The Homeless as Human Subjects

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During my senior year of high school, on a bitter Saturday morning in January, I found myself at the entrance to the Boston Common assisting other volunteers from the Sock Exchange charity in organizing food and clothing for distribution to the homeless of the city. Here, just steps away from the Massachusetts State House, resides a large population of Boston's homeless, who always look forward to the first Saturday of each month to receive a sandwich, clothing, and human interaction from the Sock Exchange volunteers.

That week I was on toiletry duty, distributing dental and personal hygiene products to our patrons. As I was restocking the floss and toothpaste, a figure stepped into my peripheral vision, causing me to glance up for a moment. Though several feet away, it was clear that he was out of place; he was bundled up from the cold, except for his hands, which were holding a clipboard and pen. He was not a fellow volunteer, nor a regular patron, but he was engaged in conversation with one of our frequenters. "That's odd," I thought to myself, "I wonder what he's selling." Just as I noticed the stranger, so did Andrea, the program leader, and she quickly hurried over to interrupt the *tete-ta-tete* and angrily shooed the man away. "Recruiters," Andrea said rolling her eyes once back at the stall. "Like for job hiring?" I asked. "No," she replied, "to be a guinea pig."

At the time, I did not understand Andrea's adverse reaction to seeing the recruiter, nor the extent of the role that homeless individuals play in research. After participating in ethics and bioethics courses, the nature of the situation became apparent to me.

In the realm of pharmaceutical research, an increasingly popular phenomenon is the employment of the homeless for the experimentation of new drugs, often antipsychotics. The rationale derives from the fact that drug companies need mentally ill subjects for testing, and the homeless population provides an ample and available subject pool (Elliot). Recruiters, like the

one from my anecdote, visit known places of congregation for the homeless: shelters, underpasses, and, apparently, the Sock Exchange and similar charitable events. The personal contact is crucial for recruiters, as it allows them to perform their salesmanship skills through the offering money and hospitable lodgings for the duration of the research study to try to persuade them into participating. One participant reported that the "recruiter made testing drugs sound like a vacation in a five-star hotel," as they described only the benefits but none of the hazards that come with drug trials (Elliot). These drug studies can pay upwards of \$2,500, which, for an economically disadvantaged population, can prove to be a strong incentive and is often the motivation behind why these individuals participate.

Today, the idea of monetary compensation is less controversial and less ethically questionable than it once was not long ago. Prior to now, paying research volunteers "was seen as problematic and, even more so, if the subjects were poor, uninsured and compromised by illness," generally the situation of a homeless individual (Elliot). With the transition of medical research into the private sector, the ethical attitude toward compensation also changed, seen with the stark increases in payment amounts, which can be well over \$6,000 (Elliot). Though some may interpret this as a simple business transaction with no ethical dilemmas, I find this to be particularly troubling, as such high compensation can be compelling for the homeless, who are economically disadvantaged and may not be able to make these types of decisions alone due to their vulnerable mental state. For example, the effect of compensation can go beyond pressuring the homeless to participate, but can instigate the taking of drugs or addictive substances just to be eligible for a study and receive payment (Elliot). In this way, I find that targeting the homeless with these methods proves to be an ethical issue in research.

To help protect humans from unethical practices and harms incurred by research, four bioethical principles were developed, first by Beauchamp and Childress and then expanded on in the Belmont Report. The principles of autonomy, beneficence, nonmaleficence, and justice have transformed the approach to ethical research involving human subjects, and can be used to analyze the treatment of participants. I believe the principles of autonomy and justice prove most useful to examine the ethics of the practice of targeting the homeless for drug trials.

As outlined in the Belmont Report, respect for persons involves treating individuals as autonomous agents and protecting those with diminished autonomy. Those with diminished autonomy are those "not capable of self-determination" which could result from illness or mental disability, and because of this, there is an obligation to protect them and their autonomy (Belmont Report 4). Though not all homeless individuals suffer from mental illness, a portion does, and they often are unable to receive the medical treatment they need. Recruiters scouting homeless shelters purposefully seek out these individuals, because they need participants with such afflictions and know that they can take advantage of their situation. But, who then is protecting the homeless individual's autonomy, and thus ensuring that they are respected as persons? There is no proxy nor guardian to act in their best protective interest, nor even to accurately and easily explain information about the study and its effects.

As such, the homeless population needs protection from undue influence, which "occurs through an offer of an excessive...reward or other overture in order to obtain compliance" (Belmont Report 8). I find that in this issue the undue influence is the large sums offered as compensation for participating. When dealing with a vulnerable and economically disadvantaged population, like the homeless, offering large amounts of money as payment is an undue influence on their decision making, since if not in their current financial state, they may

otherwise not consent to testing, as they would not be as desperate for money. These individuals are "at their lowest state, and they'll say yes to anything" when facing this possible income (Elliot). Researchers are exploiting others' economic desperation. Furthermore, even though offering money may be ethically acceptable for populations with full autonomy, it is still an undue influence on the homeless, since they, particularly those with a mental illness, have diminished autonomy, are not being protected, and are particularly vulnerable to this type of economic incentive (Belmont Report 8). These practices of recruiting and unduly influencing the homeless disrespects them as persons, and thus is unethical.

The principle of justice can also be used to analyze the ethical issue of targeting the homeless for research purposes. Justice deals with "who ought to receive the benefits of research and bear its burdens" (Belmont Report 5). An injustice involves a burden being imposed unduly (Belmont Report). Recruiting heavily from the homeless population to test pharmaceuticals places an undue burden on the group. As previously mentioned, one of the reasons the homeless are preyed upon for these studies is because of the high rate of mental illness present within the population (Elliot). They are being "systematically selected simply because of their easy availability [and] their compromised position" (Belmont Report 6). But, mental illnesses do not only manifest in the homeless. Mental illnesses are prevalent throughout society, regardless of socioeconomic status. Because of this, an undue burden is placed on them. Additionally, the homeless will most likely never experience the benefits from their participation in the study, as they have limited access to healthcare and lack funds to afford the tested drug. The burden, then, is disproportionately falling on the poor, while the benefits fall on the wealthy. According to the principle of justice, it is apparent that the targeting of the homeless for their participation in research studies is an injustice, and is subsequently unethical.

Thinking back to that cold winter day, I now understand Andrea's aggressive reaction towards to recruiter and her desire to protect those in need from him. She was, in a sense, acting as a de-facto proxy, a role that this population desperately needs in these situations.

The idea of researchers seeking out the homeless in shelters and offering them lump sums for participation in studies seems to me inherently problematic. In difficult and desperate situations, such as homelessness, it is only natural for one to do what is necessary to survive. But, in my view, these researchers are preying on and instigating these vulnerable people into putting their lives at risk. To respect their personhood fully and act justly, while also allowing for their ethical participation in research, there should be extra restrictions and guidelines when involving the homeless. Admittedly, not everyone may share my perspective. Fortunately, the bioethical research principles of autonomy and justice assist in guiding the normative judgment that the practice is an unethical one. It is my hope that in the near future, more attention will be given to the unethical research practices inflicted on this marginalized population, which will then result in better protections for them.

Works Cited

- The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects in Research
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