Role of Financial Incentives Along the ART Adherence Continuum: A Qualitative Analysis From the HPTN 065 Study

Elizabeth Tolley[1], Jamilah Taylor[1], Allison Pack[1], Elizabeth Greene[2], Jill Stanton[2], Wafaa El-Sadr[3], and Theresa Gamble[2]

[1]Social & Behavioural Health Sciences Division, FHI 360, Durham, NC [2] Science Facilitation Department, FHI 360, Durham, NC [3] ICAP at Columbia University and Harlem Hospital, New York, NY

BACKGROUND

The Stages of Change (SOC) theory (Figure 1) suggests that individuals adapt incrementally to behaviours like adherence, requiring different strategies over the behaviour change continuum. Financial incentives (FIs) are one strategy that has been proposed to motivate adherence. In HPTN 065, patients in care and on ART for a minimum of three months were eligible to receive a $70 gift card no more than every 3 months if they were virally suppressed at their HIV care visits. This qualitative sub-study examined adherence barriers and the role of FIs to increase viral suppression (VS) among HPTN 065 study participants who were categorized into SOC-related adherence stages based on changes from their baseline to follow-up viral load tests. More specifically, we examine the role that FIs played in helping participants achieve and/or maintain viral suppression. We seek to:

- Identify barriers and facilitators experienced by patients receiving FIs in HPTN 065;
- Examine whether barriers and facilitators differed by stages of a SOC-related adherence continuum;
- Assess what role patients perceived the FI intervention to play in adhering to medication.

Figure 1: Stages of Change (SOC)

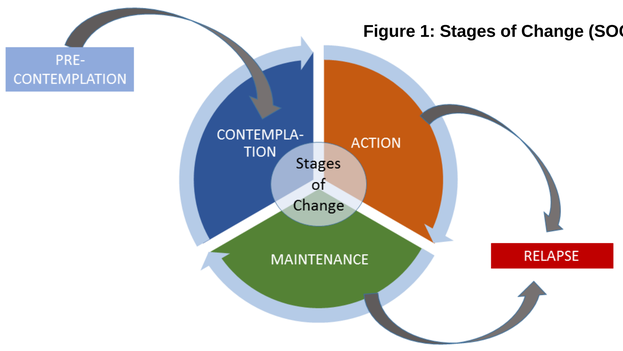

Table 2: Socio-Demographic and Behavioral Characteristics, by SOC-Related Groups

N=73	Low Adherers N=13	Action N=29	Maintenance N=31
Sociodemographic Characteristics			
Mean age	37.8	44.7	45.3
Gender:	% (No.)	% (No.)	% No.)
Male	31 (4)	62 (18)	81 (25)
Female	62 (8)	34 (10)	19 (6)
Transgender	7 (1)	4 (1)	0 (0)
Race:			
Black	69 (9)	62 (18)	48 (15)
White	0 (0)	17 (5)	23 (7)
Other	31 (4)	21 (6)	29 (9)
Ethnicity:			
Hispanic	23 (3)	21 (6)	26 (8)
Non-Hispanic	77 (10)	79 (23)	74 (23)
Education Level			
Some or no high school	54 (7)	38 (11)	16 (5)
High school/GED	23 (3)	21 (6)	29 (9)
Some college or Associate Degree	23 (3)	34 (10)	39 (12)
Bachelor's Degree or higher	0 (0)	7 (2)	16 (5)
Income			
$10,000 or less	77 (10)	59 (17)	35 (11)
> $10,000</= $40,000	23 (3)	24 (10)	26 (8)
> $40,000</= $80,000	0 (0)	4 (1)	26 (8)
> $80,000	0 (0)	0 (0)	13 (4)
Missing	0 (0)	4 (1)	0 (0)
ART naïve at baseline	0 (0)	14 (4)	29 (9)
% of follow-up viral loads suppressed	37	89	100
Mean # of gift cards received	2.1	5.4	6.0
Behavioral Characteristics (based on qualitative analysis)			
When diagnosed:	% (#)	% (#)	% (#)
At least 20 years ago (1980s-1992)	23 (3)	17 (5)	26 (8)
Some time ago (1993-2006)	31 (4)	38 (11)	35 (11)
Recently (Since 2007)	38 (5)	38 (11)	29 (9)
Unclear	8 (1)	7 (2)	10 (3)
Pre-contemplation: Described delay initiating ART	16 (2)	34 (10)	35 (11)
Ever relapsed	31 (4)	24 (7)	16 (5)
Adherence problems experienced (past/present):	% (#)	% (#)	% (#)
Pill-related (memory, side effects)	69 (9)	52 (15)	39 (12)
Psychosocial (stigma, depression, stress)	46 (6)	31 (9)	23 (7)
Structural (insurance, housing, drugs, jail)	38 (5)	28 (8)	13 (4)
Any current adherence problems	85 (11)	55 (16)	35 (11)
Expressed intrinsic motivation	92 (12)	93 (27)	90 (28)
Motivated by FI to change behavior	23 (3)	38 (11)	10 (3)
Found FI to be a nice reward	8 (1)	48 (14)	16 (5)
Uses adherence aids	69 (9)	79 (23)	61 (19)

METHODS

We conducted semi-structured interviews with 76 participants exiting from HPTN 065. For analysis, we categorized 73 participants with baseline viral load test results into three adherence levels (Maintenance, Action and Low Adherers), using baseline and quarterly viral load tests to explore differences in perceived adherence barriers, facilitators and patterns, as well as the effect of FIs on adherence behavior. In addition, we examined all 76 participants' data for information about pre-contemplation and relapse stages, as participants often described themselves in these stages prior to being in the study.

All interviews were conducted in English by trained interviewers.[1] Interviews were audio-recorded and transcribed verbatim. Transcripts were then uploaded into NVivo 10.0 (QSR International) and analyzed thematically, following a process of reading, coding, data display and data reduction. Initial codes included: Medication Adherence; HIV Testing, Diagnosis and Acquisition; Opinions of the Program; and Impact on Patient. Though not explicitly assessed, the SOC framework guided analysis.

Table 1: SOC-Related Analysis Groups and Definitions

SOC Group	Definition
Maintenance	ART-naïve or on ART with VS at baseline and consistently maintained VS over the course of the study
Action	ART-naïve at baseline and ≥ 50% but < 100% VS over course of study; or on ART but not VS at baseline, but from 50-100 VS over the course of the study
Low Adherer	ART-naïve or on ART but not VS at baseline and <50% of viral load tests suppressed over the course of the study
Pre-Contemplation	Discussions about delaying ART treatment after HIV diagnosis from any sub-study participant
Relapse	Discussions about stopping ART treatment from any sub-study participant

1 One interview was partially conducted in Spanish.

RESULTS

Overall, participants' characteristics resembled those of the HPTN 065 study. However, some differences in socio-demographic and other characteristics exist across the three SOC adherence groups (Table 2).

PRE-CONTEMPLATION: While no participants were characterized as in the pre-contemplation stage at the time of enrollment in the sub-study, about a third of participants (n=23) described periods of pre-contemplation after receiving their HIV diagnosis (Table 2). Most were diagnosed early in the epidemic and attributed delays to fear of taking medications perceived as toxic.

I was diagnosed in 1990. I did not start taking medication for about 10 years. So, around 2000 I started taking medication. And my concern was … I was concerned about taking any medication. Well, back in the 90's, I've had friends who have gone through so much hell taking medication, and I felt that as long as I wasn't sick … as long as I wasn't sick, I was going to just prolong it as long as I could. (66-year-old gay Black male)

Recently diagnosed patients were less likely to fear the drug regimen itself, but needed time before they could think about taking the medication, mostly due to shame, denial or depression.

When I found out I had to start taking medicine it was a big shocker for me because, it was like... I wasn't in denial about my illness but suddenly everything became real […] I went back and forth with my doctor, letting her know I was having some trouble with, with coming to terms in taking the medicine. So she actually prescribed it and I didn't take it for about two months and a half… (30-year-old straight bi-racial woman with two children)

LOW ADHERENCE GROUP: All 13 participants in the Low Adherence Group had been taking ART before joining the study. They described their adherence as mixed or low and admitted to forgetting pills; some were willfully non-adherent at times. Many attributed their difficulties with adherence to depression or sadness. Some experienced on-going challenges with drug or alcohol use.

And I try to take care of myself [the] best way I know how. Sometimes I do forget my medication because I'm so busy all over the place, but when I do take it I make sure I take it. You know, I try to take it every day. I try not to miss a day. But sometimes when you're very, very busy – cause at one time I just sat home, I would not take the medication, I'm a tell you that. I don't know if I was, I don't know what my mental state was at that time and I really believe that I just didn't care. Because I just couldn't come to grips of why that man would do that to me. (48-year-old single straight Black woman)

FI did not appear to play a role in incentivizing adherence. Most Low Adherers suggested that the FI didn't change their adherence much, or at most, it was a nice thing to receive some extra cash.

RESULTS (cont.)

ACTION GROUP: Almost all (n=29) assessed themselves as being good or even excellent adherers currently, but acknowledged that adherence could still be a challenge. Unlike those in the Low Adherence Group, these participants reported that small lapses appeared to strengthen their resolve.

Well, I want to sustain it [my low viral load]. That's why I continue to take it without having any problems. There are some times when I miss a dosage, especially at night. I feel bad about that. But I just do the next day and … after I come to the clinic and they do the blood and they find out that I'm still non detectable, [it] makes me feel good…. I may fall asleep before it's time. Then I wake up in the middle of the night and say, well I'll just start again the next day. (58-year-old gay Black man)

Most participants (n=21) in the Action Group found FIs to be motivating to achieve adherence. Most were clear about the importance of taking their medications as they were prescribed. But, many also indicated that remaining adherent was hard, and FIs made it a little easier.

MAINTENANCE GROUP: All but one participant in this group (n=31) described a high level of commitment to being adherent to their medication currently – even when it meant overcoming barriers. They made declarations like *"It doesn't control me"*; *"I still keep taking my medicine no matter what"*, and *"I know what I got to do."* Most appeared to have committed themselves to the process of adhering to treatment. They described filling their own pill boxes, arranging their schedules to accommodate pill-taking, and finding ways to take their pills even when away from home.

I always carry my pills in my pocket. …Well, you know what? I'm … I'm very … very picky when it comes to stuff…. I have this thing of taking it 12 midnight, 12 afternoon, 12 midnight, 12 afternoon. So I know that when 12 o'clock hits, or 12 afternoon like today, I have (them) in my pocket, get a glass of water, drank it, take my pills, I'm good. So I already have this thing of carrying them on me if I'm going out. (33-year-old single gay Hispanic man)

More than other groups, Maintainers tended to reflect on the barriers they had overcome – the positive changes in their medication regimens and consequently the positive feelings they had about their regimens. Many also identified how the love and support of others around them – from family members, sexual partners and healthcare providers – helped keep them focused on being adherent.

None expressed negative attitudes towards FIs. The majority felt that it was good to provide FI, especially for those who had a problem adhering. Only a few (n=3) felt that FIs helped them improve their own adherence. About half (n=14) were clear that their intrinsic motivation and having integrated medications into their daily routine – and not the FI – drove their own adherence.

RELAPSE: Only two participants had viral load suppression at baseline and did not have sustained viral load suppression during study follow-up. In addition, 16 participants in the Low Adherence, Action or Maintenance Groups described relapse in adherence prior to joining the study. The reasons for relapse included incarceration or homelessness, drug addiction (crack or crystal meth), excessive alcohol use, and lack of health insurance or money for day-to-day needs.

DISCUSSION

Our sub-study provided an in-depth understanding of the patterns of medication adherence experienced by patients participating in an FI intervention, including their perspectives on the role that FIs played in promoting or sustaining their adherence. Over a third of sub-study participants were already on ART and virally suppressed upon entering the FI intervention. Although generally appreciated, the FIs appeared to have little impact on the adherence-related motivations and behaviors of this group. Others were art-naïve or not suppressed at study entrance. FIs provided the additional nudge needed for many to better integrate behaviors that would help them become and remain undetectable. However, the FIs were insufficient to help a small group of participants overcome adherence barriers.

LIMITATIONS

- Use of a proxy measure – the percent of viral load tests identified as virally suppressed – rather than a structured SOC tool to approximate the SOC stage.
- Potential for low recall of adherence-related barriers among long-term maintainers.

CONCLUSION

FI effectiveness may vary across the SOC continuum. FIs may have greatest impact for those who are ART naïve or have not yet formed explicit adherence routines or habits, such as those in our action group. FIs may be insufficient to overcome adherence lapses when strong social or structural barriers are present, and are probably unnecessary for those who have strong intrinsic motivations and well integrated habits to support adherence.

ACKNOWLEDGMENTS

We would like to thank those who participated in the interviews for this sub-study as well as the interviewers, participating sites, and the protocol team for their dedication to this project.

The HIV Prevention Trials Network is sponsored by the U.S. National Institute of Allergy and Infectious Diseases, the U.S. National Institute of Mental Health, and the U.S. National Institute on Drug Abuse, all components of the U.S. National Institutes of Health.