

Feminist Theory Reveals a Need for Justice over Autonomy in Research Ethics

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ABSTRACT

Feminist scholarship has remained similarly engaged in questions surrounding consent, with particular focus on sex and sexuality. This year, in the wake of the #MeToo movement, we have witnessed a cultural shift towards a willingness to address the perils of sexual consent under patriarchy. In the context of this cultural reckoning, I see no better time to apply feminist epistemology to the fraught nature of consent to a bioethical framework. Feminist bioethicists, such as Susan Sherwin, have long argued for a wider consent model that privileges justice over a focus on autonomy. Using radical feminist theorist Catherine MacKinnon's work on consent and sexual harassment, I will support Sherwin's claim by arguing for a more nuanced understanding of power and structural social hierarchy that exists in every aspect of our society, including research.

Keywords: feminism, autonomy, informed consent, justice

INTRODUCTION

Informed consent has remained one of the more debated topics within research ethics. Many scholars and bioethicists have wondered the best way to obtain it, who should give it, and if it is even necessary at all. Feminist scholarship has remained similarly engaged in questions surrounding consent, with particular focus on sex and sexuality. This year, in the wake of the #MeToo movement, we have witnessed a cultural shift towards a willingness to address the perils of sexual consent under patriarchy. In the context of this cultural reckoning, I see no better time to apply feminist epistemology to the fraught nature of consent to a bioethical framework. Feminist bioethicists, such as Susan Sherwin, have long argued for a wider consent model that privileges justice over a focus on autonomy. Using radical feminist theorist Catherine MacKinnon's work on consent and sexual harassment, I will support Sherwin's claim by arguing for a more nuanced understanding of power and structural social hierarchy that exists in every aspect of our society, including research.

ANALYSIS

It should be noted I am not trying to conflate engagement in sex/sexual violence with engagement in research. However, I *am* attempting to find useful parallels to dissect the broader issue that applies equally to both, which is an issue of meaningful agreement across power differentials. There is a false idea, within research ethics and our society at large, that consent is the gatekeeper of a just and

reciprocal experience. As feminist theorist Catherine MacKinnon writes, “The presence of consent does not make an interaction equal. It makes it tolerated, or the less costly of alternatives out of the control, or beyond the construction, of the one who consents”.¹ A new model incorporating radical feminist scholarship and focusing on structural inequality as opposed to individual choice is necessary to ensure truly ethical research practices.

Informed consent is a widely discussed topic in research ethics, one that presents many challenges. According to U.S. law and the principles of bioethics, physicians, scientists and researchers are required to obtain the informed consent of their patients or subjects before initiating treatment or collecting scientific data. True informed consent, as defined in bioethics, requires the disclosure of all relevant information to a competent participant who is capable and permitted to make a totally voluntary and educated choice. Typically, as Paul Appelbaum writes, “such disclosure includes the nature of the patient’s condition, the nature and purpose of the proposed treatment, and the risks and benefits of the proposed treatment and of alternative treatments, including the option of no treatment at all” [2]. In other words, the participant is supposedly free to utilize their full autonomy in determining what they do, and do not, want to be done with their body.

Informed consent in research ethics is often framed under the specific lens of the preservation of autonomy, and, consequentially, autonomy is usually heralded as the most important of bioethical principles with regards to consent. There are obvious cases in which informed consent, as defined, cannot be reasonably given due to limited autonomy. Traditional bioethics tends to focus on cases of limited autonomy as individual circumstances of language barrier, cognitive impairment, or mental instability. As Appelbaum writes, “when patients lack the competence to make a decision about treatment, substitute decision makers must be sought. Hence, the determination of whether patients are competent is critical in striking a proper balance between respecting the autonomy of patients who are capable of making informed decisions and protecting those with cognitive impairment”.² Typically, the determination of limited autonomy is defined on individualistic terms based on a subject’s specific health limitations. I propose this is not a useful enough starting point, as this idea of individualistic autonomy has many limitations, namely, the exaltation of autonomy assumes falsely that every individual has the same operational ‘access’ to it. We need to be considering autonomy in a structural, rather than individualistic framework.

Furthermore, the recognition on the part of traditional bioethicists that autonomy is not universally equally distributed already reveals a soft admission to the fact that autonomy is not the best model upon which to rely. However, by choosing to focus only on the more ‘obvious’ examples of limited autonomy such as dementia, and mental capacity, as opposed to larger social determinants of a type of compromised autonomy such as in the case of gender, race, and class, traditional bioethics reveals an unwillingness to address larger societal issues of justice and power.

Arguably, the space in which the most prolific theorizing on the role and perils of consent and autonomy in society has been feminist theory. Radical feminist theory, a line of thought emerging out of the second-wave feminist movement, specifically has grappled with the concept of “consent” and “free-choice” under uneven power structures. As radical feminist scholarship considers the mechanisms underlying rape and sexual harassment, the notion of consent as a fraught concept is brought into unique focus. Catherine MacKinnon, one of the most prominent radical feminist and legal scholars, and the inventor of the term “sexual harassment” has written prolifically on this subject. In her work, MacKinnon theorizes on the illusion of female choice under patriarchy given gender oppression and uneven power structures and argues that the presence of consent is not a robust enough concept to differentiate rape from sex because women are not truly free to make unencumbered choices with regard to their sexuality. She writes,

The law of rape presents consent as free exercise of sexual choice under conditions of equality of power without exposing the underlying structure of constraint and disparity...if rape is less a question of unwanted sex than of unequal sex, if equality not autonomy is its primary issue, if internal psychology is less determinant of these criminal acts than leverages external conditions and gendered social behaviors, the existing conceptual framework together with its lexicon of examples, has been fundamentally beside the point all along".³

According to MacKinnon, the concept of consent is beside the point: in order for consent to even be possible, the two actors entering into an agreement must be equal in power. Since this equality is non-existent, the discussion should instead involve the levelling of the playing field before we can worry about coming to an agreement.

These ideas from second wave feminist theory have recently re-emerged as a way to discuss the fallout from the revelations of the #MeToo movement. As Brit Marling published in *The Atlantic* in response to the Harvey Weinstein sexual assault scandal, "the things that happen in hotel rooms and board rooms all over the world (and in every industry) between women seeking employment or trying to keep employment and men holding the power to grant it or take it away exist in a gray zone where words like 'consent' cannot fully capture the complexity of the encounter. Because consent is a function of power. You have to have a modicum of power to give it".⁴ This reiterates MacKinnon's claim that obtaining consent is inadequate in addressing inequality across power differentials. Without an equality of power positions, consent is not only meaningless, but presents a red herring.

Even if we falsely accept the equality of the two parties, consent as a concept inherently implies a differential in power, as one agent necessarily initiates as another acquiesces. In fact, *The Oxford English Dictionary* defines consent as the "voluntarily acquiesce in what another proposes or desires" [3]. Similarly, *Black's Law Dictionary* defines consent as "voluntarily yielding the will to the proposition of another" [3]. Therefore, using consent as a marker for an equal exchange is a fundamental misconception. As MacKinnon writes, "intrinsic to consent is the actor and the acted-upon, with no guarantee of any kind of equality between them, whether of circumstance or condition or interaction [3].

While some may argue discussions of sexual consent are too specific to be applied to issues of research consent, this is not the case. Research, like gender dynamics under a patriarchal social system, is rife with inequities of power. Doctors and researchers similarly occupy a traditionally masculine role of paternalism and authority over their subjects, just as men hold power over women under patriarchy. It is also important to note the history of colonial abuses in academic and biomedical research that has contributed to this contemporary power imbalance. As Indigenous theorist Lina Tuhiwai Smith writes, "from the vantage point of the colonized...the term 'research' is inextricably linked to European imperialism and colonialism" [5]. She continues:

Research is one of the ways in which the underlying code of imperialism and colonialism is both regulated and realized. It is regulated through the formal rules of individual scholarly disciplines and scientific paradigms, and the institutions that support them (including the state). It is realized in the myriad of representations and ideological constructions of the Other in scholarly and 'popular' works, and in the principles which help to select and re-contextualize those constructions in such things as the media, official histories and school curricula.⁵

Research is not a neutral truth-seeker, but rather a historically situated institution built off the values of imperialism. Much of the establishment of research as a field has relied heavily on the stratification of the colonizers (researchers) from the colonized (subjects).

While the goal of this paper is not to argue for the conflation of sexual consent with research consent, it should be noted that there are meaningful historical and contemporary examples of patients, particularly women, who have been taken advantage of in the name of science in manners that are sexual in nature. Consider the performance of pelvic exams by medical students on anesthetized women without their consent: according to an article published in 2012, women undergoing gynecological surgeries were asked to give consent to allowing medical students be involved in their care, but not explicitly allowing them to do educational exams on them while unconscious. As a medical student stated, "For three weeks, four to five times a day, I was asked to, and did, perform pelvic examinations on anesthetized women," whom had only given implicit consent to his *presence* during surgery [6]. According to the United States Department of Justice the legal definition of rape is "penetration, no matter how slight, of the vagina or anus with anybody part or object without the consent of the consent of the victim".⁶ Accepting this definition, what these patients endured was ostensibly a form of rape. In the United States, there are only four states (Hawaii, California, Illinois and Virginia) "where doctors are legally required to obtain specific consent for pelvic exams under anesthesia".⁷ Furthermore, a study found that medical students who had completed a clerkship in obstetrics or gynecology did not believe consent for pelvic exams under anesthesia were warranted.⁸ These attitudes suggest that while issues surrounding sexual consent and research consent are distinct, there are important overlaps that point to a larger structural problem in society. Research is not created in a vacuum. It is created by and for the culture in which it is produced; in this case, the same culture that also permits and encourages gendered sexual abuse.

Taking a cue from feminist theory, we can see that by focusing only on autonomy and ignoring issues of structured oppression and violence, the current model of informed consent in medical research is fundamentally skewed in favor of the powerful. As feminist bioethicist Susan Sherwin writes, "autonomy language is often used to hide the workings of privilege and mask the barriers of oppression".⁹ By choosing to focus only on issues of autonomy we artificially make research ethics an individualistic issue rather than a systemic one. Like MacKinnon, Sherwin too argues that the idea of choice under systems of oppression is illusory. She writes, the "illusion of 'choice' in the context of informed consent can operate as a mechanism to insure compliance with care provider's preferences".⁹ Not only is the ontology of choice illusory, the framework of emphasizing autonomy often serves to blame victims for their own mistreatment. According to Sherwin, in emphasizing choice as the gatekeeper of impartiality, advocates "not only fail to deflect responsibility from victims, but rather attribute it to them".⁹

This phenomenon can be clearly seen in the recent discussion surrounding the prevalence of sexual assault in the work place. In response to Harvey Weinstein's outspoken victims, many have asked questions to the tune of, "if she felt uncomfortable, why didn't she just leave" or "why didn't she tell anyone?" Not only does this unimaginatively ignore the realities of power differentials, it also serves to blame victims for being victimized. Focusing on the victims' choices as if they were as free and unencumbered as Weinstein's is wrong, and misses the point entirely. The emphasis on women's autonomy here insidiously and paradoxically serves not to embolden, but rather undermine, their subjectivity. Sherwin writes that "the concept of autonomy, rather than working to empower the oppressed and exploited among us, in practice often serves to protect the privileges of the most powerful".⁹ Additionally, Sherwin writes that "theories that place priority on autonomy—at least as the concept is commonly interpreted—must be understood as primarily protecting the autonomy of those who are already well-situated, while sacrificing the necessary prerequisite for autonomy for others".¹⁰ Assuming both parties have 'equal' access to autonomy in this situation is not only callously inappropriate, it also relies on clumsy reasoning that serves only to bolster power differentials rather than level them. And this, of course, does not merely apply to women subjects but to other marginalized groups be they based on race, class, sexuality, etc.

An emphasis on autonomy not only serves to unfairly place blame on the victim, it also obscures structural oppression that limits autonomy in the first place. As Sherwin explains,

This individualistic approach to autonomy makes it very easy for people of privilege to remain ignorant of the social arrangements that support their own sense of independence, such as the institutions that provide them with the exceptionally good education and a relatively high degree of personal safety. Encouraged to focus on their own sense of individual accomplishment, they are inclined to blame less well-situated people for their lack of comparable success rather than to appreciate the cost of oppression. This familiar sort of thinking tends to interfere with people's ability to see the importance of supportive social conditions for fostering autonomous action.¹¹

Our project as bioethicists should rely less on maintaining and bolstering what is ultimately the golden rule of autonomy myth, and focus rather on enlightening and unmasking the various power structures at play that limit various groups' access to power. Rather than a focus on individual choice, "we need to question how much control individual patients really have over the determination of their treatment within the stressful world of health care services" [11].

CONCLUSION

Overall, the current model of informed consent as it is currently understood at best misses the point, and at worst promotes damaging neoliberal notions that place blame on individuals rather than on structural inequality. In the case of research ethics, consent and its function as a measurement of autonomy fails because the power between the researcher and subject is inherently unequal. This is not to suggest that in this scenario autonomy is actively stripped from the subject by the researcher, but rather that the dice were loaded before either entered the room. Autonomy, regardless of the efforts of bioethics, is simply not equally accessed in our society as it stands today. The incorporation of feminist theory serves to challenge the current model by accurately and forcefully confronting the realities of our unequal world. Not only does this application reveal parallels in how power is negotiated similarly throughout different realms in society, it also helps to illuminate the larger ethical issues that warrant attention. As Sherwin writes, "feminist health care ethics does not only change the way we handle traditional bioethical problems; it also changes the agenda of the discipline by making visible a whole range of new ethical problems [11]. Taking a feminist approach to bioethics reveals a need to move toward a justice model and away from an autonomy model in order to more vigorously account for structural inequality within biomedical research.

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