresponding Author:

Deborah Vitalis.
Email: dvitalis@uclmail.net

receiving ART.¹¹ The country has a generalized HIV epidemic, with heterosexual sex being the primary mode of transmission.¹¹ Patients have universal access to ART, with ART treatment services provided free of cost at all public health sector facilities. With effect from 2013, the country commenced provision of lifelong ART for HIV-positive pregnant women.¹³

Despite the relatively high HIV prevalence, there are few studies on ART adherence in the Caribbean,¹⁴⁻²⁰ none from Guyana, and none focusing on adherence in pregnancy and the postpartum period. Thus, there is the need to expand on current knowledge to provide information for developing policies and improving national treatment programs catering to the dynamics of the epidemic. This article reports the findings of a qualitative study that explored the perspectives of HIV-positive pregnant and postpartum women and health care providers about barriers and facilitators to ART adherence in Guyana.

Methods

Study Setting

The study was conducted within 2 of the 10 administrative regions of Guyana, regions 3 and 4. Region 4, which includes the capital Georgetown, is the most heavily populated region with 41.3% of the population, and the 2 regions contribute to 55% of the total population and 80.1% of reported HIV cases.¹¹ Participants were recruited from 5 public sector health facilities: West Demerara Regional Hospital, Campbellville Health Centre, Dorothy Bailey Health Centre, Betervewagting Health Centre, and Georgetown Public Hospital Corporation. All study sites provide comprehensive HIV treatment and care services free of charge and also provide primary and other specialized health care services to the general population.

Guyana's HIV cascade of care includes patient-initiated or provider-initiated rapid HIV testing and counseling; referral for treatment at specialized HIV clinics or health centers; free antiretroviral drugs, clinical monitoring, and diagnostic tests; case management; and treatment support inclusive of support groups and home-based care.

Sampling

Participants were selected through homogenous sampling methodology,²¹ a purposive technique to choose a group based on similar characteristics to obtain an in-depth understanding of the determinants and characteristics of ART adherence. Clinic patients were selected to include similar numbers of pregnant and postpartum women who had delivered in the last year. They had to be at least 16 years of age, had to be HIV positive, had to have initiated ART prior to or in the current pregnancy, and had to be able to give consent. The primary author was facilitated by the nurse supervisor to identify patients typical of the target group. Health care staff comprised social workers, nurses, and doctors and were considered eligible if they provided care to HIV-positive women at the facility.

Participants were selected until no new information was obtained from the interviews (saturation).

Data collection

Data were collected between February and April 2012 using semistructured interviews. The primary author interviewed 24 pregnant and postpartum women and 9 health care providers. Interviews were conducted in English at the clinics and were audio recorded with participants' consent.

The interview topic guides were developed taking into consideration the literature on adherence and prevention of MTCT²²⁻³⁶ and were pretested by independent researchers with experience in the field, local health care providers, and residents. The guides for the HIV-positive women captured participants' experiences relating to adherence and HIV treatment and care, including living situation; experiences with their HIV diagnosis; disclosure; issues around mental health and coping; and pregnancy thoughts, desires, and expectations. Health care providers' guide included questions on role in the clinic, treatment criteria and response, women's adherence, strategies by health workers to improve adherence, and infant feeding.

The study was granted ethical approval from the Guyana Ministry of Health Institutional Review Board and University College London. Written informed consent was obtained and code numbers used for all participants.

Analysis

Interviews were transcribed verbatim, maintaining the creole used, and all transcripts were double-checked against the voice data files for completeness and accuracy. The authors used the Framework Method for managing and analyzing qualitative data^{37,38} which includes the following 5 steps: familiarization—in-depth knowledge of the data by listening to the audio recordings and reading the transcripts and associated notes; thematic analysis—developing codes; indexing—applying the codes to relevant segments of the data transcripts; charting—use of a spreadsheet to reduce the volume of data by creating summaries or snapshots of the data in cells aligned with key themes, which allows the researcher to see and compare relationships within and between codes; and mapping and interpretation—to identify and generate concepts or themes emanating from the data and explore any associations within those relationships.

The first step in the analysis process entailed multiple readings of the transcripts. Initial coding was generated from themes in the interview guides and the research questions. The authors (D.V. and Z.H.) initially hand-coded the same transcripts to increase coding rigor and identify new codes. A coding framework was then developed in NVivo 10 qualitative data analysis software³⁹ and codes assigned to the transcripts. During this process, additional codes were created to identify other themes that emerged in the transcripts and did not fit established codes, and themes were merged and reorganized as needed. In addition, a framework matrix was designed for

Table 1. Demographic Characteristics of HIV-Positive Women.

Characteristics	n = 24
Age	
<20	1
20-29	16
30-39	7
Median age	28
Ethnicity	
African	9
East Indian	7
Mixed	7
Amerindian	1
Education	
None	1
Primary	4
Secondary	19
Religion	
Muslim	1
Hindu	3
Christian	20
Marital status	
Single	9
Married	3
Common-law	12
Occupation	
Counselor	1
Domestic	1
Security guard	2
Hair/cosmetologist	2
Self-employed	2
Housewife	16
ART regimen	
Atripla	15
Combivir + LPV/r	4
Truvada + EFV	2
Truvada + ZDV + LPV/r	2
Combivir + NVP	1

Abbreviations: ART, antiretroviral therapy; EFV, efavirenz; LPV/r, lopinavir/ritonavir; NVP, nevirapine; ZDV, zidovudine.

Table 2. Demographic Characteristics of Health Care Providers.

Characteristics	n = 9
Age	
20-29	1
30-39	1
40-49	2
≥50	5
Gender	
Male	2
Female	7
Ethnicity	
African	5
East Indian	1
Mixed	3
Education	
Secondary	1
Postsecondary	1
University	7

the major themes containing brief sections of the relevant quote in the corresponding cell. The coding process was reviewed and discussed with the other coauthor.

Results

Sample Characteristics

Clinic patients were all Guyanese nationals, comprising 11 pregnant and 13 postpartum women, aged 18 to 39 and median age 28 (Table 1). Three of the women were primigravidae, while the others already had children. More than half (14) of the clinic patients had been diagnosed with HIV during the current or previous pregnancy, and only 2 pregnant women had been prescribed ART for the first time in the current pregnancy. The 9 health care providers included all eligible clinic staff (3 doctors, 1 medex, 4 midwives, and 1 social worker). They ranged in age from 28 to 61 years, with the majority having a university education and being of Christian faith. All were Guyanese nationals, except 1 Cuban doctor. Health workers' experience providing care and support to HIV-positive women ranged from 1 year to 12 years, with an average of 7 years of experience (Table 2).

Impact of Pregnancy on Adherence

The majority of the pregnant as well as postpartum women reported that they were always adherent during pregnancy, with reported differences in adherence in the pregnancy and postpartum period. Those who were not adherent usually missed doses, ranging from 1 or 2 days to a week at a time, and some reported that they did not disclose their nonadherence to their health workers. Women who had been nonadherent before getting pregnant stated that they took their ART better during pregnancy (to reduce the risk of HIV transmission to the baby), which was confirmed by the health workers. Overall, adherence emerged as being better during pregnancy, as this period appeared to have a positive influence on the women's ability to adhere:

I: ... when you're pregnant you're taking them better?

P: Yea

I: And why were you taking them better when you're pregnant?

P: To avoid the mother-to-child transmission disease

I: Ok, any other reason?

P: Fuh [for] betta health fuh the baby, fuh nothing doan wrong with me along with da chile [child], an fuh jus protection. (29-year-old, housewife, postpartum, 3 children)

I would say pregnancy, because they within their cognitive they're thinking this is a short-term thing and they adhere well during that period; ... that whatsoever should happen after, let it happen but once the baby is safe. (Provider: 28-year-old male social worker)

In the subsequent section, we discuss the main themes derived from the analysis: (1) concern for the well-being of children, (2) ART-related factors, (3) disclosure, (4) socio-economic issues, and (5) religious and cultural beliefs (Table 3).

Table 3. Key Themes, Barriers, and Facilitators of ART Adherence.

	Facilitators	Barriers
Concern for the well-being of children	<ul style="list-style-type: none"> • Desire for an uninfected/healthy baby • Desire to see children grow up and care for them 	
ART-related factors	<ul style="list-style-type: none"> • One-tablet, once-daily regimen 	<ul style="list-style-type: none"> • ART side effects • Pill burden
Disclosure		<ul style="list-style-type: none"> • Nondisclosure (only reported by providers)
Social and economic issues		<ul style="list-style-type: none"> • Lack of finances • Lack of food
Religious and cultural beliefs	<ul style="list-style-type: none"> • Religion as a source of strength and comfort 	<ul style="list-style-type: none"> • Belief that the church/pastor could heal them • Belief in an indigenous remedy

Abbreviation: ART, antiretroviral therapy.

Theme—Concern for the Well-Being of Their Children

Desire for a Healthy Child Enhances Adherence

An overwhelming desire for a healthy baby was a strong motivator for most of the pregnant women to diligently adhere to their ART regimens or for those who had skipped or missed to get back on track. Women who had not been compliant before pregnancy reported taking ART better during pregnancy:

... because I didn't want my child to be HIV positive. (31-year-old housewife, postpartum, 1 child)

Health care providers also reported that the desire for a healthy baby contributed to better adherence:

I: ... What are some of the factors that help the women take their medication, the pregnant women, what do you think helps them to take their medication?

P: The fact that they don't want their children to get infected. (Provider: 53-year-old midwife)

Women who had planned their pregnancies or indicated really wanting the baby reported a particularly strong desire to adhere to their medication.

Desire to Care for Their Children Enhances Adherence

Some mothers expressed being worried about the well-being of their children if their health deteriorated and complied with treatment to stay healthy. Women reported the desire to care for their children as giving them the courage to live, though some had contemplated suicide:

Right now I ask de father, I want to live to see me two children dem, this unborn one, and me other daughter outside (22-year-old, pregnant, housewife, 1 child)

P: I had want to commit suicide, kill meself...

I: And what prevented you from doing that?

P: I remember I have three children to live for. (22-year-old housewife, postpartum, 3 children)

Theme—ART-Related Factors

Antiretroviral Therapy Side Effects Inhibit Adherence

Medication side effects were one of the primary reasons given for nonadherence, and women indicated that intolerable side effects were the reasons for their intermittent or complete nonadherence. Women experienced side effects irrespective of whether they were prescribed the fixed-dose or multiple compound regimen, which ranged from mild or moderate (feeling faint, drowsiness, headache, and upset stomach) to quite severe (vomiting, diarrhea, feeling intoxicated, and nightmares).

P: I does feel drowsy, drowsy. Sometime, when I feel bad, I does vomit. Every time I drink it, I does vomit, so I don't drink it . . .

I: Ok and how many drugs you have to take right now?

P: Seven

I: And have you been taking them now?

P: They get me vomiting so I does drink it every other day. (22-year-old, pregnant, security guard)

Although the side effects of the medication were a hindrance to good adherence for some women, others found solutions to cope with their discomforts. For example, women on the fixed-dose combination drug took their medication prior to retiring to bed in the evening, thereby eliminating those "bad" feelings and waking up refreshed the following day:

I: Ok, and how do you feel after you take this one tablet once a day?

P: I feel like I've drink two bottles of vodka.

I: Two bottles of vodka, wow!

P: Large bottles of vodka. I feel really intoxicated, like I was just at a rum shop and all I was doing is sitting there and drinking

I: Oh, ok, what do you do when you get that feeling?

P: I go in my bed and lie down and sleep, sleep it off.

I: And then, how you do feel afterwards when you wake up?

P: You wake fresh, you don't feel anyway. (18-year-old, hair-dresser, pregnant with first child).

Regime Simplicity

The fixed-dose combination of once-daily Atripla was a more convenient regimen for the women, even among those who

experienced side effects and enabled better adherence, particularly among those who had been on a multiple compound regimen:

- I: So this pregnancy they put you on one tablet now, so you only take that at night?
 P: Yes
 I: Ok, since you've been put on this one tablet, have you stopped at any time?
 P: No, I don't
 I: Have you ever skipped a dose?
 P: No
 I: You never forget to take it at night?
 P: No (29-year-old, pregnant, domestic, 4 children)

Theme—Disclosure

Disclosure Does Not Influence Adherence

Almost all women had disclosed to at least one person but were wary of relatives reacting badly, with some women only disclosing to a friend out of fear of being shunned by relatives or partners. For some women, living arrangements and reactions to disclosure were sources of stress, with some experiencing stigma and discrimination, such as verbal abuse, being shunned or having to use separate utensils, and uncomfortable or unhealthy living conditions. Despite the varied experiences with disclosure, no strong theme emerged related to disclosure and adherence, with women who had not disclosed finding creative ways to store and take their ART. However, health workers reported that nondisclosure contributed to nonadherence. Antiretroviral therapy medication was stored in handbags, closets, and in a suitcase under the bed. One 32-year-old housewife described taking her ART as having “to hide and sneak to use the medication,” whenever her family visited for a few days:

- P: It's a big experience right now to me because it's like I'm taking the tablets and if my family around I have to hide, I have to have it lock up in the drawer and those things. And when they're not around, I could take out my tablets before 8[PM] and I would have it with me and I'll go drink them . . . Now, if they're around . . . I have to hide and sneak to use the medication
 I: How do you take it when they're around?
 P: Sometimes I would take the medication out and they would be outside talking to me and I'll say excuse me one minute and I'll go inside and take up the medication and have it on me in my pocket, or have it on me somewhere and then me say I have to go to de washroom and I take it. I don't miss it, I don't miss my medication, I don't. (32-year-old, pregnant, housewife, 2 children)

Theme—Socio-economic Issues

Inadequate Food and Finances Inhibit Adherence

Both clinic patients and health care staff indicated that inadequate food and lack of finances were deterrents to adherence. About half of the pregnant women who were nonadherent cited

lack of food as the reason for skipping doses. These women divulged that taking ART on an empty stomach would give them “bad feelings” or make them feel sick. Many of the women interviewed were dependent on family or a combination of family and partner for financial support. Some women were unable to attend their clinic appointments due to lack of money for transportation, while others sometimes borrowed money to do so:

- P: Well right now my worry is finance. Finance, money, that does give me headache right now, cause I'm not working. Right now my brother is at home, he ain't working, my mother doan work, so fuh [to] come to clinic today is borrow I had to borrow a \$1000 (US\$5) from a friend, till when my brother get money he give me and I could pay her back. (34-year old, housewife, postpartum, 2 children)
 I: How many appointments have you missed?
 P: Not much
 I: And what's the reason for you being unable to come to the appointments?
 P: Like financial problems
 I: Financial. Any other problems?
 P: No. (29-year-old, housewife, postpartum, 2 children)

Some of the women reported that they were unable to take their medication due to lack of food, with health workers also reporting that women were unable to take their medication on an empty stomach:

- I: How often did you miss?
 P: Say that ah drink today, I might skip tomorrow, drink de nex day
 I: And how often you would do that for?
 P: Not all steady, but sometimes like if I don't have like food or things to eat, that day I gon skip. (34-year-old, housewife, postpartum, 2 children)

The National AIDS Program Secretariat has an active food bank, but some women did not seem to benefit from this resource, with one clinic occasionally providing their clients with rations obtained from their own resources.

Theme—Religious and cultural beliefs

Religious and Cultural Beliefs Had a Mixed Impact on Adherence

Some postpartum women's beliefs that religion would cure them resulted in nonadherence to their medication. These women hoped to be healed by God and attended churches where pastors boasted of their ability to heal those having the disease, as described by this midwife:

- . . . they would drop [out of clinic] for three, four months and they gun [will] call and say they been to some Pentecostal church and de [the] Pastor say they heal, and they ain't got need for treatment . . . (Provider: 61-year-old midwife).

A few women believed that there was an indigenous cure, as a pregnant woman hoped to travel to the hinterland to be cured by an indigenous person (Amerindian), but only once the baby was born in case the “cure” was harmful:

- I: You never tried any [bush medicine]?
- P: Dem seh because ah pregnant.
- I: Because you’re pregnant?
- P: Yeah.
- I: Oh, ok.
- P: When ah done get de baby.
- I: Then you’ll take the bush medicine?
- P: Yeah.
- I: You think the bush medicine will work?
- P: It will work, yeah; I have a friend, right.
- I: Uh huh.
- P: And the Amerindian man seh she pick some kinda bush.
- I: Mm hmm.
- P: Fuh get fuh boil it and drink it.
- I: Mm hmm.
- P: And the bush cure she.
- I: She’s now cured?
- P: Yes, and she ain’t got it [HIV]. She went and she tek [took] nuff, nuff [many] test. (37-year-old, pregnant, housewife, 4 children)

Strategies Used for Remembering Medication

Most women had ways of remembering to take their medication. Some women incorporated taking ART into their daily routine so that it became a “normal” part of their lives. Other women relied on their watches, clocks, or cell phone alarms or associated taking their medication with routine activities such as watching a particular television program, while others were reminded by relatives or children.

Clinic Support and Women’s Views of Health System

Health workers utilized a variety of measures to enhance patients’ adherence. Nurses, social workers, and pharmacists were tasked with counseling patients throughout enrollment. Some clinics had active support groups. Others provided pill-boxes and frequent reminders during clinic visits. A majority of the pregnant and postpartum women were satisfied with the services and support they received from the staff at the clinics:

- I: And how about this clinic, how have you been treated at this clinic?
- P: Good, actually I enjoy coming here because I love my doctor; an my nurse, an the receptionist they’re good. (29-year-old, housewife, postpartum, 3 children)

Although some women reported negative experiences at home, in their communities, or other health facilities, health care staff at the study sites should be applauded that none of the

women reported any occurrences of stigma and discrimination and appreciated the manner in which they were treated:

- ...well everybody treat you normal. Nobody don’t discriminate like you have HIV or so, they treat you like a normal person. (21-year-old housewife, postpartum)

Women also valued the staff for maintaining the privacy of their medical information:

- ... Since I’m coming here in 2006, nobody don’t know that I’m HIV-positive. If even if they come here, and they see me here and they know me, they wouldn’t know that I’m HIV-positive. (32-year-old, pregnant, housewife, 2 children)

Discussion

The findings from this study highlight some of the myriad issues confronting the women, as they initiate or maintain their ARV regimens. Similar adherence issues were observed irrespective of whether the women were pregnant or postpartum or lived in urban or rural areas. Barriers identified for both pregnant and postpartum women included lack of food, lack of financial resources, religious and cultural beliefs, and medication side effects. Nondisclosure of HIV status was identified as a barrier only by health care providers. Facilitators comprised concern for the well-being of the unborn baby or wanting to be around for other children and were primary motivating factors for adherence, which have also been identified in other studies.^{40–42} To the authors’ knowledge, this is the first study of its kind to explore ART experiences and the barriers and facilitators of ART adherence in pregnant and postpartum women in the Caribbean.

The findings of this study confirm prior reports that adherence is better during pregnancy compared to the postpartum period,^{1,43,44} probably because the concern of transmitting the virus to the child is heightened during this time. Although some women reported good adherence, there were periods of nonadherence in the study population that are the cause for concern.

Food insufficiency has also been reported in the literature as a barrier to ART adherence for HIV-infected persons including pregnant women, and^{45–48} has the potential for adverse outcomes on maternal, fetal, and newborn health.⁴⁷ Despite the importance of sufficient food, few women appeared to benefit from the existing food bank. Health care staff should screen all women for food insecurity and liaise with the food bank to ensure they receive the necessary food assistance. This short-term fix should be coupled with interventions at a higher level through poverty alleviation/reduction strategies.

The unique finding that nondisclosure did not adversely affect adherence contradicts other studies in the literature,^{46,49} as women who had not disclosed their HIV status found innovative ways to ensure that ART medication was taken. This reveals the commitment and drive of pregnant women in

Guyana and should be taken into account when the issue of disclosure and adherence is discussed.

Nondisclosure is inextricably linked with fear of stigma and discrimination which has been attributed to nonadherence in other studies.⁵⁰⁻⁵² The fact that some women reported stigmatizing experiences from family, community, and other health facilities need to be further assessed and remedied as well as the effects of self-stigma/internalized stigma on adherence. It should be noted that consecutive Guyana HIV country progress reports describe the continuing “challenge” of stigma and discrimination, despite the wide-ranging efforts of the Government of Guyana.^{11,53,54}

Many women found creative solutions to aid their adherence, such as storage of medication to avoid inadvertent disclosure, medication reminders, and switching dose time to reduce side effects. Health care workers could capitalize on their clients’ successful strategies and share these with other women with similar concerns during one-to-one counselling, support group, or peer-educator sessions.

The suboptimal level of adherence reported by the pregnant and postpartum women during the in-depth interviews is a worrying trend that warrants timely intervention for successful treatment outcomes. Women should be closely monitored during clinic visits to address potential barriers to optimum ART therapy. Research to date on ART medication suggest that nonadherence is primarily due to factors beyond the patient’s control such as the health system, regimen, and poverty,^{55,56} of which the latter 2 were identified in this study. Side effects of ART and pregnancy-associated nausea compounding their experiences would exacerbate negative effects, thereby making adherence difficult.¹

It was quite evident from the in-depth interviews that religion had a positive effect for some (when used as a coping mechanism) and negative effect for others (nonuse of ART because they believe they have been healed by a religious leader) on adherence behavior. Guyana is a deeply religious society with diverse religious groups and thus the role that religion/spirituality plays in the lives of women vis-à-vis their ART medication should be discussed during treatment and care sessions. An assessment by providers when women initiate treatment and at various times throughout the care and treatment cycle could ameliorate potential problems as suggested by Wasti et al⁴⁹ and Trevino et al.⁵⁷

The women in this study expressed depressive symptoms of which the magnitude over time might be far greater than actual reports. Future observational studies are warranted to determine the magnitude of these mental health issues. In addition, alleviating the economic hardships identified in this study (food and finances) has been advocated as another type of intervention to address mental health problems since they are both contributors of mental distress.^{58,59}

Limitations

The findings in this study may not reflect the entire population of women with HIV in Guyana, since participants were

recruited from current clinic attendees and did not include the views of women who had dropped out of care. This subset of women would more likely have a higher probability of nonadherence and may have been confronted with different barriers than those described here. Future studies with this key group need to be undertaken. Social desirability may have influenced some women to report on what they thought acceptable behavior than what they actually experienced. To reduce this, questions were structured in a way to put the women at ease prior to engaging them in discussion of sensitive issues, and this may have diminished this effect. Women were also assured that individual reports would not be shared with their clinicians. The recall of past events may have introduced recall bias, as studies have shown that memory fades with time.^{60,61} Participants may have erred in their recollection of their behavior over the course of a few days to longer periods of time.

Conclusion

The lived ART experiences of women in Guyana can be grouped into 2 broad categories. The first is related to the act of actually taking their medication, where their tenacity is displayed in efforts made to ensure ART is taken, despite nondisclosure of status, utilizing a variety of prompts as medication reminders and managing side effects. The second relates to the significance of ART to them in terms of reduced risk of MTCT, a healthy baby, and the possibility of better health for themselves to enable them to care for their children. However, issues related to poverty, mental health, food insecurity, and medication side effects reduce adherence and need to be adequately addressed.

Acknowledgments

The authors would like to express their profound gratitude to the women and health care providers who participated in this study. Finally, thanks to Audrey Prost and Lorraine Sherr of University College London for their constructive feedback.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

References

1. Nachega JB, Uthman OA, Anderson J, et al. Adherence to antiretroviral therapy during and after pregnancy in low-income, middle-income, and high-income countries: a systematic review and meta-analysis. *Aids*. 2012;26(16):2039–2052.
2. World Health Organization. *Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection: Recommendations for a Public Health Approach*. 2nd ed. Geneva, Switzerland: World Health Organization; 2016:429.

- <http://www.who.int/iris/handle/10665/208825>. Accessed August 15, 2016.
3. Chesney M. Adherence to HAART regimens. *AIDS Patient Care STDS*. 2003;17(4):169–177.
 4. Battaglioli-DeNero AM. Strategies for improving patient adherence to therapy and long-term patient outcomes. *J Assoc Nurs AIDS Care*. 2007;18(1 suppl):S17–S22.
 5. Horne R, Weinman J. Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *J Psychosom Res*. 1999;47(6):555–567.
 6. Horne R, Cooper V, Gellaitry G, Date HL, Fisher M. Patients' perceptions of highly active antiretroviral therapy in relation to treatment uptake and adherence: the utility of the necessity-concerns framework. *J Acquir Immune Defic Syndr*. 2007;45(3):334–341.
 7. Poppa A, Davidson O, Deutsch J, et al. British HIV Association (BHIVA)/British Association for Sexual Health and HIV (BASHH) guidelines on provision of adherence support to individuals receiving antiretroviral therapy (2003). *HIV medicine*. 2004;5(suppl 2):46–60.
 8. Bartlett JA, Shao JF. Successes, challenges, and limitations of current antiretroviral therapy in low-income and middle-income countries. *Lancet Infect Dis*. 2009;9(10):637–649.
 9. Balfour L, Kowal J, Silverman A, et al. A randomized controlled psycho-education intervention trial: Improving psychological readiness for successful HIV medication adherence and reducing depression before initiating HAART. *AIDS Care*. 2006;18(7):830–838.
 10. The Joint United Nations Programme on HIV/AIDS. How AIDS changed everything—MDG 6: 15 years, 15 lessons of hope from the AIDS response. UNAIDS, 2015. http://www.unaids.org/sites/default/files/media_asset/MDG6Report_en.pdf. Accessed August 20, 2016.
 11. Ministry of Health. Guyana AIDS response progress report: Jan-Dec 2014. Ministry of Health, Guyana, 2015. http://www.unaids.org/sites/default/files/country/documents/GUY_narrative_report_2015.pdf. Accessed August 20, 2016.
 12. WB. Country Data: Guyana. World Bank, 2015. <http://www.worldbank.org/en/country/guyana>. Accessed August 20, 2016.
 13. M.O.H. Guyana Global AIDS Response Progress Report, 2012–2013: MOH, ed. Guyana: Presidential Commission on HIV and AIDS; 2014.
 14. Harvey K, Carrington D, Duncan J, et al. Evaluation of adherence to highly active antiretroviral therapy in adults in Jamaica. *West Indian Med J*. 2008;57(3):293–297.
 15. Allen CF, Simon Y, Edwards J, Simeon DT. Adherence to antiretroviral therapy by people accessing services from non-governmental HIV support organisations in three Caribbean countries. *West Indian Med J*. 2011;60(3):269–275.
 16. Malow R, Dévieux JG, Stein JA, et al. Depression, Substance Abuse and Other Contextual Predictors of Adherence to Antiretroviral Therapy (ART) Among Haitians. *AIDS Behav*. 2013;17(4):1221–1230.
 17. Aragonés C, Sánchez L, Campos JR, Pérez J. Antiretroviral therapy adherence in persons with HIV/AIDS in Cuba. *MEDICC Rev*. 2011;13(2):17–23.
 18. Harris J, Pillinger M, Fromstein D, et al. Risk Factors for Medication Non-Adherence in an HIV Infected Population in the Dominican Republic. *AIDS Behav*. 2011;15(7):1410–1415.
 19. Williams M, Clarke T, Williams P, Barton EN. The mean levels of adherence and factors contributing to non-adherence in patients on highly active antiretroviral therapy. *West Indian Med J*. 2007;56(3):270–274.
 20. Duke N, Aboh S, Bosivert N. Analysis of resistance testing in South Trinidad. *West Indian Med J*. 2010;59(4):400–402.
 21. Patton MQ. *Qualitative Research and Evaluation Methods*. 3 ed. Thousand Oaks, CA: Sage; 2002.
 22. Armistead L, Morse E, Forehand R, et al. African-American women and self-disclosure of HIV infection: Rates, predictors, and relationship to depressive symptomatology. *AIDS Beh*. 1999;3(3):195–204.
 23. Bachrach CA, Newcomer S. Intended pregnancies and unintended pregnancies: distinct categories or opposite ends of a continuum? *Fam Plann Perspect*. 1999;31(5):251–252.
 24. Carver CS. You want to measure coping but your protocol's too long: consider the brief COPE. *Int J Behav Med*. 1997;4(1):92–100.
 25. Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: a theoretically based approach. *J Pers Soc Psychol*. 1989;56(2):267–283.
 26. Farber EW, Mirsalimi H, Williams KA, McDaniel JS. Meaning of illness and psychological adjustment to HIV/AIDS. *Psychosomatics*. 2003;44(6):485–491.
 27. Kalichman S, Kalichman M, DiMarco J, Austin W, Luke K, DiFonzo. Stress, social support, and HIV-status disclosure to family and friends among HIV-positive men and women. *J Behav Med*. 2003;26(4):315–332.
 28. Kirshenbaum SB, Hirky AE, Correale J, et al. “Throwing the dice”: pregnancy decision-making among HIV-positive women in four U. S. cities. *Perspect Sex Reprod Health*. 2004;36(3):106–113.
 29. Koopman C, Gore-Felton C, Marouf F, et al. Relationships of perceived stress to coping, attachment and social support among HIV-positive persons. *AIDS Care*. 2000;12(5):663–672.
 30. Kumar A, Waterman I, Kumari G, Carter AO. Prevalence and correlates of HIV serostatus disclosure: a prospective study among HIV-infected postparturient women in Barbados. *AIDS Patient Care STDS*. 2006;20(10):724–730.
 31. Ladzani R, Peltzer K, Mlambo MG, Phaweni K. Infant-feeding practices and associated factors of HIV-positive mothers at Gert Sibande, South Africa. *Acta Paediatr*. 2011;100(4):538–542.
 32. Proctor VE, Tesfa A, Tompkins DC. Barriers to adherence to highly active antiretroviral therapy as expressed by people living with HIV/AIDS. *AIDS patient care STDS*. 1999;13(9):535–544.
 33. Rivero-Mendez M, Dawson-Rose CS, Solis-Baez SS. A Qualitative Study of Providers' Perception of Adherence of Women Living with HIV/AIDS in Puerto Rico. *Qual Rep*. 2010;15(2):232–251.
 34. Simoni JM, Mason HR, Marks G, Ruiz MS, Reed D, Richardson JL. Women's self-disclosure of HIV infection: rates, reasons, and reactions. *J Consult Clin Psychol*. 1995;63(3):474–478.
 35. Sowell RL, Seals BF, Phillips KD, Julious CH. Disclosure of HIV infection: how do women decide to tell? *Health Educ Res*. 2003;18(1):32–44.

36. Wesley Y. Why women want children: defining the meaning of desire for children and the construction of an index. *J Natl Black Nurses Assoc.* 2007;18(1):14–20.
37. Gale N, Gale G, Heath E, Cameron S, Rashid S, Redwood. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol.* 2013;13(1):117.
38. Green J, Thorogood N. *Qualitative Methods for Health Research.* 2nd ed. London, UK: Sage; 2010.
39. *NVivo qualitative data analysis Software* [computer program]. Version 10. Melbourne, Australia: QSR International Pty Ltd; 2012.
40. Ekama SO, Herbertson EC, Addeh EJ, et al. Pattern and determinants of antiretroviral drug adherence among Nigerian pregnant women. *J pregnancy.* 2012;2012:851810.
41. Ciambone D, Loewenthal HG, Bazerman LB, Zorilla C, Urbina B, Mitty JA. Adherence among women with HIV infection in Puerto Rico: the potential use of modified directly observed therapy (MDOT) among pregnant and postpartum women. *Women Health.* 2006;44(4):61–77.
42. Wood SA, Tobias C, McCree J. Medication adherence for HIV positive women caring for children: in their own words. *AIDS Care.* 2004;16(7):909–913.
43. Vaz MJ, Barros SM, Palacios R, et al. HIV-infected pregnant women have greater adherence with antiretroviral drugs than non-pregnant women. *Int j STD AIDS.* 2007;18(1):28–32.
44. Bardeguéz AD, Lindsey JC, Shannon M, et al. Adherence to antiretrovirals among US women during and after pregnancy. *J Acquir Immune Defic Syndr.* 2008;48(4):408–417.
45. Kalichman SC, Pellowski J, Kalichman MO, et al. Food insufficiency and medication adherence among people living with HIV/AIDS in urban and peri-urban settings. *Prev sci.* 2011;12(3):324–332.
46. Sanjobo N, Frich JC, Fretheim A. Barriers and facilitators to patients' adherence to antiretroviral treatment in Zambia: a qualitative study. *SAHARA J (J Soc Aspects of HIV/AIDS Research Alliance).* 2009;5(3):136–143.
47. Young S, Wheeler A, McCoy S, Weiser S. A review of the role of food insecurity in adherence to care and treatment among adult and pediatric populations living with HIV and AIDS. *AIDS Behav.* 2014;18(Suppl 5):S505–515.
48. Musumari PM, Feldman MD, Techasrivichien T, Wouters E, Ono-Kihara M, Kihara M. "If I have nothing to eat, I get angry and push the pills bottle away from me": a qualitative study of patient determinants of adherence to antiretroviral therapy in the Democratic Republic of Congo. *AIDS Care.* 2013;25(10):1271–1277.
49. Wasti SP, Simkhada P, Randall J, Freeman JV, van Teijlingen E. Barriers to and facilitators of antiretroviral therapy adherence in Nepal: a qualitative study. *J Health Popul Nutr.* 2012;30(4):410–419.
50. Mephams S, Zondi Z, Mbuyazi A, Mkhwanazi N, Newell ML. Challenges in PMTCT antiretroviral adherence in northern KwaZulu-Natal, South Africa. *AIDS Care.* 2011;23(6):741–747.
51. Awiti Ujiji O, Ekström A, Ilako F, Indalo D, Wamalwa D, Rubenson B. Reasoning and deciding PMTCT-adherence during pregnancy among women living with HIV in Kenya. *Cult Health Sex.* 2011;13(7):829–840.
52. Ngarina M, Popenoe R, Kilewo C, Biberfeld G, Ekstrom AM. Reasons for poor adherence to antiretroviral therapy postnatally in HIV-1 infected women treated for their own health: experiences from the Mitra Plus study in Tanzania. *BMC Public Health.* 2013;13:450.
53. Ministry of Health. Guyana AIDS Country progress report 2010–2011. Ministry of Health, Guyana, 2012. www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce_GY_Narrative_Report.pdf. Accessed February 8, 2014.
54. Ministry of Health. Global AIDS response progress report: Jan 2012–Dec 2013. Ministry of Health, Guyana, 2014. http://files.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2014countries/GUY_narrative_report_2014.pdf.
55. Mukherjee JS, Ivers L, Leandre F, Farmer P, Behforouz H. Antiretroviral therapy in resource-poor settings. Decreasing barriers to access and promoting adherence. *J Acquir Immune Defic Syndr.* 2006;43(suppl 1):S123–S126.
56. Munro S, Lewin S, Swart T, Volmink J. A review of health behaviour theories: how useful are these for developing interventions to promote long-term medication adherence for TB and HIV/AIDS? *BMC Public Health.* 2007;7:104.
57. Trevino K, Pargament K, Cotton S, et al. Religious coping and physiological, psychological, social, and spiritual outcomes in patients with HIV/AIDS: cross-sectional and longitudinal findings. *AIDS Behav.* 2010;14(2):379–389.
58. Shin S, Munoz M, Caldas A, et al. Mental Health Burden Among Impoverished HIV-Positive Patients in Peru. *J Int Assoc Phys AIDS Care (Chic).* 2011;10(1):18–25.
59. Burgess RA. Supporting mental health in South African HIV-affected communities: primary health care professionals' understandings and responses. *Health Pol Plann.* 2015;30(7):917–927.
60. Coughlin SS. Recall bias in epidemiologic studies. *J Clin Epidemiol.* 1990;43(1):87–91.
61. Fadnes LT, Taube A, Tylleskär T. How to identify information bias due to self-reporting in epidemiological research. *Int J Epidemiol.* 2009;38(2):3.