



Can Voluntary Participation in Medical Research Be Exploitative?

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Abstract

This paper critiques the claim that medical research is not exploitative if participants volunteer to undergo it. I argue that consent cannot be a sufficient basis for non-exploitation since agents can reasonably consent to unfair distributional outcomes given a grossly unjust status quo. Hence, any evaluation of the fairness of a research programme must be able to account for normatively relevant structural sources of injustice. This may be done by incorporating an inter-transactional parity condition into the conventional transactional account of exploitation, and supplementing it with a framework capable of accounting for wider, community-based effects.

Keywords: Distributive Justice; Exploitation; Medical Research Ethics

In this paper, I present a critique of the libertarian claim that medical research is not exploitative whenever individuals volunteer to participate. My argument is twofold. First, I argue that the moral wrong of exploitation can be present even where valid consent is obtained, as agents can reasonably consent to unfair distributional outcomes if doing so improves on a status quo that is highly unjust to begin with. Second, following Vida Panitch (2013) and Danielle Wenner (2018), I argue that any conceptual framework for evaluating the fairness of some distribution of benefits must therefore be able to account for normatively relevant structural sources of injustice. I conclude by acknowledging that the relationship between exploitation and moral permissibility in a non-ideal world is not clear cut. Therefore, conclusions for policy and the regulation of medical research in practice must transcend the question of exploitation.

It is useful to begin by defining exploitation. A transaction is commonly understood to be exploitative if one party A takes *unfair* advantage of another party B in the transaction. This may arise from a failure in either: a) the transactional process, i.e. from a lack of valid consent on B's behalf; or b) the transactional outcome, i.e. where B does not receive her fair share of the benefits and burdens generated by the transaction. Taking voluntariness to mean informed consent, the claim that medical research cannot be exploitative if participation is voluntary amounts to the claim that satisfying a) is a sufficient condition for

satisfying b). In other words, as long as valid consent is obtained, the outcome of a transaction cannot be deemed unfair or wrongful in a way that justifies intervention.

What are the grounds for this claim? Operationalising the concept of fairness in the definition of exploitation requires an underlying theory or standard of distributive justice. Our aforementioned claim is likely grounded in the libertarian view of distributive justice as being whatever a free market, characterised by voluntary market relationships between informed, competent agents, dictates. On this view, the fact that A gains more than B is not in itself morally troubling insofar as B receives a fair share of the benefits; wherein fairness is established not by any objective measure but by B's own subjective determination of the matter, as captured in the informed consent condition.

However, this account of justice cannot hold given the imperfections of markets in the real world. The notion that fairness can be adequately captured by informed consent relies fundamentally on the assumption that agents have the ability to negotiate fair terms and turn down transactions that they deem unfair. However, this is unlikely to obtain in situations where the baseline positions and bargaining power of agents are highly unequal. Indeed, these are the very conditions that enable the taking of unfair advantage, since in the absence of choice disadvantaged agents can rationally consent to inequitable agreements as long as doing so improves on their expected outcomes.

For instance, concerns about exploitation in medical research usually centre on clinical trials conducted by first world pharmaceuticals in low-income countries, where local standards of care and healthcare provision are often significantly poorer. In these settings, there is usually a surplus of willing participants for whom participation in such trials is their only means of obtaining any treatment, and therefore have virtually no bargaining power. This allows research sponsors from high-income countries to profit by utilising low-income settings for riskier research, or to reduce costs by offering far lower standards of care than would be required in an equivalent trial in a high-income setting (Wenner 2018). In such cases, wrongful exploitation occurs even if valid consent is obtained, as the better-situated party, A, takes inappropriate advantage of structural inequalities and B's disadvantaged position within them to offer B a worse distribution of benefits and risks than she might have otherwise demanded as fair. Under such conditions, a more appropriate baseline for fairness might be an assessment of what an individual would consent to in a counterfactual transaction in which the exploitable disadvantage is removed (Mayer 2007).

This claim, however, may be challenged by those who question the salience of structural or background inequalities to the fairness of specific transactions. According to the *non-worseness principle*, for example, it cannot be morally worse for A to interact with B than to not interact with B if i) the interaction is better for B than non-interaction, ii) B consents to the interaction, and iii) the interaction has no negative effects on others (Wertheimer 1996). Appealing to a principle like this, one could argue that offering poorer terms of contract in low compared to high-income settings, whilst not ideal, is not necessarily inappropriate or exploitative where doing so does not deprive low-income participants of any benefits they would otherwise be entitled to, and in fact still benefits them.

However, such a position provides an unsatisfactory basis for understanding exploitation, particularly in the context of international medical research. There are strong reasons to regard background conditions as normatively relevant to assessments of fairness, since ex-ante inequalities and power differentials can greatly influence the ex-post distributive justice of individual transactions. This is particularly so given the injustice of existing structural inequalities. Taking the luck egalitarian perspective that inequality in a distributive outcome is only just insofar as it is grounded in differences in morally relevant features such as choice

and desert (Arneson 1989), the fact that some agents are significantly disadvantaged on grounds of morally arbitrary characteristics, such as birthplace or geographical location, is surely unjust. Hence, principles like non-worseness that take an unjust global institutional order as an acceptable baseline, and thereby grounds for denying an agent a fair share of the benefits she helped produce, cannot be an adequate basis for understanding exploitation.

Indeed, considering the historical and sociological origins of global structural inequalities, a case can be made that members of the developed world owe a collective duty of redress to the global poor for their part in bringing about this injustice. This would lend support to the adoption of a more demanding account of the duty of non-exploitation held by medical researchers conducting trials in low-income countries. However, it can be argued that even if such a collective duty of redress exists, it is not immediately clear how it would translate into duties on the part of specific individuals or institutions. On the one hand, appealing to such a collective duty as justification for strengthening the duty of non-exploitation in medical research seems to place an undue and disproportionate moral burden on researchers, considering that most developed-world citizens do nothing to benefit the global poor to no great moral admonition.

On the other hand, it can be argued that researchers do owe special obligations to their subjects that other developed-world citizens do not, due to the nature of the relationship between researcher and research subject. According to the interaction principle, one has special responsibilities to those with whom one interacts which one would not have if one had chosen not to interact with them at all (Wertheimer 1996). This accords with a respect-based view of exploitation: if exploitation consists in deliberately interacting with another in a way that degrades or fails to respect their inherent value, then it is in some respect worse than neglect, even if neglect can sometimes have worse consequences (Sample 2003). Under this view, mutually beneficial studies can still be exploitative if they employ ethical double standards because the moral wrong of exploitation must be understood in deontological rather than purely consequentialist terms. According to egalitarianism, moral agents identical in non-arbitrary respects are deserving of the same concern and respect; hence to deny a research subject the share of benefits that would be enjoyed by another who made the same contribution, on the basis of arbitrary differences, is to deny them the same concern and respect. Consequently, if developed-world researchers choose to conduct research in vulnerable populations, they must treat the wellbeing of their subjects with the same concern and respect as they would equivalent subjects in non-vulnerable populations, particularly where they share in a collective duty to redress the injustices that birthed these vulnerabilities. Where they not only fail to do this, but deliberately seek to profit from the injustices, there should be little doubt that they have committed the gross moral wrong of exploitation (Panitch 2013).

The upshot of this is that any conceptual framework for assessing fairness and exploitation in international medical research must go beyond purely *intra*-transactional features, such as consent, and account for the structural and background inequalities that affect it. What might such a framework look like? Panitch (2013) argues that this may be achieved by incorporating a requirement for inter-transactional parity into the conventional transactional account of exploitation, so that the fairness of the benefit share enjoyed by developing world research subjects is judged not relative to their own meagre starting points, but to those of their less vulnerable counterparts in the developed world. This ensures that any unfairness in the *ex ante* status quo is not carried forward into the distributional outcomes of transactions. Thereby, equal concern and respect for the wellbeing of all research participants can be shown.

Lending greater consideration to structural inequalities may also require us to broaden our conceptualisation of exploitation. Wenner (2018) argues that medical research programmes cannot be reduced to isolated transactions between researchers, sponsors and participants, because they produce benefits and burdens that apply to entire communities rather than to individuals alone. For instance, international clinical trials may benefit host communities by facilitating skill and resource transfers from high to low-income countries. Conversely, host communities may incur costs if scarce local resources are diverted to research that would ultimately benefit only developed world patients. As community-wide benefits or costs can significantly impact the overall size and distribution of the benefits of a programme, they can exert some influence on global structural inequalities, and are therefore of normative significance to broader assessments of fairness and exploitation. Perhaps unsurprisingly, many of the solutions currently proposed as means of ameliorating exploitation in international clinical research focus on ensuring that research delivers sufficient benefits to host communities, such as being responsive to the health needs of the local community, rather than to individual participants. This suggests that the purely transactional account of exploitation currently assumed in research ethics is insufficient, and a conceptual framework that can address the exploitation of communities as distinct from the exploitation of individuals is required as well (Wenner 2018).

In this paper, I have argued that consensual medical research can nonetheless be exploitative by showing that consent cannot be a sufficient condition for fairness in situations where existing inequalities significantly constrain one party's ability to bargain on terms. In such situations, any approach for evaluating fairness or exploitation in a particular transaction or programme must be able to account for any wider, structural sources of injustice that are normatively relevant. However, it should be noted that whilst all exploitation is morally reprehensible, the relationship between exploitation and its permissibility in various contexts in the real and non-ideal world is not clear. Arguably the biggest challenge to introducing more demanding regulatory standards for fairness is the fact that it could result not in more equitable benefit sharing but in non-compliance or withdrawal, which could lead to worse outcomes if the implicated research was nonetheless Pareto optimal. Therefore, conclusions for policy and regulation – such as whether specific trials should be approved or specific interventions to ameliorate risk of exploitation be introduced – should transcend normative considerations alone and be informed by empirical assessments of expected outcomes.

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