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Typologies of altruistic and financial motivations for research participation: A qualitative study of MSM in HIV vaccine trials

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Abstract

Questions arise concerning participants' motives in risky studies, such as HIV vaccine trials (HVTs). We interviewed in-depth 20 gay/bisexual men**.** Participants described both altruistic and non-altruistic motives. Altruistic motivations emerged primarily, with nine typologies: 1) cultural; 2) community-related; 3) familial; 4) religious; 5) professional; 6) political (e.g., HIV activism); 7) moral (e.g., making up for past wrongs); 8) existential (e.g., providing sense of meaning); and 9) other psychological (e.g., emotional gratification). Views of compensation varied: not a factor (55%); added incentive (25%); main motivator, but in conjunction with altruism (15%); and primary motivator (5%). HVT participants thus often have both altruistic and financial motives, and related typologies emerged. These findings have critical implications for studies on HIV, other conditions, and research ethics.

Keywords

HIV vaccine trial; motivators for participation; altruism; compensation

Introduction

Understanding the motivations of medical research participants is important to ensure that these individuals are agreeing to participate voluntarily without undue influence or coercion, and potentially to assist in appropriately recruiting and retaining participants (Brown, Fouad, Basen-Engquist, & Tortolero-Luna, 2000; Sengupta et al., 2000), but many questions about such motivations remain. Research Ethics Committees (RECs) and Institutional Review Boards (IRBs) assess the risks and benefits of studies to ensure that the risks are minimized and are commensurate with benefits; but crucial questions also emerge concerning how potential study participants themselves view and make decisions of whether to participate.

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The health belief model posits that individuals decide whether to engage in a specific health-related activity based partly on their perceived susceptibility and benefits involved (Janz & Becker, 1984). But how individuals view these issues concerning research studies is often unclear. Studies examining participants' motivations have found that motivational factors can be categorized, broadly, as either self-oriented or other-oriented (i.e., altruistic) (Sugarman et al., 1998). These differences in primary motivation factors can be attributed to both participant and research-specific differences (Miller & Rosenstein 2003; Schafer, 1982; Sullivan, 2001).

HIV research continues to raise critical ethical concerns, since it involves participants from marginalized or vulnerable populations, who may be involved in stigmatized and/or illicit sexual or drug-related behaviors. These issues are vital since researchers often face challenges recruiting members of various minority groups at highest risk for HIV.

HIV vaccine trials (HVTs) have posed particularly critical ethical concerns. These studies test products that have in have the potential to help stymie the HIV pandemic, but no effective vaccine has yet been found. One vaccine candidate, using an adenovirus type 5 vector, in fact increased, rather than decreased, the risk of HIV infection among uncircumcised, adenovirus seropositive men (Buchbinder et al., 2008). Nonetheless, HVTs continue, given the potential public health benefit.

HVT participants have both self-oriented motivations and altruistic intentions. Prior to the existence of actual HVTs, researchers conducted "preparedness" studies in both developed countries (Buchbinder et al., 2004; Gross, 1996; Hays & Kegeles, 1999; Koblin, Avrett, Taylor, Stevens, 1997; Koblin et al., 1998; MacQueen et al., 1999; Starace et al., 2006; Strauss et al., 2001) and developing countries (Jenkins, Temoshok, Virochsiri, 1992; Celentano et al., 1995; Périssé et al., 2000; Ruzagira et al., 2009; Sahay et al., 2005) to investigate attitudes and prospects for subject enrollment, with respondents' willingness to participate in HVTs ranging widely from 6.3% to 95%. However, respondents' initial willingness to participate could diminish over time (Bartholow et al., 1997; McGrath et al., 2001). Between developed and developing nations, no significant differences have been found in motivation for HVT participation (Dhalla & Poole, 2011). In both developed and developing countries, motivations for participation, include financial compensation, types of personal benefit (e.g., receiving medical care, potential protection against HIV) (Celentano et al.; Jenkins et al.; Koblin et al., 1997) and altruism (Brooks, Newman, Duan, Ortiz, 2007; Hays, Kegeles,; Koblin et al., 1998; MacQueen et al.; Meyers, Metzger, Navaline., Woody, McLellan, 1994; Newman et al., 2006; Newman, Duan, Kakinami, Roberts, 2008). Motivations in actual HVTs have also been financial gain, perceived medical benefit, and altruism (Buchbinder et al., 2004; Colfax et al., 2005; Gray et al., 2008; Harro et al., 2004; Jenkins et al., 1999; Tarimo et al., 2010).

Yet altruism has been viewed and assessed in varying and limited ways. At a theoretical level, sources of altruism have been explored – why, in the presence of limited resources and competing needs and wants, humans might be willing to sacrifice for others. Plato argued that people are always acting out of self-interest, even when seemingly acting in the interest of others – e.g., members of a group will help other members and by extension, themselves

(Plato, 1997). Similarly, Aristotle believed that friends share in one another's pleasure and pain. (Aristotle, 2009) Comte coined the term "altruism" in 1851 and theorized that acting in the interest of others is inherent to humans (Comte, 2016).

Empirically, studies on altruism have used a variety of both quantitative (e.g., binary or Likert scales, categorical or forced item responses) and qualitative (focus group, semi-structured interviews) assessments, resulting in highly heterogeneous results. For instance, helping to find a vaccine, making a contribution to medical or scientific research, as well as helping the community have all been considered altruistic motives (Buchbinder et al., 2004; Cassileth et al., 1982; Colfax et al., 2005; Hallowell et al., 2010; Harro et al., 2004; Sutherland et al., 1998). Some studies have categorized many different responses under altruistic motives (e.g., fulfilling moral principles, or diminishing the impact of HIV/AIDS worldwide) as falling within the same category (Jenkins et al., 1999; MacQueen et al., 1999; McGrath et al., 2001; Périssé et al., 2000; Tarimo et al., 2010). A recent review of 12 studies on motivators to participate in actual HVTs offered a categorization of several types of altruism vs. personal beliefs, and divided altruism, based on its outward manifestations, into three types: microsocial (e.g., helping friends and family), "mesosocial (e.g., helping community),and macrosocial (e.g., helping to stop the epidemic) which included moral obligation (Dhalla & Poole, 2014). Yet none of the 12 studies examined the same set of categories or subcategories. Questions also arise as to whether altruism and personal benefits interrelate in any way, and if so, how. Additionally, though compensation is often also cited as a motivator for participation (Colfax et al., 2005; Gray et al., 2008), HVT studies have not examined the relative degree to which compensation is a motivator in decision-making about participation vs. altruism.

These issues are critical, since IRBs and researchers can best ensure the proper conduct of studies (e.g., participant recruitment, enrollment and retention) by being as aware as possible of participants' views and motivations concerning research, understanding why participants are enrolling in studies, and ensuring that these individuals are doing so for appropriate reasons.

Many questions thus remain concerning how study participants view and respond to altruism and financial motivations for enrolling in studies. Hence, we examined motivations for entering an HVT using in-depth qualitative interviews – how, and to what relative degree participants see altruism, personal benefits, and compensation as motivators. The HVT (a phase II B vaccine study) was not designed to provide any direct personal benefit to participants; and altruism and financial motivations arose as the major incentives for enrolling. Hence, this paper focuses on these two sets of motivations.

Methods

Participants in the present interview study were HIV-seronegative men who have sex with men (MSM) enrolled in the HVT. The HVT's endpoints were to assess the vaccine's immunogenicity, and ability to reduce viral load if participants became HIV-infected. Compensation for the HVT was approximately $1,000 over the five-year period of the trial, which included the risk of receiving injections of a vaccine that has the potential increase the

risk of HIV acquisition. Participants were compensated per study visit and the amount depended on the study activity – $10 for test result review (4 visits per year); $25 for completing screening procedures; $50 for providing biological specimens (14 visits); and $75 for vaccination (4 visits). Some visits involved providing biological specimens (e.g., blood collection as high as 280 milliliters).

Participants in the interview study were recruited by HVT staff who approached these men during HVT follow-up visits over a 12-month period in 2009-2010. As summarized on Table 1, we interviewed 20 informants, ranging from 23-48 years of age; 7 were White, 10 African-Americans, 1 Asian, 1 Latino, and 1 self-identified as African-American/Latino. All but one had graduated from high school, and 80% had completed at least some college.

We used a 1-2 hour semi-structured qualitative interview, asking about understandings of HVT, perceptions of the HVT informed consent process, possible therapeutic or preventive misconceptions (Appelbaum, Roth & Lidz, 1982), and decisions, reasons and motivators, including financial incentives, involved in enrolling and remaining in a HIV/AIDS vaccine trial, (See Appendix for sample questions). We obtained separate informed consent for the interview study, and interviewed participants once, between one and 21 months after they entered the study –depending generally on when they were next returning to the HVT research site for a follow-up appointment as part of the HVT. Respondents were paid $20/ hour for the interview. The Columbia University Department of Psychiatry IRB approved the study. All participants gave informed consent.

The interviews were audiotaped, transcribed, and content-analyzed, informed by grounded theory (Corbin. & Strauss, 2008). Two of the authors (JB and LJC) independently examined a subset of interviews to identify categories of recurrent themes and issues that were subsequently given codes. Coding of the interviews involved a two-phase process. In the first phase, the coders systematically coded blocks of text to assign “core” codes or categories. When analyzing the interviews, a topic name (or code) was inserted beside the excerpt of the interview to indicate themes being discussed. Each coder analyzed the interviews separately and subsequently worked together to reconcile the independently developed coding schema into a single scheme and into a coding manual. For the second phase, thematic categories were subdivided into secondary or subcodes, which were refined and merged when suggested by associations or overlap in the data. Codes and subcodes were used in the analysis of all the interviews. Major codes (or categories) of text included, for example: reasons to participate, and trial recruitment process. Subcodes (or subthemes) were conceptual and thematic subdivisions of these larger categories, including, for example, altruistic motives, personal motives, and financial motives. To ensure coding reliability, both coders coded all interviews. We have provided excerpts from interviewees below, identifying each by subject number and race/ethnicity.

Informants’ responses to the question about financial motivations fell into one of three categories overall, and are thus presented as such below. These three financial categories are mutually exclusive, with each participant fitting into only one of these three categories. In contrast, the altruism categories were not mutually exclusive (i.e., several participants expressed more than one motivation, and thus fit into more than one category). Hence, also

given the size of sample and the number of altruistic categories, we did not quantify these altruistic responses. Moreover, the study was not designed to yield such calculations.

Results

As seen in Table 2, participants revealed a range of motivations for participating (i.e., both entering, and remaining, in the HVT), which can be broadly categorized as 2 overall types – altruistic and financial – under which several subtypes emerged. Specifically, ten types of altruism and four types of financial motivation arose. Individuals frequently mentioned several subcategories involved in their decision to participate. The length of time participants had been enrolled in the study did not appear to affect motivations for participation in the ongoing HVT. As seen below, participants consistently spoke in the present tense (rather than in the past tense) concerning motivations that led them to enroll and remain in the study. Participants who had only recently entered the HVT drew more on their feelings concerning initial enrollment, while those who had been participating longer drew more on their ongoing experiences as well, but the two groups did not appear to differ in any major or systematic ways.

Altruism

Under the broad heading of altruism, we identified ten different "typologies": cultural, community, familial, professional, religious, political, experiential, moral, existential and psychological. Most participants did not have a single motivation, but instead, a combination of different motivations.

Cultural—Several participants cited cultural sources – generally related to the culture in which they were raised – for motivations for helping.

> I think it's based on a cultural thing, because of being Filipino, it ties to that. Culturally, it's very important that we give back to the community – help out people that are unfortunate. (**#4**, **A**)

Conversely, participants were motivated, too, by negative perceptions of the broader mainstream community and culture of which they were a part. Perceptions of selfishness more broadly within mainstream culture can also fuel altruism. "One of the reasons why I wanted to be involved is that it's such a 'capitalism, me me me' world that no one cares unless it's them…and by then it's too late." (**#2**, **A)**

Community—Relatedly, participants often mentioned their desire to help their current communities as a motivation. However, these respondents conceptualized and defined their community differently. As MSM, many distinguished in some way between the community in which they had been raised, and the one(s) in which they now lived or participated. Moreover, they often felt that they now belonged to more than one community per se – several of which they wanted to assist.

> I am helping my community, as far as gay men, black gay men in the community I live in, the poor community…I'm here, I'm all of those. I've got to be helping one way or another. (**#10**, **AA**)

Several individuals felt, however, that every little bit could be beneficial – that cooperative efforts were needed to reach a common goal.

> It's the trickle-down effect. Eventually, it will help everybody. So, I do feel like it's going to help. But if you've got only three people of a community of 10,000 helping, the community isn't going to get any help. (**#9**, **AA**)

Some informants viewed engagement in the HVT as a community activity – with each individual's participation serving as one tiny piece of a much larger need. Some respondents readily acknowledged and accepted that their participation in the large collective endeavor of a vaccine trial was likely just one small step in a lengthy process:

> No one is expecting this specific vaccination to be the miracle vaccination that cures all by any stretch of the imagination. But it does seem like a stepping-stone on the way there… (**#3**, **W**)

The step of participating in an HVT could benefit not just themselves, but their community more broadly.

This form of altruism can be especially strong since the HIV epidemic has severely hit the communities of which these men are members.

> I was really interested in the HIV vaccine trial for several reasons. One, I feel like HIV affects the African-American male community much more drastically. (**#16**, **AA**)

Familial—Some respondents described their altruistic behaviors as stemming from their familial background. This impulse could arise from implicit or explicit parental teaching. ("It's really important that everybody does something to give back to the community, which is something my mother always kind of instilled in me." [**#7, W**]) Parents communicate this value in a range of ways from indirect to direct – through example or explicit statements. One informant, for instance, described his parents as being "…socially involved in the community." His mother also admonished him:

> My mom was like, "Most people aren't lazy welfare bums. Most are down on their luck." We pay taxes because we have more. We are going to help them. Because what happens one day if you're down on your luck? What if you have to get on welfare?" (**#2**, **AA**)

His mother taught him the importance of helping others because it might improve the likelihood of reciprocity in the future.

Such altruism might be instilled not by a family as a whole, but rather by one parent alone, and might be related partly to organized religion.

> My mother was a church-going, God-fearing woman, so that's how she raised me. But my father: he does the helping, but help yourself first, and then worry about helping somebody else. (**#15**, **AA**)

This participant roots the familial basis of his altruism in his mother's religious beliefs, which shaped how she raised him. Thus, in many instances, familial, religious, and cultural

sources of altruism can be intertwined and fully distinguishing between them can be difficult, if not impossible.

Religious—As suggested earlier, some respondents felt that religion in their early family environment as motivated their altruism. Yet, bad experiences with religion could motivate altruism, too, as a personal response to perceived bias by some religious practitioners. Individuals observed hypocrisy in religion that led them to live in more spiritually or religiously engaged ways. The hypocrisy perceived by one participant, for instance, made him feel that people are not generally willing to put others' interests ahead of their own. This realization motivated him to behave differently, and to try to help others.

> My parents were Jehovah's Witnesses. What was challenging for me was that that environment was very hypocritical. I'd sit there, and they talked about love your neighbor as you love yourself. And then they turn around, and lived down the block from us and don't invite us to dinner. I grew up, and realized: it's a nice theory, to do good for everyone else…But most people aren't going to – they're not going to want to do that. (**#2**, **AA**)

Similarly, conservative homophobic religious views can also motivate altruism:

> I was raised Italian Catholic. I have a lot of resentment toward the Catholic Church, and society as a whole – how they treat people in the LGBTQ community. So I was not able to be who I was at an age when I should have been – which makes me sad. So it's very personal to me. It's not about me or my future, but more about the future, the next generation to follow – if I can help out in any way. (**#13**, **W**)

Professional—Being or knowing a healthcare professional, especially in one's family, also motivated a number of respondents. One participant attributed his appreciation of the need for research participation to family members who work in healthcare, such as, "his uncle and cousins, who learn a lot from studies like this, a lot about diseases and how to prevent them, like how to find cures…" (**#4, A)** These family members inspired participants**.** ("Most of time when they come home from work, they're talking about how they help people or what happened." [**#18**, **AA**]**)** These informants, most of whom were in their early 20s, and several of whom were unemployed or underemployed, were thus able to feel gratified, like their relatives in healthcare, by helping others.

Political—Political considerations can also motivate HVT participation. The epidemic has affected both the US and many nations around the world more broadly, and some participants see this epidemic in political terms. ("The HIV virus is getting very bad in the country, very bad in the world generally." [**#1, W**]) Participants perceived global injustice since the epidemic disappropriately affected poorer countries.

> HIV and AIDS is just an incredible threat to the global population and certainly in underdeveloped countries. It's just running wild, and unfortunately very little is being done. (**#17**, **W**)

For one participant, taking part in a HVT followed from his ongoing participation in HIV/AIDS political activism. One set of potential involvements can thus precipitate others in a similar realm.

> I felt like somebody needs to do something. I started working more formally in [HIV/AIDS organization] trying to educate people, and just helping out people. Then I started volunteering with a center for HIV law and policy.…any little thing I could do. Participating in this [study] was like the next step. We wouldn't have had vaccines for anything if people didn't participate. Somebody has to do it. **(#2, AA)**

Respondents felt that HVTs were empowering, and could be of worldwide significance, even leading to global change. ("I feel that by participating in this, I could be contributing to, to something that could change the world eventually." [**#3, W**])

Experiential—Several respondents described intimate personal experiences with HIV/AIDS among themselves, close friends and family members as furthering a key source of altruism as well. "Why did I decide? I have a lot of friends; I know a lot of people that have HIV. It might help them." (**#12, AA/L**)

Specifically, many participants have witnessed the horrors of the disease, both medical and social (e.g., stigma), and chose to participate "because my parents have had friends that had HIV. I've been around it. The stigma is the worst of it." (**#5**, **AA)**

Several men experienced HIV/AIDS closely in their immediate or extended family or community.

> My dad works with a lot of bands. A band that he was working with for many, many years were all like my uncles. The drummer ended up having AIDS. So he was kind of like an uncle. We all slept on the same tour bus. So it was real close. (**#5, AA**)

He explains that had it not been for this experience, he probably would have not participated in this study:

> I wouldn't have wanted to do the research, except for the fact that there is so much misconception and stereotype about AIDS. I was able to see up-close and personal how this person was able to function. If you looked at him, you'd never know. I'm like, oh, okay. (**#5, AA)**

Moral—For some informants, HVT participation was a means for atonement or making up for past wrongs in their lives. Several of the respondents who expressed these attitudes were in 12-step recovery programs and/or had been in jail. ("I did too much wrong. If I could give back to the community or help the community with a cure or something, I did my part." [**#11**, **AA]**)

A sense of balancing moral scales arose – of possible ultimate redemption:

> At least I did something before I passed or moved on. I wasn't a really bad person; but you know, everyone has their flaws. So I figured: try and even out the scale a little bit. (**#11**, **AA**)

Participation in the HVT can itself represent an explicit form of atonement:

> I've been part of negative stuff all my life. I ran the streets for a long time. I did drugs so many years. I tore down my community. I sold and did a lot of drugs. I hurt a lot of people. So eventually, I mean: I don't do nothing negative no more, so I'm going to be part of something positive. Now I want to help. (**#9**, **AA**)

He goes on to express regret about not just past things he has done, but also the past loss of opportunities to explore and reach his potential in the. He continued that, "Sometimes, I feel like I could have changed things. I'm not Martin Luther King or Malcolm X. I just feel I could have made a difference." (**#9**, **AA**)

This desire can affect fundamental issues of one's identity – how one sees oneself as a person. Another informant said,

> Sometimes I just do these small little things, like treating my parents not as good as I should have… regrets that I wish I hadn't done this in the past. None of us are perfect. We all have things we feel we could have done better with, so I feel like doing this study, doing good things, helps you become a better person. I think that the better person you are, the better. No one wants to have a world full of bad people. So, I guess, doing good things contributes to a better world. (**#14**, **W**)

Existential—Related to this sense of moral behavior, participation in HVTs appealed to individuals as a means of providing a sense of larger meaning and purpose. Some participants felt motivated by the prospect of being a part of something greater than themselves, of potentially wider importance:

> It is bigger than myself. It's bigger than a lot of people. Bigger than you. Bigger than all of us. It's real. It's not fake. It's something serious that a lot of people died from. (**#11**, **AA**)

Participation offered these individuals a vital sense of purpose and personal fulfillment.

> I am helping a cause. Because I think I have a cause. Because my cause is to educate the LGBT community, to make life easier for us. If I can help in some ways, in a small, small way for vaccination for HIV, I just – whatever I can do, I want to do. (**#13**, **W**)

Other Psychological/Emotional—These men described how participating and following these varied altruistic impulses generated and/or took the form of emotional gratification, manifesting itself as feelings of pride about contributing.

> It's *very* fulfilling for me. I would not feel proud of participating in a study on the effects of sugar on people. I don't really boast about being in this, but I'm very proud of being in this. (**#3**, **W**)

Given the uncertainty of the HVT outcome, informants wrestled with how much they could feel pride in their participation. Some hope to feel emotional gratification to be part of a heroic feat, if the vaccine is to found effective. One respondent who had regretted earlier actions in his life added,

> This would be interesting, if they actually do come up with something. I might just…tell people that I did it… that I'm the reason why they got the cure. (**#9**, **AA**)

He made these statements perhaps jokingly, but suggested the emotional gratification he derived, or hoped to derive, from participation. ("I've done so much negative in my life, that it actually… it makes me feel like I'm doing something. At least I could tell my kids, I was a part of something positive." [**#9, AA**]) His motives are partly moral – making up for past wrongs – but he suggests that he also seeks personal emotional gratification and desire to have a legacy, more than a larger, more abstract moral sense of justice.

Other respondents similarly expressed their desire for self-esteem, and to be highly regarded. Since many of these informants' lives are in transition, they were often especially glad to have a sense of pride, and of being seen or treated as special. At times, they, too, spoke half-jokingly, reflecting in part uncertainty about how realistic this goal was, given that one person's participation represents a small, though still important part.

> What made me feel the best, though, like I was the first person from this area to enroll in this study. I was like a superstar. Everybody wanted to see me. I'm just doing my little part to help, hopefully to find a vaccine. (**#15**, **AA**)

Another man added, "I wanted to be a part of it. Maybe my name will go up somewhere as a part of this." (**#8, AA**)

Financial

Respondents at times also mentioned financial compensation as a factor in decisions to participate, but such monetary gain generally did not appear as sufficient in and of itself for entering and remaining in the study, and several informants said they would have participated even if there was no compensation. As seen in Table 1, these men each readily fit into one of four mutually exclusive categories concerning financial compensation. Specifically, compensation had no effect on participation for 55% (n=11), was an added incentive for 25% (n=5), a main motivator but in conjunction with altruism for 15% (n=3), and the primary motivator for only 5% (n=1).

Overall, the fact that many of these men were unemployed or underemployed or in transition affected them both directly and indirectly. As indicated above, given the lack of stable work or relationships, participation in HVTs often in fact provided a source of meaning for them. Given this relative lack of stability, compensation itself might have been very motivating, but the amounts of compensation were not extremely high.

For 15% of participants, altruism and compensation played mutually-reinforcing roles. Neither was necessarily sufficient in and of itself. As one participant said:

> At the beginning, it was pretty much for extra spending cash. But I chose this particular study because my parents have had friends that had HIV. So I said, it's pretty much a win-win. Win-win as in I know that I would be doing something that I support, and I would also make a few extra bucks from it. (**#5**, **AA**)

Compensation was generally not a motivator by itself, but rather, in conjunction with other considerations. ("I was unemployed and needing the money. That was why. I'm not going to lie about that. And at the same time, I know a lot of people with HIV." [**#9, AA**])

Funding, though not a deciding factor, was often nonetheless appreciated. ("I was not here for the money, although I am unemployed right now. So, it doesn't suck." [**#13, W]**).

Yet with other participants, compensation was an insufficient motivator in and of itself. ("I probably would've still participated even they weren't paying me." **[#7, W]**)

Some explicitly said that compensation was not in any way a consideration, and that

> Initially, when I decided to participate, I didn't even know you got paid for it, so that wasn't a factor. Compensation never even crossed my mind at the time. Just the fact that I wanted to help." (**#14, W**)

Most saw the potential social benefits of the HVT as outweighing the compensation. ("I would still do it, because of the fact that this vaccine trial is a way for us to try to determine whether or not we can actually find a vaccine." **[#6, L**])

For a few participants, financial benefit was not a significant motivation for entering the study, but served as an additional incentive to maintain follow-up appointments. ("I probably would have done it for free. But that definitely gets you to the appointment." [**#2, AA**])

Compensation can serve to provide extra incentive to adhere to various aspects of the protocol:

> It motivates you to show up on time. If you feel you're not being compensated, it's like you can start taking liberties with the responsibilities that you have (**#20**, **W**).

Compensation also serves as an appreciated acknowledgement that one's time is important:

> The amount of money that I end up getting from this study, is not even really pocket change. It definitely does make me feel that at least my time is valuable, which does make me feel good about missing two hours of work – that I'm getting paid something for missing those two hours of work. (**#3**, **W**)

Discussion

These data suggest that a wide variety of types and sources of altruism, and of financial attitudes, reflecting key aspects of prior and ongoing lives, can motivate HVT participation. Altruism emerges here as a complex phenomenon, with several critical aspects. Specifically, these data suggest ten broad types of altruism– cultural, community, familial, religious, professional, political, experiential, moral, existential, and other psychological/emotional – though these were not mutually exclusive. Financial compensation, too, frequently served as

an added incentive, though it usually appeared insufficient in and of itself. Both altruistic motives and compensation affected both entrance into the study and continued participation in follow-up visits over time. Belief that HVTs may be effective and have broad social benefit helped motivate these informants, but different individuals may be compelled by different types or aspects of such presumed social benefit. The perceived potential success of studies can also influence motives for, and rates of, participation. Broad public and community education about the results of ongoing studies can thus be highly important.

The types of altruism that emerged here vary in certain regards, but can nonetheless be seen as falling across a spectrum (e.g., from relatively more outwardly to more inwardly motivated). These types vary, too, in how much they may be significantly formed in childhood vs. adulthood.

In contrast, prior individual studies have tended to view altruism as a simple unidimensional entity. While Dhalla and Poole (2014), in their descriptive review of 12 studies, conceptualized altruism as divided into three categories based on its outward manifestation – as microsocial mesosocial, and macrosocial (which includes moral) – and as separated from personal benefits, the present data highlight further critical aspects, dimensions and complexities involved. Altruistic and personal issues appeared here as often closely entwined. An individual may want to engage in any of these three “social” categories (e.g., microsocial, mesosocial, or macrosocial) because of various underlying personal reasons (e.g., need for personal meaning). “Moral” motivations can also be not only “macrosocial” and “mesosocial”. For instance, participation in an HVT because HIV has affected one’s close friends can be both “mesosocial” and moral. Similarly, participation to find an effective vaccine may be “macrosocial”, but also result from desires to aid one’s community, which these authors categorize as “mesosocial”.

Hence, lumping disparate types of altruism into only three broad categories, and separating out psychological motivators appears to blur and lose critical distinctions and differences between several phenomena. These data suggest that underlying sources and more outward manifestations of altruism can differ, and are critical to distinguish; and that these underlying sources are vital.

HVT participation can also constitute an indirect form of altruism as it does not necessarily provide clear or immediate benefits to others, since vaccine efficacy by definition remains unknown, and participants may be unsure exactly how their HVT participation would help. The decision to participate is generally based not on outcome per se (e.g., necessarily finding a vaccine), but rather on intent to help.

Altruism has been defined and viewed differently in other disciplines (Fehr & Fischbacher, 2003; Hoffman, 1981; Krebs, 1970; Monroe, 1994; Piliavin & Chaing, 1990; Rand, 1982; Simon, 1993) as well, often seen as varying across as a spectrum from strong (purely altruistic) to weak (purely self-interested [Krebs & Van Hesteren, 1992]), but the present data illustrate other critical dimensions and subcategories. Specifically, a variety of sub-categories or typologies appear to exist in practice that can be important to recognize. Altruism can vary in its sources and manifestations (e.g., cultural, religious, moral, political,

existential and/or other) and in the degree to which it entails each of these. In the lived lives of these individuals, philosophical dichotomies extensively discussed in the past literature (i.e., whether altruism is ultimately selfish or not) do not appear to readily apply. Rather, the present data highlight how altruistic behavior can reflect both larger desires to help others as well as personal gratification (e.g., providing sources of meaning and satisfaction, and opportunities to atone for past wrongs), and consists of several subtypes.

While compensation is often cited and assessed as a motivator among participants in HVTs (Colfax et al., 2005; Gray et al., 2008), how participants view compensation relative to other motivating factors has not previously been examined. Compensation as a motivator has been assessed with various methods, often using a binary (yes/no) question (Gray et al., 2008), a presentation of different possible amounts of payment (Dunn, Kim, Fellows, Palmer, 2009; Halpern, Karlawish, Casarett, Berlin, Asch, 2004), or a single Likert scale (e.g., from strongly agree to strongly disagree on it being a consideration) (Colfax et al., 2005).

Yet the present data highlight how respondents frequently weigh and combine a variety of complex factors in their decisions to participate in a study. The four-category typology of roles of compensation we present here (from having no effect on participation, to being an added incentive, to being a main motivator but in conjunction with altruism, to being the primary motivator) may be useful in future studies on participation in HIV and other studies.

Research Agenda

These data have several implications for further research and scholarship, suggesting needs to consider the depth, breadth, complexity and inter-relatedness of these concepts, and types of participants' motivations. Future studies can examine, for instance, whether, how, and how much each of these types of altruism may be differentially associated over time with enrollment, retention, and adherence in various kinds of studies. Research can also explore, among larger samples, how the typologies here may be associated with factors such as gender, socioeconomic status, education, ethnic/racial, cultural or religious background, sexual orientation, and specific types of health behaviors or decisions. Future research can more fully examine, too, potential roles and importance of compensation as a motivator – particularly, how participants weigh compensation against altruistic benefits (e.g., whether participants are willing to accept less compensation for higher altruistic benefits or vice versa), and whether social desirability may be associated in any way with responses to questions about these issues and if so, to what degree. Research can, for instance, develop and assess recruitment messages informed by different kinds of altruistic statements from participants – for instance, statements from men who feel that participation allows them now to "atone" for past mistakes that they feel they have made in their lives.

"Best practices"

These data have critical implications for future practice. IRBs and researchers may focus only on direct benefits, but may want to consider the possibility that participants may view, conceptualize, seek and value benefits more widely – i.e., altruistically. These data suggest that individuals may participate in studies because of perceived benefits not directly to themselves, but indirectly to their communities. Still, this distinction may not always be

clear-cut, and individuals may see benefits to their community as well as to themselves in various ways. Researchers, IRBs and others may benefit from investigating and paying more attention to these issues; for example, how respondents of diverse socioeconomic, ethnic and racial backgrounds may perceive motivations for study participation differently.

Enhanced comprehension of participants' perceptions of research can help IRBs and researchers ensure that enrollees are understanding and entering studies for appropriate reasons, with full informed consent.

Knowing why participants enroll in a study can also help researchers in appropriately improving both recruitment and retention. Though prior research has suggested that interventions aimed at prevention of HIV and other diseases might consider efforts to recruit participants from communities that are wary of research by mentioning altruism; the present data highlight potential benefits of articulating not a unitary notion of altruism, but instead considering each or all of the different types here, emphasizing particular types, depending on the specific population. This approach should in no way be used to unduly influence or manipulate respondents, but instead, could enhance subject and community understandings of potential benefits of important studies that can aid communities, and thus these individuals' health and well-being.

Educational Implications

These data suggest needs to enhance the education of researchers, IRBs and potential study participants and communities about these issues, to assist with appropriate conduct of both research and participant protection by aiding ethically-proper recruitment and participant retention.

This study has a few potential limitations. We interviewed high-risk MSMs, but not other populations (e.g., heterosexual men and women), whose motivations for study participation may differ. However, we believe that the broad typologies of altruism identified here may arise with other groups as well, though potentially with some variations. Future studies can explore these possibilities. As shown on Table 1, 80% of participants had some college education, but many were unemployed or under-employed, which may have affected their willingness and ability to participate in this interview study, and the HVT. Their relatively-low employment status may have given them less purpose and self-esteem in their lives, prompting them to seek to participate in a meaningful activity, which these studies served to do. Yet these groups of men of relatively lower socioeconomic status are at increased risk for HIV, and their attitudes are thus extremely important to understand through research. Nonetheless, selection bias is possible in all research, and may have occurred here, related to socioeconomic status, and can be probed more fully in further research. Participants did not indicate that their motivations changed significantly over time. Respondents described their motivations in the present – rather than in the past – tense, seeing their enrollment, entrance and ongoing participation in the study as part of a continuum. In their perceptions and lived experiences, informants did not differentiate between these phases of study participation. Nonetheless, much larger future studies among participants in other settings and studies can explore the possibility of such changes. It is conceivable that individuals who dropped out of the study may have experienced initial recruitment and ongoing participation in the study

differently than did these informants (who stayed in the protocol), however, such individuals could not be interviewed (since they had dropped out).

It is possible that social desirability played a role here – i.e., that respondents may have been reluctant to report purely financial motivations. Yet, participants readily discussed altruism without prompting, and with strong emotional convictions. Most gave compelling reasons why compensation was not significant by itself for them. Participants appeared to report their motivations in forthright and accurate ways. Most informants viewed the amount of compensation as nominal (an added bonus), but not the primary motivator for participating. Future research can explore these issues more fully, too.

In sum, understanding reasons for enrolling in research can potentially shed light on key aspects of these motivations, and enhance appropriate recruitment and retention of research participants.

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Appendix A: Sample Questions from the Qualitative Review Guide

- How did you come to be part of the vaccine study? How did you hear about it?
- Why did you decide to get involved?
- What factors influenced your decisions to enter the study? To remain in the study?
- Did financial factors affect you? If so, how?
- What other factors influenced you in deciding to take part in the project?
- What information was helpful to you in deciding to take part in the study?
- Some people decide before walking in the door. When did you actually decide to take part in the study?
- What do you see as the possible benefits of being in this study?
- Why do you think others choose not to participate in the vaccine study? What makes you different?
- Has being involved in the vaccine study affected your life? If so, how?

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Table 1

Subjects' demographics and perception of compensation as a motivator

Subject Number	Age	Ethnicity	Educational Attainment	Category of Work	Role of Compensation as a Motivator
1	33	W	College student	Blue collar	Added incentive
2	28	AA	College graduate	Professional	Added incentive
3	23	W	College graduate	Blue collar	Not a motivator
4	32	A	College student	Not Working	Not a motivator
5	23	AA	Some college	Blue collar (Part-time)	Main motivator in conjunction with altruism
6	29	L	Some college	Not working	Not a motivator
7	27	W	College graduate	Professional	Not a motivator
8	42	AA	HS/GED	Blue collar	Added incentive
9	39	AA	Some college	Not working	Main motivator in conjunction with altruism
10	41	AA	HS/GED	Blue collar (Part-time)	Sole motivator
11	44	AA	HS/GED	Blue collar	Not a motivator
12	28	AA-L	Some college	Blue collar	Not a motivator
13	45	W	College graduate	Not Working	Not a motivator
14	27	W	College graduate	Professional	Not a motivator
15	43	AA	HS/GED	Not Working	Not a motivator
16	29	AA	Graduate degree	Professional	Not a motivator
17	48	W	Some college	Not Working	Not a motivator
18	47	AA	Some college	Blue collar	Main motivator in conjunction with altruism
19	45	AA	College graduate	Blue collar	Added incentive
20	43	W	Graduate degree	Skilled Labor	Added incentive

Note: A = Asian; AA = African-American; L = Latino; W = White

TABLE 2

SUBJECTS' MOTIVATORS FOR PARTICIPATION IN HIV VACCINE TRIAL

Motivators for Participation	
Altruism	**Typologies of Altruism** • Cultural values that altruism is important • Community – community values giving back to and helping the community • Familial – family taught that helping others is important • Religious – related on personal religious upbringing • Professional – being a healthcare professional or having family or friends who are healthcare professionals • Political – activism in response to the HIV/AIDS epidemic • Experiential – personal experiences with HIV/AIDS • Moral – making up for past wrongs in life • Existential – provides a sense of meaning and purpose • Other psychological/emotional – obtaining emotional gratification
Financial	**Role of Study Compensation** • Sole motivator • Important motivator in conjunction with altruism • Added bonus but not a main motivator • Not a motivator