What do Researchers Owe the Researched?

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Introduction:

Beginning in 1984, Frank Plummer established a relationship with commercial sex workers in an urban slum of Nairobi Kenya, called Pumwani.[1] The observational cohort study followed 3,000 commercial sex workers in an open cohort to follow their Sero-conversion to HIV through consistent exposures.[1] Even though women in the study were exposed to HIV four or more times a day, a small group of women never sero-converted to HIV. At one point in the study, approximately 110 women remained uninfected with HIV despite up to 500 exposures.[2] The study has gained global attention, with millions in funding, and landmark discoveries in the HIV/AIDS field. Plummer's team discovered that HIV can be transmitted through breast milk and established a link between co-infections and increased risk of HIV contraction.[2] The study has been on-going for over thirty years, and approximately sixty women remain uninfected with HIV.[1] Hawa, a member of the study since it's conception, is one of these special women, known as HIV Exposed Sero-Negative (HESN). Despite all of these accomplishments, Hawa and most of the other women remain commercial sex workers. They earn less than $2 a day and see five to fifteen customers a day.[1] She and her five children still live in a one room, mud hut in the village slum of Majengo.[1] This case outlines the ethical question, "what relief or benefits are owed to research participants?" While Hawa's situation is devastating, what responsibility does Plummer and his team have to her and the other women in the cohort? Researchers must balance undue inducement with relief of oppression, all while attempting to maintain research ethics.

Balancing Undue Inducement and Relief of Oppression

Anyone can see that Hawa and the other commercial sex workers in this study are living in desolating conditions. But, who's responsibility is it to pull them out? Many criticize Plummer's work for not finding a more suitable employment opportunity for the women in his studies, such as training the women in a marketable skill. This moral dilemma calls into question undue inducement, where the benefits of a study pressure individuals to participate against their better judgement.[3] While this typically refers to financial incentive, it can also apply to Hawa's case of employment training. Women working in commercial sex work may feel extreme pressures to escape their current employment and agree to any study that offers an out. Their participation in the study would no longer be voluntary and this benefit exploits an already susceptible population.[3] Instead, Plummer's team offered health care, which is otherwise difficult to acquire as a commercial sex worker. Health care is a human right and offers a pathway to a healthier life. The opportunity for health care does not pressure women against their better judgement to participate and instead serves as Relief of Oppression for a service they should already receive.

Lavery et al. states that Relief of Oppression (ROO), "aims to bridge the gap between a narrow, transaction-orientated account of avoiding exploitation and a broad account emphasizing obligations of reparations for historic injustices."[4] In Plummer's case, the provision of health care serves to address the gap in health care coverage being experienced by commercial sex workers. If the study were to exchange job training for participation in the study, it would be more transactional – as compared to providing health care, a public service in Kenya. Relief of Oppression is analogous with the principle of harm reduction, which is precisely what Plummer's team offered.[4] Women in the study were offered condoms, STI/STD testing, and taught condom-usage negotiation skills.[1] These services help reduce the harm experienced by working in commercial sex without being a transactional exchange for participation. Relief of Oppression differs from undue inducement in the sense that provisions in ROO are not

marketable/financially high value.[4] Job training holds significant value, and would cause undue inducement among participants in the study.

Solution

To combat potential undue inducement, and instead prioritize Releif of Oppression, harm reduction and sustainable services should serve as the solution. Harm reduction targets occupational health and safety.[4] In the case of commercial sex work, condom promotion and negotiation skill-building, STI/STD health services, and peer education serve as occupational health and safety. These elements were elements of Plummer's study design before the team even discovered the HIV Exposed Sero-Negative women. These services remained in place as the study progressed, even though some of these efforts would hurt their sample size.

An honest question must be asked to every researcher – "Do you feel comfortable continuing to work with a vulnerable population without providing a solution?" The Institutional Review Board (IRB) takes special precautions regarding studies working with vulnerable populations but does not completely ban the study design. For examples, studies on prisoners have unique considerations associated with their study approval but can still be allowed. If a researcher works with cases on death row, where they believe the prisoner is clearly not guilty – is it the research team's job to act as their defense team? No, researchers are not expected to have duel-degrees and act as free legal-aid. As harsh as it may sound, Plummer and his research team should not be expected to serve as social services to lift their participants out of commercial sex work. The difference between the prisoner example and the commercial sex worker example lies within the stigma associated with each situation. Prisoners tend to have a "guilty-as-charged" stigma surrounding them, dehumanizing and isolating the individual. Commercial sex workers are seen as victims of systematic oppressions. Removing the stigma surrounding incarceration displays how prisoners are also victims of systematic oppressions. Both of these groups tend to experience educational disparities, socio-economic disadvantages, and class/race discriminations by society. Instead of blaming Plummer for exploiting Hawa and the other women in the cohort, more emphasis should be placed on categorizing commercial sex workers as vulnerable populations, so that research standards can evolve and improve.

Overall, research tends to take the "human" out of the participant. The real solution to cyclical inequities lies within acknowledging that each study is rooted in human suffering. Researchers should not be expected to solve the lives of their participants, but instead can offer harm reduction and sustainable services to their participants rooted in human compassion. One of these harm reduction methods may be to link participants with an outside organization that does specialize in removing the participant from their compromising environment. Not only would these organizations be more qualified to do such work, but it would also clarify the role of the researcher. In Plummer's case, harm reduction includes sexual, reproductive-targeted health care, and condom promotion and negotiation skill building.[1] Further efforts could have been made by Plummer and his team to establish clinics within Majengo that are not dependent on research funding. Capacity building within Pumwani to promote sustainable health care services would address the needs of commercial sex workers and establish additional employment opportunities within the village. Hawa and the other women in the cohort should be categorized as vulnerable populations, and Plummer's team should be given the chance to improve their research standards as such. Finally, instead of providing the employment counseling, Plummer's team should link women in the cohort to an organization that addresses this issue. As it stands now, Plummer is not exploiting Hawa, and is working in his limited role as a researcher.

Conclusion:

Plummer's research did not begin with a search for HIV Exposed Sero-Negative women. Their research team discovered monumental findings about HIV transmission and accidental discovery of HESN women within the cohort shows promise for a potential vaccine.[1] Harm reduction was always an aspect of their study design with over 7 million condoms dispensed.[1] According to Arnason and Schroeder and The Universal Declaration of Human Rights, a lack of health care is an injustice.[3] Plummer's team worked to provide Relief of Oppression for over thirty years, providing health care to women that would not otherwise receive these services.[1,4] The ongoing research has established corrective justice experienced by women discriminated against for their profession and righting a wrong of injustice.[3] While many criticize Plummer's research for exploiting Hawa, and there is evidence for this as well, commercial sex workers are not considered vulnerable populations according to the IRB. Plummer and his team cannot be expected to lift women out of commercial sex work, just as other researchers are not expected to defend prisoners in jail.

Instead of blaming Plummer and his research team for working within their limited roles as researchers, more validation should be given to the benefits of harm reduction and emphasis placed on categorizing sex workers as vulnerable populations. Plummer, and similar research projects, should use their resources to connect their participants with qualified organizations. In this case, Plummer's team provides Relief of Oppression through harm reduction strategies, and corrective justice through provisions of health care for over thirty years, working well within his limits as a researcher.

References:

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