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# LETTER TO THE EDITOR: Financial incentives to motivate pediatric HIV testing – assessing the potential for coercion, inducement, and voluntariness

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Financial incentives (FI)—in which money is given to an individual in return for a certain action—have been highly effective in motivating a variety of health-related behaviors and HIV interventions, including HIV prevention [1, 2], testing [3–6], linkage to care and retention [7, 8], and treatment adherence [9–11]. Despite their increasing use in research and programs, there are ethical concerns, including the potential for coercion and unintended social harm [12, 13]. Using FI to motivate pediatric HIV testing raises special ethical concerns in this vulnerable population, particularly because the incentives are provided to caregivers who take children for testing.

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## Background and Rationale

Pediatric HIV testing and treatment maximizes survival and reduces morbidity [14–16]. However, there are programmatic gaps in the testing cascade that result in late diagnosis and preventable deaths [17]. Index-case testing strategies targeting HIV-infected parents receiving care increase uptake of pediatric HIV testing [18–20]; however, the majority still opt not take their child for testing, due fear, misconception of risk, and financial barriers [18, 21]. FI may be an effective intervention to incentivize HIV-infected parents to test their children.

The Financial Incentives to Increase Pediatric HIV Testing (FIT) Pilot Study (NCT02931422) tested the effect of small FI (USD 5–15) to motivate HIV-infected caregivers to test their children. Eligible caregivers were randomized to one of three FI values at recruitment, which would be given to the caregiver upon return for child testing (*manuscript under review*). The one adverse event recorded during the study was categorized as a social harm; an 11-year-old girl ran away from home temporarily to avoid being tested for HIV. In addition to social harms, the study team attempted to assess the potential for coercion and unintended harm using a structured questionnaire. Analyses revealed discordance between questions assessing coercion or a lack of voluntariness ("Did the offer of money make you feel like you had no choice, you had to test your child?") and intention to test ("When would you have tested your children without the incentive?"). Specifically, parents who stated they would have tested their children for HIV even without FI also indicated that they felt the incentive gave them no choice but to test, potentially suggesting FI were ethically problematic because they were coercive. A literature review of other FI studies revealed no agreement how best to measure or report coercion [1, 22]. The study team thus engaged the Treuman Katz Center for Pediatric Bioethics at Seattle Children's Hospital to provide guidance in how to assess coercion and other ethical considerations related to FI.

## Ethical analysis

Concerns about the use of FI are often framed by researchers, ethicists, and ethics review committees in terms of 1) coercion, 2) undue inducement, and 3) lack of voluntariness. However, these concepts are often used without precision and clarity. Additionally, most existing scholarship focuses on the ethics of FI for research participation, rather than the use of FI to promote behavior change to improve health outcomes. We will argue that, in the context of FI use for behavior change, researchers should not focus on misplaced concerns about coercion or undue inducement, but try to measure the impact of FI on voluntariness or the potential for social harms.

### Coercion

Although most IRBs consider incentives coercive if a person feels they have no choice but to perform the incentivized behavior, this is based on widespread confusion about the concept of coercion [12]. The influential Belmont Report states that "coercion occurs when an overt threat of harm is intentionally presented by one person to another to obtain compliance," [23] suggesting that there are two important features of coercion: (1) it is morally wrong,

and (2) it requires an intentional threat of harm. Scholars have extended this definition to note that threats to violate someone's rights if they do not comply also count as coercive [24].

Some argue that financial incentives offered to people living in poverty are coercive if individuals have no reasonable alternative but to do what is necessary to be paid. However, Wertheimer and Miller describe the case of a woman who is diagnosed with breast cancer and is offered urgent, life-saving surgery; there is nothing morally wrong about the offer, despite the fact that the patient has no reasonable alternative. They argue that "genuine offers cannot coerce" [24].

For pediatric HIV testing, however, it is possible that parents interested in financial incentives will force their children to be tested or impose consequences if they refuse. Parents generally have the authority to require their children to engage in activities that are intended to benefit their children, ranging from brushing their teeth to staying in school. This suggests that, in general, there is not necessarily anything wrong with parents requiring their children to take an HIV test, provided it does not go beyond the limits of acceptable treatment of children (such as resorting to abuse or threats of violence). Incentives at such low levels as offered in the FIT study seem insufficient to motivate parents to mistreat their children. Nevertheless, measuring whether and how often social harms occur is important to inform future implementation.

### Undue inducement

Incentives or inducements are widespread and well-accepted; people generally receive compensation for employment, for instance. Undue inducement is problematic and can occur in research when financial incentives are high enough to tempt participants to ignore high risks or make decisions contrary to their core values [25]. Determining whether an incentive is unduly large varies by context and circumstance. Perhaps the most prominent model in the literature for determining whether payments are undue inducements is the 'Wage-Payment Model', which concludes that payments that are similar to what an individual would otherwise earn for similar work and the amount of time required are not undue [25]. However, pediatric HIV testing and treatment offers substantial, proven benefits for the children involved, and few risks. Additionally, the incentives being offered ranged between $5–$15, the highest level representing an estimated cost of transportation and two days' lost wages. Testing a child typically takes a half day of time, requiring a parent to skip a half or full day or work—or only slightly more than the Wage-Payment model would require. In this population, mean monthly income was $83 (median [IQR]: $48 [$15–$100]). Given that these incentives are not unduly large by comparison to what individuals could earn otherwise, it is unlikely that parents would ignore risks or violate their deeply-held values because of these payments [26]. In fact, given the low risks and significant potential for benefit involved, higher incentives could also be ethically appropriate. This is because financial incentives to promote healthy behaviors can be autonomy-enhancing, in that they help people to "bring about a personal change they might already desire, through a means with which they are already familiar" by eliminating financial or other barriers to action [27]. Arguably, an even stronger case can be made that financial incentives to promote

healthy behaviors are welfare-enhancing, which is the appropriate ethical and legal focus of parents making decisions on behalf of their children.

### Voluntariness

Coercion and undue inducement are two types of interference with a person's ability to make a voluntary decision, but there are other, more subtle influences on decision-making. For instance, a person might have the perception that they are being coerced, and even if that perception is inaccurate, it may influence their decision nonetheless. Although coercion and undue influence are not significant ethical concerns in this context, ensuring voluntariness is more complicated. First, it is hard to know what counts as sufficiently voluntary, since there are many different influences that can affect day-to-day decision-making [28]. Few, if any, decisions are completely voluntary. Second, measuring voluntariness is challenging. Previous studies have sought to measure voluntariness by determining whether some individuals choose *not* to participate, whether participants report feeling pressure to participate in a study, and whether participants know they could refuse participation or withdraw; however, each of these approaches has limitations. Some individuals may choose *not* to participate at the same time that other individuals feel their decision was not their own. In other studies, although some research participants have reported feeling pressure to participate in research, when asked about the source of the pressure, it comes from their child's illness, not the study team [29]. Finally, some research participants who reported knowing they could withdraw also indicated a belief that the clinic would not let them quit [30]. This suggests that questions seeking to measure voluntariness should be carefully crafted to determine whether pressure felt by study participants could be attributed to a specific and ethically problematic source.

## Summary

Coercion and undue inducement are not significant ethical concerns in offering FI for pediatric HIV testing, provided FI are not so large as to exert undue influence and the interventions are beneficial and not excessively risky. The authors are currently working to measure voluntariness in the uptake of FI and social harms that may result from their use, which are challenging issues that merit further attention.

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