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“The money, it’s OK but it’s not OK”: patients’ and providers’ perceptions of the acceptability of cash incentives for HIV treatment initiation in Cape Town, South Africa

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Abstract

Incentive-based interventions are used to encourage HIV testing, linkage to HIV care, and antiretroviral therapy (ART) adherence. Studies assessing efficacy of cash incentives have raised questions about the perceived ethicality of and attitudes towards incentives. Here we explore patients’ and health providers’ perspectives of the acceptability of a conditional cash transfer for ART initiation after receiving a positive HIV test through community-based services in resource-poor communities in Cape Town, South Africa. Drawing on in-depth interviews with patients and health care workers, we find that, despite the perception that cash incentives are effective in promoting ART initiation, significant ambivalence surrounds the acceptability of such incentives. The receipt of a financial incentive was highly moralized, and fraught with challenges. Increasing

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the acceptability of cash incentives through careful design and delivery of interventions is central to the potential of this type of intervention for improving outcomes along the HIV care continuum.

Keywords

conditional economic incentives; conditional cash transfers; contingency management; linkage to care; HIV/AIDS; antiretroviral therapy; HIV care continuum; South Africa

Introduction

Incentive-based interventions have proven effective in reducing risky sexual behaviour [1, 2]; increasing uptake of medical male circumcision [3] and HIV testing [4]; and improving linkage to HIV care [5–8], antiretroviral therapy (ART) adherence and viral suppression [9–12]. Monetary and non-monetary incentives can address barriers associated with linkage to care, such as transport costs [13], and increase the immediate reward from linkage, and thereby counter factors such as present bias – the tendency of people to overweight immediate costs and underweight of future benefits. As a strategy to mitigate social and structural barriers limiting engagement with care, particularly in resource-constrained settings, UNAIDS guidelines recommend implementing financial incentives linked to clinic attendance as part of a comprehensive HIV response [14].

To date, most studies have focused on evaluating the impact of incentives, with limited evidence available on the acceptability of incentives to patients, health care providers or policy makers, and specifically on the acceptability of financial incentives for linkage to HIV care [13, 15, 16]. Two qualitative studies in the United States, among participants in the HPTN 065 (TLC-Plus) Study, found a financial incentive was highly acceptable due to perceptions that the intervention was effective and due to the emotional benefits gained through feeling cared for. However, in this study, philosophical concerns were raised about incentives for health behaviour change; with the concern that paying people for health behaviours may create negative attitudes towards the intervention [15, 16]. In the context of HIV treatment for pregnant women in South Africa, study participants believed that a supermarket voucher incentive would motivate them to return to the clinic [13]. About 23% found incentives unacceptable due to the perception that people should be personally responsible for their own health and should attend their visits without receiving anything additional for doing so. Some participants equated the incentive to a bribe for healthy behaviours. In light of this evidence from South Africa and beyond, the acceptability of cash incentives warrants further exploration due to ethical concerns around using financial incentives in health promotion [17, 18].

In sub-Saharan Africa (SSA), health systems are often fragmented and overburdened, and patients face multiple barriers to HIV care, including financial costs (e.g., transport), fear of stigmatisation, long clinic wait times, and many hassle factors (e.g., applying for leave from work, finding childcare etc.) [13, 19, 20]. Given the high HIV burden in the region and efficacy of ART in reducing AIDS-related morbidity, mortality and onward transmission [20, 21], substantial financial and human resource gains would be achieved by increasing the proportion of patients who initiate ART early, and remain in care [22]. In this context, and particularly within poorer communities where structural barriers to accessing care are most pressing, incentives hold promise as a cost-effective intervention for both increasing individual well-being and, indirectly, strengthening health systems.

Drawing on qualitative data collected as part of the iLink Study, we explored patients' and health providers' perspectives of the acceptability of using a conditional cash incentive for ART initiation after receiving a positive HIV test in Cape Town, South Africa. While several interventions use an incentives-based approach in the South African context, gaining a better understanding of the acceptability of this approach is essential for the potential sustainability and scalability of these types of interventions. Interventions that are not acceptable to patients and providers are unlikely to succeed. Sekhon et al (2017) [23] developed a framework that explores the multiple components that should be considered in relation to the acceptability of healthcare interventions. The framework underscores that 'acceptability' is a multifaceted and complex construct, shaped by a range of factors. In our study, we focused on two understudied dimensions of the acceptability of health care interventions as identified by Sekhon et al (2017): affective attitude, or how participants *feel* about the intervention; and ethicality, the measure of the match between the intervention's value system and their own. This area of work warrants further investigation as most of the current theoretical discussion [24] about the use of financial incentives for health behaviours does not address the issues of concern here: affect and ethics.

Methods

The iLink Study (April 2015 to August 2016) enrolled individuals diagnosed HIV-positive and referred for ART by a well-known and established mobile health clinic in Cape Town. Primary results of the study have been presented elsewhere [25]. ART-referral was based on National Department of Health guidelines at that time: a CD4 count ≤ 500 cells/μL. Study eligibility included being 18 years or older; being ART-naïve; and owning a cell phone. Participants completed a baseline survey and were randomly assigned (1:1) to the control or intervention group. The control group received the standard of care: counselling on the benefits of early ART initiation, referral to an ART clinic, and follow-up telephone counselling by the mobile clinic staff (up to six calls over six weeks). The intervention group received the standard of care plus a voucher that could be exchanged for R300 (~$25USD) cash if ART was started within three months. After ART initiation, participants in the intervention group met with the study staff to verify ART initiation and receive the incentive.

In-depth interviews were conducted with iLink Study participants who received the incentive or were successfully contacted three months after baseline enrolment (N=64). Forty-one agreed to participate and were interviewed either after ART initiation if they received the incentive, or for all other participants, as soon after the 3-month follow-up as possible. Interviews were conducted in the participants home-language, Xhosa, by experienced interviewers, in a safe and private location agreed upon by the interviewer and participant (e.g., participants' homes or private rooms at public libraries reserved for the purpose of our study). A semi-structured interview guide was designed to explore (1) feelings about participation in the study, (2) general perceptions regarding monetary incentives, (3) attitudes towards and perceived efficacy of the study incentive, and (4) alternative solutions to encourage treatment uptake.

In-depth interviews were also conducted with staff – HIV counsellors, nurses, health educator and patient registrant – of the mobile clinic that partnered in the iLink Study and provided the HIV testing and ART referral services. Nine interviews were conducted prior to enrolment of study participants and six interviews at the close of study enrolment, with all interviews conducted by trained interviewers in English. The pre-study semi-structured interview guide was designed to explore 1) perceived barriers and facilitators for patients linking to care; 2) general opinions about incentives; and 3) perceptions about study intervention. The post-study semi-structured interview guide was designed to explore 1) general perceptions about offering patients incentives for ART initiation; 2) attitudes towards the study intervention; and 3) perceived efficacy of the study intervention.

Audio recordings of interviews were professionally translated and transcribed into English. Interview transcripts were imported into Nvivo (QSR International Pty Ltd.) for analysis. For the patient data, an inductive, team-based approach was used to identify themes from the interviews, using a data-driven approach to the process. The study team met regularly to review, define and name themes. Two team members independently coded the same sample of one third of the transcripts, with discrepancies discussed and resolved to refine the codebook and coding. Using the final codebook, the principal investigator (BMB) coded the remainder of the transcripts. Data analysis for the provider interviews used a combination of inductive and deductive approaches, following the specific elements of the Sekhon et al framework (2017) that guided this analysis, namely affective attitudes and ethicality. First transcripts were read and reread for emergent themes that were discussed by the principal investigator and first author (AS). The second analytic step was to apply the coding framework described above to all transcripts to explore themes from both patient and provider perspectives. In the analyses of all of the data, potential links between emergent themes and the dimensions of affective attitudes and ethicality of incentives [23] were explored. A further advantage of having data from the patient and provider perspectives was that it allowed us to compare and contrast these perspectives, thereby contributing to a richer and deeper understanding of attitudes and perceptions of incentives.

Results

An effective approach

Both patients and HCWs shared the belief that providing a cash incentive to initiative ART was likely to be effective in motivating timeous linkage to care. As one participant explained:

> “It certainly does motivate because the day I woke up to go to the clinic… I did not want the three months to lapse and then I cannot get the R300,1 wanted to get it. It did motivate me to go because I knew that I would get something from it.” [Female, 43, intervention group]

Others described the incentive as an “encouragement”, but also expressed what they described as “shock” and “surprise” at the good news that they were going to receive an incentive. Much of the language used underscored participants' view that the incentive was generous. In the absence of other forms of economic security, participants pointed to how the incentive could be used to fill the gaps associated with structural factors that may have prevented them from linking to care. Others spoke explicitly about using the cash from the incentive to pay for transport to attend clinic visits, or to buy lunch while at clinic visits that could last the whole day. One participant explained:

> "I think the money is going to help us. For example, if I don't have transport money to go to the clinic". [Female, 21, intervention group].

Although participants agreed that cash incentives to link to HIV care were likely to be effective, almost everyone also simultaneously expressed negative views.

Moralised Money: a negative discourse on cash incentives

The first and most common negative view expressed was that offering a cash incentive would undermine patients' internal motivations to link to care. As one patient explained:

> "Yes the person would rush to the clinic because they want to get the money but may later feel lazy to go to the clinic when they are not given the money. So I am not quite sure how people would be motivated to go to the clinic other than to be encouraged by money." [Male, 35, intervention group].

Several participants raised concerns that the once-off nature of the incentive might increase patients' likelihood of disengaging from care after the cash was spent. In the absence of the incentive, there was a concern that people who did not have the internal motivation to link to care would stop taking their treatment. The incentive was thus described as "right for some but not right for others", where a moral assessment was made about who had the motivation to take responsibility for their own health.

What participants saw as most valuable was interest and investment in one's own health and well-being, even in the absence of the incentive. As one participant explained:

> "For a person to receive a contribution to look after their health it's not important. What is important is to do what the doctor tells you to do." [Male, 49, intervention group]

Ultimately, neither patients nor HCWs wanted patients to appear motivated to link to care by the promise of an external reward. Participants were concerned that receipt of an external reward could supersede what they saw as most important: the individual, internal motivation to do what was right for themselves and their health. To care for ones' health just "to get something" (i.e., an incentive) was repeatedly described as problematic.

Moreover, some patients expressed that the offer of an incentive was itself insulting to them, because it implied that they lacked individual commitment to their own health:

> "It doesn't mean we need to get money in order to start treatment." [Male, 24, intervention group]

HCWs also tended to frame their thinking and judgement about incentives mostly around intrinsic motivation, rather than linking incentives to external factors. One HCW, for example, spoke at length about the structural barriers that patients face in accessing HIV treatment and how patients just need a little help ("even 10 Rand" [~$0.80USD]), but then later in the interview expressed very negative views about incentives:

> "It is hard for me to agree that incentivising people to change a behaviour that is for their own good." [HCW pre-study Interview 7]

The intervention was thus perceived in a simultaneously positive and a negative light: as having the potential to shift peoples' engagement with the health system, but also as a potential threat to their investment in their own health.

Although concern was discussed in more general terms in relation to incentives to link to care, the fact that the incentive was *cash* added another layer of moralisation and discomfort. When patients were asked about receiving a cash incentive, they often laughed awkwardly and explained how they would spend the money on others' needs, including buying things like food for their children and family members, instead of using the money for more individualised, personal benefit. In interviews with patients, only one spoke about spending the cash to purchase items for herself, including toiletries. As she described her purchases to the interviewer she laughed almost hysterically, which could point to her acknowledgement of the fact it was not entirely socially acceptable for her to admit that she would spend the money she received from starting ART on herself in this way.

Participants spoke about their worries that some patients would spend the money on the "wrong" things, like alcohol, cigarettes and drugs. In the pre-study interviews, HCWs were unsure as to whether the incentive would be successful. They expressed concern over what they thought patients might spend the incentive on, but also pointed to the dangers of introducing incentives as an additional factor that could undermine patients' commitment to treatment.

Both HCWs and patients saw cash incentives as "paying" or "bribing" or "buying" patients to do what they believed they ought to want to do for themselves anyway: take responsibility for their own health and take treatment irrespective of receiving an incentive. The sentiment expressed by one participant was echoed by many others:

> "I mean why should you be paid for your own health because the help is for your own benefit." [Female, 34, intervention group]

During interviews, participants spoke in ways that highlighted their negative judgement of people whose motivation to link to care was primarily driven by the receipt of a cash incentive. Participants spoke in ways that underscored the fact that they would not be supportive of interventions that could be seen as bribing people to link to care. In contrast, when asked at the end of the interview for suggestions on other ways that could help people start ART, most participants first mentioned some form of incentive, but in these cases, it was non-monetary incentives such as food parcels, vouchers or transport support.

Affective attitudes to the incentive: a range of challenges

Another potentially negative aspect of the incentive voiced by HCWs was that it could create future expectations for patients that they will receive some kind of reward for engaging in care. In a pre-study interview, one of the healthcare workers described patients' "whole mentality" as being:

> "…if I am going to do something about my own health, I must get something for it. You have to pay me and that is just how it is, people are coming to us asking, you know; we will test but isn't there like money, do I not get money or something for it" [HCW pre-study Interview 7]

HCWs also worried that patients might 'game the system'. They were concerned that patients ineligible for the incentive (having already been tested and/or initiated on ART) would deceive them to access the incentive, thus wasting HCWs time, or making them feel foolish by accessing care services just to get the incentives. For example, one HCW said,

> "It is a lot of money in the communities that we work in. … I think we are going to have people deceiving us and say they have never tested before and they do not know their status whereas they already know their status. So it would have to be really kept under wraps, we are thinking about this and how we can really hide the study and what would be involved in it. " [HCW pre-study Interview 7]

In addition, some participants raised concerns that the conditionality of the incentive (i.e., needing to start ART within three months) would be unfair to individuals who were prevented from meeting the condition through reasons outside their control, including clinic-based and family challenges. Some examples of external factors that excluded participants from receiving the incentive included lost tuberculosis (TB) test results, having to be on TB treatment and having to attend to a sick mother in the Eastern Cape; all of which prevented linkage within the permitted time frame.

HCWs also expressed safety concerns as they worried that offering a cash rather than a non-monetary incentive would increase the likelihood of opportunistic crime. Implicit in this notion was the fact that money would be a greater temptation to steal than vouchers or other potential incentives that could have been offered. Despite the fact that actual cash was not being kept by study staff, nor on site, this fear was expressed by multiple HCWs. The concern was more likely linked to the fact that if people in the community became aware that the study was giving participants cash to link to care, people might then attempt to commit robbery at the study site.

Discussion

While the application of incentives for behaviour change along the HIV care continuum is increasing and has proven effective in many cases, little is known about how acceptable such interventions are to providers and patients in sub-Saharan Africa. Our findings align with previous studies that show that both patients and HCWs believe that cash incentives are effective in encouraging linkage to care. Participants pointed to the fact that to receive an incentive made them feel cared for, which echoes findings from studies elsewhere [15]. However, we also found that, overall, there is a strong ambivalence towards incentives, which underscores that perceived effectiveness cannot be equated with universal acceptability. Instead, using two dimensions of the acceptability of incentives as outlined by Sekhon et al (2017), we focused our analysis on how participants felt about the intervention (i.e., their affective attitude towards it), and the participants' perception of the ethicality of the intervention [23]. The incentive was perceived as having the power to shift patients' engagement with the health system, and there were deep concerns about how a cash incentive specifically could shift patients' individual engagement with and investment in their own health.

Cash incentives were strongly moralized by both HCWs and individuals who had recently received a positive HIV test result and been offered an incentive to start ART. Patients spoke disparagingly about how "other people" might behave in relation to linkage to care or use of the cash incentive, while HCWs expressed a more widespread concern that patients' intrinsic motivation to link to and remain in care is fragile. Both respondent groups thus expressed moralizing views that can be seen as twofold: on one hand it allows for a particular kind of discourse to be perpetuated that some people do not have the inherent and intrinsic motivation to do the right thing for their health, which is to link to care irrespective of receiving an incentive. In this framing, some are simply seen as being driven to act not for the "right" reasons but to be motivated by the fact that they might receive a monetary incentive to link to care. Second, to receive a cash incentive is spoken about as being a powerful threat to peoples' intrinsic motivations to take care of one's own health, and as having the power to tempt people to spend the money on things like drugs and alcohol.

Importantly, patients and HCW generally failed to associate the need for cash incentives with external or situational factors, such as structural barriers to ART initiation like transport costs and food insecurity. This absence in itself has significant implications for the design of incentive programs as it likely underpins the moralizing discourse around cash incentives. Instead, individuals framed the need for, and therefore the perceived rationale behind the incentive program, in terms of individual factors like intrinsic motivation. This was striking as both HCWs and patients had a good understanding of, and had spoken at length about, the multitude of structural barriers patients face in access to care, and how patients require assistance in overcoming these barriers. This finding aligns with the concept of the fundamental attribution error, which is a cognitive bias that causes people to underestimate the influence of environment-based situational factors on people's behaviour, and to overestimate the influence of personality-based dispositional factors (i.e., the tendency people have to overemphasize personal characteristics in judging others' behaviour)[26].

Participants perceived that the intention behind the offer of a cash incentive was to reward people for a health behaviour that they otherwise did not have the intention to enact and framed this negatively as a bribe or payment. Patients found this offer offensive, as it was seen to imply that they lacked the intrinsic motivation to take care of themselves. A feeling potentially compounded by HIV-related internalised stigma, and the perception of how poorer and more marginalized individuals are judged by people with greater wealth (and power). Health care providers felt that such a reward could undermine intrinsic motivation and consequently result in poorer health outcomes. From a program-design perspective, our findings indicate that it is important to have a communication strategy to counter this tendency to associate cash incentives with intrinsic motivation. To be acceptable, cash incentives need to be framed as a tool that is designed to help people achieve what they would like to, or plan to do anyway, by countering structural barriers and other factors that increase the costs of linkage to care, like clinic waiting times [19].

Findings indicate that it is not necessarily incentives in general, but cash incentives specifically that drove a strong ambivalence towards the study intervention: participants' first suggestions for an alternative intervention to encourage people to link care involved non-monetary incentives (e.g., food parcels). Thus, incentives that are non-monetary, and explicitly address an external barrier to link to care, like transport costs or food insecurity, may be more acceptable. In many contexts, however, monetary incentives will be more effective and/or feasible because, among other things, they can provide an immediate reward, they can be used to counter many different barriers (from transport costs to present bias), can be logistically easier, and can be valued more highly than alternatives [27]. When incentives are monetary, rather than non-monetary, program implementers will likely have to expend greater effort obtaining the level of buy-in, and perhaps political buy-in in particular, that will create the environment for the success, scalability and sustainability of the program [28].

In relation to incentive programs more generally, our findings indicate a number of perceived negative externalities that could weaken the acceptability of such interventions. These include creating or contributing to a climate of expectation around peoples' linkage to care; creating an unsafe clinic environment; and disengagement from care by people who were able to start ART because the incentive addressed structural barriers but then could not overcome these barriers without further incentives. Future studies are needed to test strategies for mitigating both the likelihood of negative externalities and the formation of negative perceptions of the incentive programs.

Limitations

The results from this study should be interpreted within the context of the study limitations. The extent to which these findings can be generalised to other, especially wealthier, patient populations is unclear. In addition, participants were drawn from a relatively small geographic area and the descriptions of the clinic services may not be applicable to other regions. A further limitation is the study context, which is characterized by a population exposed to multiple research studies. Thus, expectations that have developed around the role of incentives in research, including 'payments' for answering surveys, may have influenced people's opinions about how the incentives are working and whether or not people perceive them to be acceptable. This focus may result in a bias towards patient perspectives, with a need in future studies to elicit additional perspectives from clinic providers. Desirability bias may have also played a role in patients choosing to tell the study staff what they perceived the research team wanted to hear about their intervention. Study measures to mitigate such bias included placing emphasis, during the consent and interview process, on the fact that there are no right or wrong answers.

Conclusion

Patients and HCWs agreed that cash incentives were likely to be effective in encouraging linkage to care, but both groups expressed ambivalence about the cash incentive. The receipt of cash produced moralizing discourses about the kinds of people who may receive it, as well as what could be bought with the cash. In order to increase acceptability, the rationale behind the use of a cash incentive should be clearly communicated with HCWs and patients alike. This clear communication could help to assuage the view that study designers doubt patients' intrinsic motivation to link to care, and ability to spend money on what would serve them best. In the absence of this thorough explanation, non-monetary incentives that explicitly mitigate specific barriers to linking to care could be seen as favourable. An important implication of the study findings is that to maximise the benefits of incentive programs, a greater understanding is needed in relation to the nature of the ambivalence towards these incentives, as well as what, from an intervention design perspective, could be done to mitigate concerns and increase the acceptability of the intervention.

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Availability of data and material (data transparency):

Data available upon request to the lead author.

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