Compensation in Medical Research: Is Money the Problem?

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ABSTRACT

The ethics of compensating research participants is perpetually debated, with opponents claiming that compensation is coercive. Yet coercive financial arrangements are commonplace, such as in the labor market where employees perform tasks in exchange for money. This article compares research participation to another risky profession – firefighting by examining four key areas: risk level, motivations, worker protections, and societal benefits. While firefighting is heralded as a noble profession, compensation for participating in research is looked upon with scorn. To protect participant autonomy and avoid paternalism, participants must also make their own decisions, even if that decision is to participate in exchange for money.

INTRODUCTION

When reviewing research protocols, Institutional Review Board (IRB) members determine whether an investigator has selected an appropriate level of compensation for study participants. One of the arguments against providing too high a level of compensation is that the promise of financial gain will entice a potential participant to make a different decision than what they would have made in the absence of compensation. Perhaps the debate should not be whether money changes a person's behavior, but whether it is unethical that money have that effect.

As many scholars have pointed out,[1] we live in a world that is full of financial enticements. Financial compensation is the basis of our labor market in which individuals perform tasks in exchange for money. Just as in research, financial compensation in the labor market is used as motivation for a person to complete a task that they would be unlikely to do in the absence of compensation.[2] The purpose of this article is to critically compare medical research participation to another risky profession, firefighting, in four key areas: level of risk, motivations, worker protections, and societal benefits.

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DISCUSSION

I. Level of Risk

While not all employment situations come with an assumption of risk, firefighting is one that is inherently risky. The risk is offset by a high level of societal benefit and financial reward, resulting in an overall positive risk-benefit ratio. In general, firefighters are held up as heroes and revered for their service. In many medical research studies, study participants assume a certain level of risk in turn for compensation. Yet the attitude of reverence does not extend to paid research participants. When tragedy strikes in a clinical trial, rather than respectfully upholding those who were harmed as heroes, monetary compensation is scrutinized. Following the tragic TGN1412 trial, Ezekiel Emanuel stated that "almost all press reports and commentaries have mentioned that the healthy research participants were paid £2000 for enrolling in a phase one trial of a new agent produced by a for-profit company, as if this necessarily signified the trial was ethically questionable."[3]

The discrepancy in responses following a tragedy illuminates the different ways in which the contributions of firefighters versus clinical research participants are viewed: fallen firefighters are upheld as heroes in the wake of tragedy whereas, clinical research participants are not. While the participants are not necessarily criticized, suggestions are made that the participants were recruited using unsavory methods. The structure that pays firefighters is not subject to similar scrutiny for enticing them to take risk.

II. Motivations

Firefighters and clinical research participants have similar motivations for offering their service. While some firefighters assume the role because of a sense of altruism,[4] others choose to pursue firefighting as their profession. Receipt of financial compensation for their services does not diminish the nobility of their action. Among career firefighters, it is reasonable to assume that they may have made a different choice if there were no payment, yet rarely is a firefighter's salary seen as coercive.

Similarly, research has shown that many research participants join clinical trials due to a sense of altruism,[5] yet many others do so for financial compensation. Even among those primarily motivated by financial gain, many factors play into their decision.[6] Both firefighters and clinical research participants accept financial compensation for their service, yet it is only research participant compensation that is viewed as coercive.

III. Worker Protections

It is possible that financial compensation for firefighters is not questioned because their profession is vital. Despite our best efforts, buildings will continue to catch fire and firefighters will put themselves in harm's way to protect others. Due to this inevitable risk, organizations such as the Occupational Safety and Health Administration (OSHA) have been established to ensure that the risks to firefighters are minimized as much as possible.[7]

Medical research similarly relies upon IRBs to minimize risks, assess protocol safety, and protect participant rights. Prior to any medical research being approved, the IRB reviews the protocol to ensure that the benefits justify the risks and that all ethical guidelines are followed.[8] It would be preferable for neither firefighters nor research participants to be put at risk, yet fires will continue to occur and new drugs will continue to be clinically tested.

IV. Societal Benefits

A common concern is that research participants are unlikely to receive the benefits of the drug post-approval.[9] There is no concern that firefighters' services do not benefit the firefighter directly. Both clinical trial participants and firefighters assume risk for the benefit of society as a whole, yet research is viewed with skepticism. There is no reason the assumption of risk should be evaluated by such different standards.

While the principle of justice dictates that no one group should bear the burden of the risks,[10] this should not be interpreted to imply that a violation has occurred if the participant is unlikely to benefit directly.[11] In fact, one of the key distinctions between medical research and medical care is that the goal of research is to expand knowledge rather than provide direct benefit, a fallacy called the therapeutic misconception.[12]

There are systematic differences in the protections provided to traditional employees compared to research participants. For example, research participants in phase one trials are considered independent contractors and are exempt from the benefits provided to employees, such as workers compensation or disability and health insurance.[13] While this point is appreciated, this is more a critique of the gig economy[14] than of the ethical implications of compensation in clinical trials.

V. Synthesis

This comparison indicates that in society it is acceptable for individuals to assume risk in exchange for financial compensation. However, in clinical research this acceptance dissolves. While a literature review may reveal the reasons for unease surrounding financial compensation in medical research, it is more important to assess who is voicing this dissent.

The debate over whether and how much research participants should be paid has been going on for decades.[15] Much of this debate occurs at an academic level. Ethicists and clinical researchers have debated what is most appropriate for the participants *ad infinitum*.[16] However, the research fails to elicit the attitudes of study participants and non-academics. Among sparse literature, the focus has been on the general motivations of study participation,[17] with only sporadic studies featuring participants' views on financial compensation.[18]

It is important to recognize that concerns surrounding financial compensation arise within the research and academic establishment not from participants themselves. This suggests that researchers hold the view that clinical research is inherently exploitative. The concern for exploitation arises despite preventive measures including a thorough review of protocols by the IRB prior to implementation and the informed consent processes in which potential participants are provided all necessary information. While there exists the possibility that the informed consent process does not properly convey all relevant information or that the IRB review is not sufficient, these are separate issues which do not directly apply to the question of financial coercion.

CONCLUSION

Clinical researchers should accept the autonomy of potential participants, leaving them free to make their own choices. Just as firefighters are free to conduct a risk-benefit assessment to determine whether or not to engage in a risky profession, potential research participants should autonomously assess the risks and benefits of participation. To believe otherwise amounts to paternalistic, patronizing behavior.

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