

Financial incentives for pediatric HIV testing (FIT): caregiver insights on incentive mechanisms, target populations, and acceptability for programmatic scale up

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Abstract

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Introduction

Children living with HIV experience gaps in HIV testing globally; scaling up evidence-based testing strategies is critical for preventing HIV-related mortality. Financial incentives (FI) were recently demonstrated to significantly and substantially increase uptake of pediatric HIV testing. However, questions remain about whether and how FI should be integrated into programmatic delivery, including concerns about unintended consequences and FI mechanism.

Methods

This qualitative follow-up study to the FIT trial (NCTNCT03049917) was conducted in Kenya. Fifty-four caregivers (adults living with HIV with one or more children of unknown HIV status) were purposively selected to fill three strata: caregivers enrolled in the trial who tested their child(ren), caregivers enrolled who did not test their child(ren), and caregivers unexposed to the trial. In-depth interviews were conducted with caregivers using

semi-structured interview guides. Transcripts were analyzed using conventional content analysis to identify considerations for programmatic integration of FI.

Results

Caregivers reported two mechanisms by which FI functioned: directly offsetting direct or indirect costs or nudging caregivers to take action sooner than they would have otherwise. Caregivers had diverse opinions about whether FI should be used to motivate caregivers to test their children, but generally found FI acceptable for broader programmatic implementation. Opinions differed on who should be the target population for programmatic scale up. While some caregivers believed FI was compensation for the person in charge of child health, others thought it should operate as income for those who were in need. Some caregivers believed FI should be targeted towards caregivers who had not tested their children despite being in HIV care for a long time. Despite overall high perceived acceptability and feasibility, some concerns were raised about unintended consequences of FI, including caregivers bringing ineligible children (or children who did not belong to them) to collect an incentive and fears of caregivers becoming dependent on FI, having a potentially detrimental impact on linkage to care and retention for children.

Conclusions

FI were considered highly acceptable and feasible for programmatic scale-up by caregivers. FI operated both by directly offsetting costs and by nudging parents to take action.

INTRODUCTION

Many children living with HIV (CLHIV) globally remain undiagnosed; children trail behind adults in achieving the UNAIDS 95-95-95 goals for HIV testing, treatment, and virologic suppression¹. In Kenya, 21% of CLHIV were undiagnosed in 2018², despite scale-up of prevention of mother-to-child transmission (PMTCT) of HIV programs and the resultant reductions in mother-to-child transmission rates³. Early antiretroviral therapy (ART) is critical in reducing pediatric HIV-related mortality⁴. Scaling up evidence-based testing strategies for improving pediatric HIV testing rates is critical for preventing HIV-related deaths among children^{5,6}.

Barriers to testing older children outside of PMTCT programs are well described and include fear of children testing HIV positive, fear of discrimination, limited training of healthcare workers to conduct HIV testing for children, limited infrastructure within the HIV testing facilities, lack of uniform data reporting systems, and financial barriers, including cost of child care, transportation, and lost salary^{7,8}. Multiple interventions were already in place to address these barriers from different levels, including expanding clinic hours, provider-initiated HIV testing and counseling, and community engagement^{7,8}. However, these interventions were not as effective on addressing financial constraints, which disproportionally influence people who were not economically autonomous⁷.

The use of financial incentives (FI) might address some of the barriers caregivers face in testing CLHIV. FI may influence decision-making by directly offsetting costs associated with transportation, missed work or school, and by increasing willingness to test⁹⁻¹¹. Despite their demonstrated effectiveness on increasing desirable health behaviors in numerous trials¹²⁻¹⁶, there are concerns that FI may have unintended consequences when offered in a programmatic setting, such as raising expectations and creating dependency, leading to decreased willingness to continue in care if FI are not provided. These potential unintended consequences should be studied to determine whether potential harms outweigh demonstrated benefits of FI for service uptake. In addition to concerns about unintended consequences, ethical issues, such as decreased voluntariness and concerns about equity, underlie acceptability of the use of FI to motivate health behavior.^{17,18}.

Gaps exist in understanding the experiences and beliefs about the use of FI to increase pediatric HIV testing from the caregiver's perspective. This study aims to evaluate caregivers' views on the motivational and social impact of offering FI in a programmatic setting.

METHODS

Study design and population

This qualitative study assessed caregiver experiences and opinions on the motivational and social impact of FI on pediatric HIV testing. The study was informed by the transtheoretical model¹⁹, which describes stages of health behavior decisions.

This study is a qualitative follow-up study to the FIT trial (NCTNCT03049917), which was conducted in Kenya in the three counties (Kisumu, Siaya, and Homa Bay counties) with the highest HIV prevalence²⁰. Adults living with HIV (caregivers) were eligible to participate in the FIT trial if they were ≥ 18 years old, receiving HIV care, and had at least one child < 13 years who was of unknown HIV status, defined as never having tested for HIV, or not completing testing after the cessation of breastfeeding. Caregivers were randomized to receive US \$0 (control), US \$1.25, US \$2.50, US \$5.00, or US \$10.00 in 1:1:1:1:1 allocation; the trial outcome was the proportion of caregivers completing testing for one or more children and the time to testing completion¹⁹.

Quantitative trial results were used to inform the stratified purposive sampling scheme for this qualitative follow-up study. Recruitment of qualitative participants occurred after the FIT trial had ended, and was conducted in 6 of the 19 trial clinics. Caregivers were stratified based on their involvement in the FIT trial and their decision of whether to test their child(ren) during the trial and included: 1) FIT study testers: participants enrolled in the FIT trial who completed testing for their children; 2) FIT study non-testers: participants enrolled in the FIT trial who did not complete testing for their children; and 3) FIT naïve: participants who were not enrolled in the FIT trial, but had children; unlike in the trial, these children did not need to be of unknown HIV status.

Data collection

Caregivers provided written informed consent to participate, were asked to complete a structured demographic questionnaire, and invited to participate in an in-depth interview (IDI). Two trained Kenyan social scientists conducted interviews using a semi-structured interview guide. Interviews lasted an average length of 22 minutes. Interviews were conducted in English, Kiswahili, or Dholuo depending on participant preference. All interviews were audio-recorded, and audio-recordings were transcribed and translated when necessary by trained staff who were proficient in English, Kiswahili, and Dholuo. Interviewers also wrote structured debrief reports following each interview, summarizing the key information obtained during the interview²¹.

Data analysis

Analysis was performed on caregiver transcripts²² using conventional content analysis with the goal of identifying caregivers' experiences with and beliefs about the use of FI for pediatric HIV testing. Specifically, analysis focused on characterizing: 1) satisfaction and personal experiences with the FI program, 2) mechanisms underlying decisions to test or not test, 3) beliefs about FIs as appropriate motivators or agents of coercion, 4) beliefs and experiences with randomization and intervention components, and 5) beliefs about scaling up the FI intervention.

A codebook was first developed deductively based on transtheoretical model domains and literature reviews of the use of FI to encourage health actions. Inductive codes were then developed based on caregivers' responses in debrief reports and a review of a subset of full interview transcripts. The codebook was refined through an iterative process of reviewing additional transcripts and assessing the codebook for accuracy to capture emerging themes. Codebook development and the coding process used a modified constant comparative approach to ensure data accuracy and reliability. After the codebook was optimized to the data set, coders (JZ, DA, KBS) completed one round of consensus coding to ensure consistency in code interpretation and application across transcripts. Coders were each assigned a group of transcripts for primary coding, and then exchanged transcript groups for review by another coder. During the review process, coders applied additional codes as

necessary, and noted any disagreements in code applications. After all transcripts have been reviewed, the coding team met again to discuss and resolve all disagreements in code application. Transcripts were coded using Atlas.ti (version 8). Queries were used to compare experiences between caregivers, and identify common and less common themes emerging from the transcripts.

RESULTS

A total of 54 caregivers participated in individual interviews. Twenty-five were enrolled and had tested their children during the FIT trial, 15 were enrolled in the FIT trial but did not complete HIV testing for their children, and 14 were not enrolled in the FIT trial. The majority of caregivers were female (76%) with primary education (72%). Overall, less than half (41%) of caregivers were employed, but the employment status varied between FIT testers (70%), FIT non-testers (33%), and FIT naïve caregivers (36%). Among FIT testers, most caregivers (84%) were parents of the children, and median number of children tested was 2. For FIT non-testers and FIT naïve caregivers, due to missing data, we were not able to analyze caregiver's relationships with children and the number of children tested for HIV (**Table 1**).

Barriers to testing children for HIV

Common barriers to pediatric HIV testing were reported by caregivers, including financial challenges (e.g. finding money to pay for transportation), time constraints, lack of support from partners, fear of discrimination, fear of having infected their children and disclosing their HIV status to their children. HIV-related knowledge – including transmission and HIV symptoms – was accurate among most caregivers. Minor gaps in HIV transmission knowledge included confusion about the relative contribution of sharing sharp objects or razor blades to HIV transmission. A few caregivers reported not being aware of the possibility of testing their children, while others reported confusion about whether a child without symptoms could have HIV, as reasons for not having tested their children in the past.

“... on my side I thought that he didn’t have [HIV] because he was someone who was older... I remembered that when I was being tested and diagnosed with HIV [that] child had been born long before that. So I was sure he couldn’t be having HIV.”

(FIT tester, 45-year-old father)

Financial incentive mechanisms: direct offsets versus nudge to encourage testing

Caregivers reported distinct mechanisms by which FI enabled them to test their children, either by directly offsetting direct or indirect costs, or by nudging them to take action in order to receive an FI. Some caregivers who had tested their children within the trial reported FI directly offset transportation costs, while others reported that FI addressed other costs not related to HIV testing, but which benefitted the child. Caregivers reported using the money to offset school fees, food for the family, pay debts, and provide treats for their child like a toy or snack.

“It was because of money because I come from far, so that issue of money hindered me from bringing them and also I don’t like going to [the nearby clinic] which I am very close to being that I am embarrassed, once you get this disease you start to feel ashamed... I just said that one day God will give me money and I will take them to [the farther clinic for testing].”

(FIT tester, 35-year-old mother)

“And in fact even the money that I was given that day, it helped me a lot, because I didn’t even [have] money that day that my child could go to school with, so I gave him transport and lunch and I also found a means of helping myself.”

(FIT tester, 30-year-old father)

However, some caregivers who had not been involved in the trial felt that motivation should come from intrinsic rather than extrinsic factors.

“According to me, it is not supposed to be used to encourage people, what should encourage someone is the health of their child, that is what should encourage someone... it is the health of the child that is important.”

(FIT-naïve, 30-year-old female caregiver)

Some caregivers who had tested their children within the trial felt that intrinsic motivation should be encouraged for long-term care of the child, given the limited perceived sustainability of FI.

“...he should tell them that...there will reach a point where there will be no money, it is not like you have to be given money when you come, they should have the heart of bringing their children to know their status even if there will be no money.”

(FIT tester, 35-year-old mother)

Financial incentive value in research studies and programmatic settings

Caregivers were asked to reflect on the value of FI they were randomized to receive in the trial, as well as potential values that might be used in a hypothetical future programmatic setting. Caregivers' feelings towards the values of FI received in the trial were mixed. Some also said they felt it was part of their responsibilities as parents to test their children and know their HIV status, and they would still bring their children for testing even there were no money.

“Money is not the reason you are bringing the child for testing, you just have to bring the child for testing so that you can know your child's status, yes it is not money given so that you can bring your child, no that is just a life that you personally decide and say that ‘I should take this my child for testing’.”

(FIT tester, 40-year-old mother)

When considering the FI value, many caregivers said that they would have still brought their children for testing had they received bigger or smaller FI. However, many caregivers also said they would bring their children for

testing faster if FI values were doubled and that a smaller value could discourage people from bringing their children.

“Interviewer: If you found more money would that have encouraged you to come immediately or you would have just come back as you had planned?”

Respondent: I would have come back immediately so that I can get it.”

(FIT tester, 42-year-old aunt)

When asked whether they felt the value of the FI they received within the trial was fair, most caregivers said they were happy about the amount they received. Most caregivers recognized that the FI value was based on luck (e.g. randomization), they were okay with whatever amount they received. However, a few caregivers were not happy with the value of FI they received, and said they wished to have received more money, but still felt content since they felt it was based on luck:

“...whatever I got I just said that it is my luck, if I get good money or little money that was my luck so I just accepted whatever I got”

(FIT non-tester, 43-year-old female caregiver)

Caregivers advised against large FI values within programmatic settings, as these might arouse suspicion, and could motivate individuals to bring other people’s children. Caregivers offered possible strategies to overcome these potential negatives, for example, checking birth certificates and performing follow-ups. In general, caregivers felt that smaller value FI being given programmatically would be perceived as transportation money.

“No, the kind of money that brings such kind of questions are big money like someone giving you a hundred thousand and you didn’t have any thoughts about that but money that is being given like the one that you gave us for transport, it is not money that can bring such thoughts.”

(FIT tester, 39-year-old uncle)

“[The money] can make some people to start a business with it, you can find someone bringing even the neighbors children so that they can get money if not that he can decide to move with them from one hospital to another, they come from [one facility] to [a different facility] and claims that they have never been tested.”

(FIT tester, 35-year-old mother)

Caregivers reported that sometimes monetary incentives could be viewed negatively, given historical experiences with money being offered to members of their community and how those exchanges took place. However, caregivers felt that if people were told the incentive was for a research study, they would not be suspicious.

Proposed target population for incentives reveals caregiver understanding of goal and mechanism of incentives

Caregivers had very diverse views of the target population for FI (refer to **Table 2** for additional quotes). Differences in beliefs depended on how they thought FI operated, and what purpose the FI fulfill. Some saw FI as compensation for the person in charge of the children’s health, and felt FI should target primary caregivers, especially mothers.

“Money, even if you give a father or a mother, it is the mothers who know the problems of her household, you know fathers will give you only half of the money and give you very little. So it is the woman, she will budget with it.”

(FIT non-tester, 49-year-old female)

Some caregivers viewed FI as income generating or substituting and felt FI should target needy people with financial challenges. Other caregivers felt the target population should be determined based on their time of enrollment on HIV care; caregivers had diverse opinions on which population should be prioritized. Some felt FI

could help motivate those newly diagnosed to take immediate action to test their children of unknown status, while others felt FI could be the nudge needed for those who have been enrolled in care longer but have still not yet tested their children.

“They need to encourage those who have just been initiated on care because the other ones are already used to taking medication, otherwise they will find it challenging... Not unless they are also given this money to motivate them because you know motivating them will make them feel like they are not alone and that they can also make it with the medication and be like the others; because at that time when they are being initiated they might have a lot of stress.”

(FIT naïve, 22-year-old female)

“...[the one who is already established in the program] already know, she knows the importance, maybe if you introduce the one who is just joining and you introduce her to money, her mind will always be thinking about money... and she will only be coming because of money. But this one who is used to, who knows that when I am called I must go and leave my job. For me, I think that’s the one who is supposed to be given.”

(FIT tester, 35-year-old mother)

In addition, some caregivers also felt that FI should not be based on who the intended recipient was. They believed everyone should be considered equal, and people should receive the FI regardless of their time enrolled in HIV care.

“I think once someone is on care their issues are the same...those things are equal, there is nothing like that because you cannot speak of an older disease or a new disease, a disease is a disease.”

(FIT tester, 38-year-old mother)

DISCUSSION

FI have the ability to motivate health behaviors, including HIV testing for children of unknown HIV status. In our follow-up study to a trial that used FI to improve pediatric HIV testing, caregivers described high acceptability for the use of FI, and many recommended future implementation of FI programs. FI were found to work by directly offsetting costs and by nudging caregivers to bump testing to be a higher priority. FI worked differently depending on the caregiver's specific barriers to testing their child(ren). In addition to financial challenges, other barriers to testing children for HIV reported by caregivers were found to be similar to those identified in previous studies^{7,8}.

Behavioral economics—which combines traditional economic theory with psychology theory—literature describes the mechanisms of FI to either operate through a “nudge”, by supporting an individual to take an action, even if the FI value itself does not fully offset their costs^{14,15,23,24}, or through directly offsetting costs^{23,24}. Comparing the two mechanisms, FI values that nudge, or alter caregivers' priorities influenced people's decision-making through psychological processes, while FI values that directly offset costs were more similar to traditional FI²⁵. Within the FIT trial, the incentive arm that did not directly offset the average costs for the study population did not have a significant or appreciable different level of HIV testing uptake from the unincentivized control, suggesting that a “nudge” was not effective in this population²⁶. This differs from the reported mechanisms by caregivers in this qualitative follow-on study.

Some caregivers in our study reported they would have been more likely to test rapidly if they received a higher FI value, while others reported that FI value would not have impacted their behavior. Within the parent trial, increasing FI values were associated with increasing uptake²⁶. Other FI trials of HIV testing that included multiple fixed value incentive arms show a heterogeneous relationship with increasing value and uptake^{13,14}, but similarly structured trials from other HIV related behaviors demonstrates a dose-response relationship between FI value and uptake²⁷. Although FI increase uptake of HIV testing, FI may be less effective in maintaining long-term effects on viral suppression^{28,29}. Therefore, the goals of FI use should be carefully evaluated before implementing FI programmatically.

Caregivers had mixed views on who should receive FI, and their opinions differed from those reported by health care workers in a prior analysis³⁰. Health care workers suggested expanding the population eligible to receive FI in a programmatic setting to include adolescents and adult men, while caregivers preferred targeting women, rarely mentioning adolescents and men. This finding existed despite a similar proportion of caregivers and health care workers being female. These differences in who the target recipients should be within a programmatic setting may create additional challenges for health facility leaders deciding whether or how to implement FI within a programmatic setting. Both health care workers and caregivers raised concerns about ensuring that the children brought for testing truly were eligible, citing concerns of caregivers bringing children that were already tested or did not belong to them. The solutions to this issue raised by caregivers included checking birth certificates or other time-intensive procedures, while solutions proposed by health care workers were more systems-oriented and included using routine program data to determine eligibility and check uptake³⁰.

Additionally, health care workers had more concerns regarding limited resources available within their health facilities in relation to programmatic delivery of FI, and worried about increasing workload associated with increased number of people bringing their children for testing³⁰. However, such comments were rarely mentioned by caregivers in this study. Similarly, health care workers had concerns about the cost of sustaining such a program³⁰ while caregivers did not raise many concerns about programmatic cost. Health care workers also discussed the option of offering non-monetary incentives³⁰, which was not raised by caregivers.

Limitations

Interviews with caregivers explored their experience and knowledge of FIT as a clinical trial, in which caregivers received different FI values. However, if FI were to be scaled up and implemented in programmatic settings, caregivers would receive a uniform amount. The differences in the value of FI offered may result in different views on acceptability of the program. It was not possible in this study to directly assess the concern of erosion of intrinsic motivation or the risk of caregivers bringing children who were not theirs for testing. Caregivers enrolled in the study reported that they would not develop dependency on FI and would not bring ineligible children. However, caregivers also reported that they cannot speak for others and cannot know how other

caregivers may react to FI. This study only included views from caregivers; it would be ideal to hear from other stakeholders, such as policymakers, to inform a more comprehensive understanding on the potential use of FI in larger programmatic settings. Participants were recruited from participating clinics in three counties in Kenya, and the results may not generalize to other counties in Kenya and other low- and middle-income countries. Finally, children >13 years were not included in this study, making our results not generalizable to older children and adolescents.

CONCLUSION

FI were considered highly acceptable and feasible for programmatic delivery by caregivers, and many of them supported the idea of future scale up. Caregivers described two mechanisms of FI action, including directly offsetting costs and “nudging” action earlier, consistent with both behavioral and traditional economic theory of FI mechanisms. Caregivers generally perceived the range of FI values in the trial to be acceptable in programmatic settings, but differed in their views about who the intended beneficiaries of such a program should be, which related to their interpretation of the underlying purpose of FI. Besides FI, parental responsibilities were also considered important in motivating parents on testing their children, suggesting possibilities of bundling health education with pediatric HIV testing. Finally, caregivers noted some potential challenges to implementation of FI in a programmatic setting, especially related to ensuring eligibility and avoiding program manipulation by families, and proposed solutions to overcome these on an individual level.

Table 1: Demographics

	FIT tester (N=25)	FIT non-tester (N=15)	FIT naïve (N=14)
	n(%) or median (IQR)	n(%) or median (IQR)	n(%) or median (IQR)
Female	16 (64%)	12 (80%)	13 (93%)
Education			
Primary	17 (68%)	13 (87%)	9 (64%)
Secondary/high school	6 (24%)	2 (13%)	4 (29%)
University/college	2 (8%)	0	1 (7%)
Employed	14 (70%)	5 (33%)	5 (36%)
Median household size	5	4	3
Number of children tested	2 (1)	--	--

Table 2: Example Quotes Related to Acceptability, Feasibility, and Sustainability

Domain	Construct	Quotes
FI acceptability	Positive experience	<i>“I felt good and I learnt that there is benefit if you bring your child, there is a benefit you get at least after that you will go and buy the child something.”</i> (FIT tester, 43-year-old mother)
FI effectiveness	Direct offset	<i>“I didn’t have transport money but it forced me to borrow transport because when I heard that I was coming to test and I already developed courage because of that push, I was courageous that even [if] he is sick, I will just start him on medications early because I am also on medication.”</i> (FIT tester, 45-year-old mother)
	Money as a push	<i>“Coming here messed my work schedule however they had told me that they were going to give me transport reimbursement following the card that I scratched yes that is why I stopped going to work and decided to just bring her. The money encouraged me a bit.”</i> (FIT tester, 39-year-old uncle)
	No incentives needed	<i>“You know the child is yours the child is yours. The doctor knows his children’s status now it is your responsibility, you can bring the child even without being given money, so that you can know their status because that child is yours. Therefore there is no need of being given money because the child is yours not his, you are the one who is supposed to look at the welfare of your child.”</i> (FIT-naïve, 22-year-old female caregiver)
Target population for FI	Primary caregivers	<i>“I think it should enroll more women than men because women are a little bit reliable and even in terms of responsibilities very few men are responsible ”</i> (FIT tester, 39-year-old father)
	Financial challenges	<i>“Mostly those who are on care, those who have this infection because you know there are those who have this infection and they look healthy and there are those who have this infection and are very needy. They don’t even have any source of income.”</i> (FIT tester, 41-year-old mother)
	Enrollment on care	<i>“Those who have just been enrolled, they are still weak in treatment... they might be discouraged and stop treatment. But those who are ongoing know what they have been through and the steps that they had to take, so they are okay, they can be explained to slowly and they understand.”</i> (FIT tester, 27-year-old mother)
	Financial challenges	<i>“...those who have been on care for a long time and they are following the rules of treatment well but they are not financially okay for sure even if you go to their home you will find that they are really [impoverished] and maybe even the government knows and have taken responsibility of paying fees for his children.”</i> (FIT non-tester, 58-year-old male caregiver)
	Children versus adults	<i>“...medication is medication, taking medication can be so hard even those who are taking medication even ones who have been on it for a while can be a defaulter and comes back to zero such that the person who enrolled recently becomes more stable, and if not followed up they can even die because of it. So I feel that if it is a program for those who are on treatment then let everyone benefit, and if it is for children then let the children benefit and adults to be left out.”</i> (FIT tester, 42-year-old aunt)
Potential negatives	Program manipulations	<i>“The negative thing that can happen is that he may start spreading to people that we only come here for money and not because we are sick and you know he might discourage even those who wanted to come when</i>

		<i>he says that we only come because of money and not because one is sick” (FIT non-tester, 35-year-old female caregiver)</i>
	Dependency on money	<i>“I’m already used to it because that money ended and it was renewed, I scratched and found out that I was continuing, don’t you see that is an addiction, like I know that if I go to [hospital’ s name] then I will get money, so when I don’t get that addiction it discourages me” (FIT tester, 43-year-old mother)</i>
	No negatives	<i>“...in my opinion I don’t see anything negative with that because I know whatever you people are doing it geared towards helping people so that even if something happened to me these ones who will remain are the future generation and you are concerned about their health. Yes so see again I might not know other people’s opinion about this.” (FIT tester, 42-year-old mother)</i>

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