

THE VULNERABLE AND THE SUSCEPTIBLE*

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ABSTRACT

Human beings are essentially vulnerable in the view that their existence qua humans is not given but construed. This vulnerability receives basic protection from the State, expressed in the form of the universal rights all citizens are meant to enjoy. In addition, many individuals fall prey to destitution and deprivation, requiring social action aimed at recognising the specific harms they suffer and providing remedial assistance to palliate or remove their plights.

Citizens receive protection against their biologic vulnerability by means of an in rem right to health [care], which is more an attitude of protection than a specific programme. When individuals become susceptible, that is, biologically weak or diseased, they also increase their predisposition to additional harm, and require social actions to treat their demeaned condition. Such assistance takes the form of positive healthcare rights.

Research on human beings has been slow to observe that the subjects recruited are susceptible, especially so if research is done in less developed countries. By mislabelling them as vulnerable – a characteristic they share with all humans – sponsors avoid registering the deprivation these people suffer, and the ethical obligation to offer them remedial help.

The distinction between vulnerability and susceptibility also marks the difference between being intact but fragile – vulnerable – and being injured and predisposed to compound additional harm – susceptible. Awareness of this difference should give additional force to the rejection of double standards in research ethics.

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THE ESSENTIAL VULNERABILITY OF BEING HUMAN

Ever since J.G. Herder (1744–1803) characterised human beings as immersed in a process of realising their true self in dependence of their cultural environment, the idea has become entrenched that we fully become human through a complex process of development. Existentialism, no less than Heidegger's Dasein, has rendered tribute to this fragile, risky and failure-prone venture. The recent works of MacIntyre and O'Neill have captured these ontological ruminations and brought them to bear on applied ethics, thus rendering them germane to the language of human rights, positive rights and bioethics.

Political philosophy has also addressed the question of human frailty. Hobbes' well-known pessimistic view of natural life – solitary, nasty, brutish and short – led him to conceive of a central power that should monopolise the use of force, disallowing men from being violent against each other according to their own impulses and whims. Man is vulnerable to his fellowmen's ill treatment, and the State must offer protection against this vulnerability to avoid lawlessness and social chaos. Being a champion of liberty and of rights, Mill also considered it necessary to protect the frailty of certain essential rights through the State's guarantee and power of intervention. The idea of vulnerability and the need for protection are accepted even by those wary of excessive governmental presence, to the point of stating that the protection of individuals is the sole valid and irrevocable function of the night-watchman state even in its most abridged, ultra-minimal version.¹

Vulnerability is a human condition from which we all suffer, and because of its universality we all agree that equal protection is due to every member of society. As societies grow more complex, the vulnerability of its members extends beyond the fear of aggression or the risk of having one's rights thwarted. Much support and assistance are required before we become fully integrated members of society:

Human beings need to learn to understand themselves as practical reasoners about goods, about what on particular occasions it is best for them to do and about how it is best for them to live out their lives . . . It is these judgements [thus developed] that are the judgements about human flourishing.²

¹ R. Nozick. 1980. *Anarchy, State, and Utopia*. Oxford. Blackwell Publishing.

² A. MacIntyre. 1999. *Dependent Rational Animals*. London. Duckworth: 67.

Such a complex process requires the development of abilities and capacities that can only accrue in a thick meshwork of social relationships. The way is paved with 'obstacles, difficulties, and dangers',³ hence the essential vulnerability of becoming and remaining a full human being. MacIntyre goes on to propose a twofold protection against the vulnerability of not achieving full human flourishing: the state as provider of a minimum, but no more than that, of security to its subjects; and the pursuance of 'the goods of family life [which] are achieved in and with the goods of various types of local community.'⁴

There is no question that dire situations occur which go beyond universal vulnerability, allowing a 'kind of harm to which those already afflicted with some measure of disability may be peculiarly liable.'⁵ This additional disability needs to be more specifically identified and, it can be anticipated, will require special forms of assistance. Turning to Onoora O'Neill, one in fact finds a more explicit elaboration of these points. She depicts human beings as '*persistently* vulnerable in ways typical of the whole species', and requiring protection for such 'ubiquitous and foreseeable' vulnerability by means of justice. In addition, human beings may become '*deeply, variably and selectively* vulnerable in specific circumstances, a state of destitution that needs to be addressed with sensitivity to and rejection of harm these individuals are prone to.'⁶ Such an ethical attitude takes the form of social virtues of care and assistance, specifically designed and applied to help those in need. MacIntyre and especially O'Neill are indicating that many individuals suffer from some sort of deprivation that predisposes them to additional and compound forms of harm. I propose to call this a state of susceptibility with the express aim of differentiating the destitute and their susceptibilities to harm from the vulnerability we all share.

Recognising that the human condition is a vulnerable one, and that political justice will protect all citizens equally in order to reduce the vulnerability of their existence, should not disregard that these principles are not always fulfilled. When justice is not served, basic human vulnerability will be unequally protected. Political regimes that do not allow justice to prevail in fairness, and unequally respect and protect human rights, are making disadvantaged citizens more vulnerable to forfeiture of their pro-

³ Ibid. p. 72.

⁴ Ibid. p. 134.

⁵ Ibid. p. 75.

⁶ O. O'Neill. 1996. *Towards Justice and Virtue*. Cambridge. Cambridge University Press: 192–193. All italics in the original.

protective rights. And yet, this still is the fundamental vulnerability intrinsic to human nature, which continues to call for universal and equal protection by means of a government committed to justice. This explains why resistance against dictatorships relies on restoring justice and human rights for all, and rejecting the unprotected vulnerability some citizens are suffering. Of course, if disrespect for human rights goes so far as to harm persecuted individuals by depriving them of basic goods like income, liberty or physical integrity, we are no longer witnessing the vagaries of essential vulnerability but facing sheer brutality that operates beyond the realm of ethical argumentation or suasion.

Vulnerability and susceptibility, being quite different conditions, must also be approached diversely. As stated, vulnerability can be reduced by equal protection to all members of society under a principle of justice. Susceptibility is a determined state of destitution and therefore can only be reduced or neutralised by measures that are a) specifically designed against the destitution in question, and b) actively applied. The susceptible, like the sick, require targeted treatment to palliate their misery.

HUMAN RIGHTS

It is a misdiagnosis of consequence to refer to the susceptible as being only vulnerable, and it will lead to indifference in the wake of harm or injury. Much of what is said about human rights falls prey to this error. Universal rights are, in essence, protective rights that are honoured by nations of true democratic nature. For the most part, people living in these nations feel guarded from the intrinsic risks of becoming and remaining fully integrated citizens of their society. The state guarantees basic liberties by securing a just social order that gives equal protection to the vulnerability of each citizen. Such constitutional obligations are defensive, not supportive; they are designed to keep individuals free from harm. Those citizens who for some reason are deprived and therefore susceptible to harm, do not fully benefit from human rights until positive welfare rights are added to the nation's agenda, and these rights will generate correlative obligations of actively pursuing the satisfaction of the needs those positive rights address. Consequently, positive rights need to be clearly specified as to who may claim what; that is, what kind and degree of susceptibility is entitled to which kind of treatment i.e. the extension and intension of these rights must be determined in detail.

In the realm of bioethics it is important to keep in mind the distinction between, on the one hand, human vulnerability, the

principle of justice that aims at making people less vulnerable, and the respect for human rights as equally valid claims to state protection due to all citizens; and, on the other hand, susceptibility as a state of deprivation that makes the affected liable to additional harm, needing specific treatment to reduce their demeaned condition. In a nutshell, the vulnerable are intact but at risk, in the same way a fine piece of porcelain is unblemished but highly vulnerable to being damaged. The susceptible are already injured, they already suffer from some deficiency that handicaps them, renders them defenceless and predisposed to further injury; their wounds lower the threshold to additional suffering.

Tailoring these arguments to the problems of health/disease, a right to healthcare could be construed as a general appeal to the community that it take preventive actions to avoid disease and foster environmental and social conditions that benefit health, in other words, that it protect the biologic vulnerability of all citizens. This is a kind of *in rem* right that does not obligate specific persons or institutions but appeals to the community at large.⁷ Nations that do provide preventive and public health medicine are responding to this right to health [care], but they still may shun any political commitment to secure medical care. For the susceptible, whose conditions make them prone to additional harm, including disease, such a general rights declaration is insufficient for they require active and aimed treatment of their destitution.

Should one consider the destitution that inhibits human growth as unsavoury, and call upon society to remove these obstacles to human flourishing, it then becomes necessary to design specific rights in the area of healthcare and medical services. These will be rights *in personam* that point at well identified institutions that come under the obligation to provide the necessary treatment to remove destitution and eliminate susceptibility.

Thus, society sees its citizens as equally vulnerable, deserving an agenda of human rights including an entitlement to health [care], developed with protective purposes that are fairly available to all. But such a management will leave unattended specific harms that make people susceptible and predisposed to additional injury, unless further obligations are accepted with the purpose of addressing the specific susceptibilities that deprive those affected from pursuing their interests. Whenever the dis-

⁷ J. Feinberg. 1980. *Rights, Justice, and the Bounds of Liberty*. Princeton. Princeton University Press.

inction between the vulnerable and the susceptible is ignored or suppressed, society will fail to exercise the social virtuosity of rejecting indifference to and neglect of others, lacking the virtues which express themselves in concern, care, beneficence, solidarity and active assistance of the deprived. Failures of this kind occur when wrongly labelling as vulnerable the aged, the poor, women, ethnic minorities, who are left in their state of destitution and discrimination because their specific susceptibilities are ignored. In what follows, I will apply these considerations to three current, hotly debated and related issues in bioethics: research on human subjects, exploitation, and transcultural paternalism.

RESEARCH ON HUMAN BEINGS

The subject of research on living beings has always been controversial, and naturally this uneasiness has permeated current practices of research on human beings, leading to a series of international proposals, the latest of which is the much discussed Declaration of Helsinki 2000. The indiscriminating talk about vulnerable populations has triggered the kind of reactions that smuggle the susceptible under the category of the vulnerable and forgets to give them special consideration, based on the assumption that vulnerability is a human given that elicits no individual responsibilities or obligations beyond the state's protection. Such an argument has been explicitly used to circumvent the ban on placebos issued and ratified by Helsinki 2000 in regard to their use in research whenever effective treatment exists, and independently of whether it is locally available or not. This clear mandate has been rejected by some authors, who believe that 'it is ethical to conduct placebo-controlled trials in countries where pregnant women do not receive any treatment.'⁸ The ban on placebos has also been ignored and contested by arguing that there is no need to provide effective treatment to subjects whose local medical resources are anyhow in no position to render such treatment available, for 'the best proven therapy standard must necessarily mean the standard that prevails in the country in which the clinical trial is carried out.'⁹ Lack of medical care makes these subjects vulnerable, so the argument goes, but researchers

⁸ C. Levine. Placebos and HIV; Lessons Learned. *Hastings Center Report* 1998; 28: 43–48, at 46.

⁹ R.J. Levine. The Best Proven Therapeutic Method Standard in Clinical Trials in Technologically Developing Countries. *The Journal of Clinical Ethics* 1998; 9: 167–172, at 168.

are under no obligation to reduce this condition if the host country has not done so. But should one regard research subjects of destitute countries as susceptible rather than only vulnerable, it would become obvious that they are already deprived – poor, undernourished, lacking in medical care – and therefore predisposed to additional harm. By denying them existing effective treatment because it is not locally available, researchers are harming these people and therefore violating the bioethical principle of non-maleficence.

Bioethicists have all too often defended double standards of research ethics in multinational investigations.¹⁰ Whereas developed sponsor nations apply a higher standard of aspirational ethics at home, they accept and propose a less demanding, pragmatic form of ethics in underdeveloped host countries, a discrimination that lacks moral consistency and ethical probity.¹¹ It may be, so sponsor institutions and their researchers continue their defence, that the control group benefits only marginally, but the participants who get the active drug under investigation are obtaining treatment that hopefully is proving superior to previous standards. Alas, when the research reaches its end point, access to the drug is interrupted and the subjects must revert to their untreated condition, which is purportedly no worse than their original stance. As long as they are considered vulnerable individuals, nothing indeed has changed, but if they were regarded as susceptible human beings, who were disadvantaged to begin with and are additionally deprived of the experimental drug that was proving beneficial, they appear to be worse off than before. Some pharmaceutical companies have issued promises that treatment would be provided to subjects beyond the time limits of their involvement in research, but compliance with these commitments has been scanty, prompting some critics to write that such promises and the explicit guidelines of CIOMS regarding the obligation to provide post-research benefits, have often only been ‘honoured in the breach.’¹²

Defenders of double standards in research ethics are regarding subjects of host countries as vulnerable, immersed in a state of frailty that may be deplorable but requires no outside effort to improve care and protection beyond what is locally available.

¹⁰ M. Kottow. Who is my Brother’s Keeper? *Journal of Medical Ethics* 2000; 28: 24–27.

¹¹ R. Macklin. After Helsinki: Unresolved Issues in International Research. *Kennedy Institute of Ethics Journal* 2001; 11: 17–36.

¹² L.H. Glantz, G.J. Annas, M.A. Grodin & W.K. Mariner. Research in Developing Countries: Taking Benefit Seriously. *Hastings Center Report* 1998; 28: 38–42.

Were they to be considered as susceptible individuals, it would become clear that sponsor countries are showing indifference to harm and neglect, ignoring the deprivations they confront and failing to exercise the social virtues of palliating destitution of their research subjects. Extending O'Neill's view, these individuals are under special conditions of vulnerability – they are susceptible, as here suggested – and nevertheless being disregarded in their plight and unethically treated.

Qualifying the demeaned lives of women in many parts of the world has shown the harm done by using the label of vulnerability and accepting its underlying fate of unalterability, instead of confronting specific susceptibilities and designing appropriate measures to reduce them. In a recent article, van Niekerk writes: 'The position of women in the current HIV/AIDS epidemic in (South) Africa is made all the more precarious by the severe form of stigmatization that people who acknowledge their HIV status currently have to face in that region.'¹³ Unfortunately, in view of his dramatic description of African women as poor, brutalised, sexually abused, devalued, illiterate, dependent, in sum, as deeply wounded, it appears as a misleading euphemism to call them 'particularly vulnerable', for a condition that needs to be recognised and emphasised as a profound damage to the very substance of these women's existence, a damage so appalling as to scream for remedial action far beyond the complacency of passively acknowledging their membership in the vulnerable status proper to the human species. Although falling prey to erroneously speaking of women as particularly vulnerable, when they should be referred to as particularly deprived or susceptible, van Niekerk does acknowledge the fact of precariousness, which sheds a more dramatic light on the unique plight of women that require very specific forms of social therapy. A. Sen has elaborated on the subject by stating that the most salient and overarching feature of the deprivation of women is their lack of agency.¹⁴ If susceptibility is a state of destitution, of actual harm being compounded with the predisposition to additional harm, it should become apparent that the most aggravating component of susceptibility is the inability to untangle the vicious circle of destitution. Exploitation and paternalism deepen disautonomy and therefore make agency an unreachable goal. It is hard to imagine a more defective way of approaching the deprivations of the destitute, and it appears

¹³ A.A. van Niekerk. Moral and Social Complexities of AIDS in Africa. *Journal of Medicine and Philosophy* 2001; 27: 143–162, at 155.

¹⁴ A. Sen. 2000. *Development as Freedom*. New York. A.A. Knopf.

all the more unfair and unacceptable to subject these women to ethically suspect research practices.

EXPLOITATION

Exploitation can be understood in the value-free meaning of achieving or acting, but in the context of bioethics it refers to the moral sense of taking undue advantage of the needy. Morally understood, exploitation is defined as utilisation – of people, circumstances, opportunities – for selfish purposes or for the sake of gaining capital out of a course of action or a chain of events. Such forms of exploitation benefit the agent and disregard the interests of, or ignore the harms that ensue to, the exploited. We are told that ‘not all wrongful action can properly be considered exploitation’, a truism that does not deny the converse fact that exploitation is always wrong because it is a sub-set of wrongful actions. It is equally true that ‘situations may be unjust without being exploitative’¹⁵ but this statement also does not work both ways, for exploitation is always unjust.

Morally understood, exploitation is insensitive and oblivious to the fact that its actions will negatively affect susceptible subjects disadvantaged by inadequate defences. Exploitation in this moral sense is invariably wrong, and yet pains have been taken to present exploitation as an ambiguous, even multivocal concept, a currently held position that has its roots in a number of distinguished classical thinkers. Plato lets Callicles present the concept that the better and superior may ‘remove by force what belongs to the inferior’, and Nietzsche is, of course, a strong champion of exploitation. But there are a number of equally perceptive scholars who believe that ‘wrongfulness distinguishes [exploitation] from non-exploitative utilization’, and that ‘[P]roper respect for others is violated when we treat their vulnerabilities as opportunities to advance our own interests or projects.’¹⁶

Exploitation in the moral sense is wrong. Is it always unjust? It is ‘whenever the weakness exploited is one which society should either prevent others from taking advantage of (by means of interference) or else prevent from occurring altogether (by means of redistribution).’¹⁷ This Millsian version would require an act to be labelled as exploitative and unjust only when it violates a person’s right and provided this right should validly be protected by society. Consequently, exploitation may be just if it does not

¹⁵ R. Macklin. Bioethics, Vulnerability and Protection. *Bioethics* 2003; 17.

¹⁶ A.W. Wood. Exploitation. *Social Philosophy and Policy* 1995; 12: 136–158.

¹⁷ *Ibid.* p. 154.

violate a right guaranteed by the state. This is certainly not the common sense understanding of justice, and we could easily agree that whoever hires an individual to do 8 hours hard work, and denies him rest, food, drink and adequate pay, is guilty of exploitation which is unjust because occurring in a setting of unequal power and one-sided negotiation capacity, an exploitation that is immoral whatever local labour laws might exist. Exploitative situations that are to the advantage of all involved might appear at a first glance to be just, but they go counter to Rawls' difference principle, which only tolerates inequalities provided they are to the greatest benefit of the least advantaged members of society.

The argument that exploitation only refers to those rights that citizens can claim social protection for has been adapted to morally excuse external action in societies that are insufficiently structured to protect their members. Why provide better medical care than currently available in a country hosting outside research? Why be more stringent about the ethical probity of research if regulations are locally underdeveloped? Why protect the weak if their own country lays no claim on protection? The less developed the rights agenda of a nation, the more freedom outside agents purport to enjoy in going about their business and in pursuance of their interests, without fear of violating rights which are locally non-existent. In doing so, the extraneous agents are exploitatively reaping undue advantages by denying the susceptible certain goods and leaving their needs unattended. Whereas exploiters might try to dissect their actions into harmlessness, it should not be difficult for the affected, or for the impartial observers bioethicists hopefully are, to determine when an action or a policy is aggressively fostering the interests of one party while the weaker one is left standing in the rain.

PATERNALISM

It is tempting to address the perceived need of the destitute from the vantage point of a benefactor, as history has shown the attitudes of miseration, misericord and compassion to be, much of which Kant rejected as an insulting kind of benevolence. Paternalism of this sort still transpires in recent writings: 'She [the pitier] does not neglect the sufferer's view of things . . . but she is prepared to find his or her preferences and judgements distorted, and to pity in accordance with her own view of the good.'¹⁸ This

¹⁸ M. Nussbaum. Compassion: the Basic Social Emotion. *Social Philosophy and Policy* 1996; 13: 27–58, at 37.

is the typical form of paternalism that has been exercised by the prosperous and defended by ethicists as being well meant and therefore morally legitimate. But paternalism is only acceptable in those cases where an authorised agent makes decisions in the name and to the benefit of disautonomous beings, as traditionally exemplified in paternal care. In contrast to this commendable form of protection, paternalism often comes from unauthorised sources, supposedly benefiting subjects who in fact are autonomous and quite capable of deciding what is good for them. When sponsor nations intrude with research protocols or import drugs that have not been authorised in their own country, they are equating vulnerability and susceptibility with lack of autonomy, and therefore exercising a morally defective form of paternal protection. This perverse kind of paternalism appears defended in such statements as: 'Neither the lack of information that some consumers may have to make their decision nor the unapproved nature of the product are sufficient conditions to make such actions unethical.'¹⁹ The title of the article rendering this quote is highly illustrative of the intentions behind the argument: 'Good Enough for the Third World.' The support it gives to the use of unapproved drugs shows an appalling lack of sensibility to the fact that these drugs will be given to highly susceptible women who will be at severe risk of additional harm.

CONCLUSIONS

We live in a world where the gap between the prosperous and the have-nots is widening. It is most unfortunate that such a state of affairs should have tempted bioethicists to commit the natural fallacy of defending that these asymmetric material conditions warrant inconsistently different ethical standards. Each culture will hopefully develop its own moral thought, but if the representatives of a more developed society decide to carry out certain activities in less affluent environments, they should not be allowed to give in to the temptation of lowering their ethical standard. Statements like the following, which certainly are unacceptable in prosperous societies, should not be tolerated when suggesting their validity for Third World countries:

Even if it turned out to be the case that the buying and selling of unapproved medical products is unethical, it does not follow that we are obligated to put an end to it. The mere fact that it

¹⁹ D. Cooley. Good Enough for the Third World. *The Journal of Medicine and Philosophy* 2000; 25: 427–450, at 443.

is wrong does not entail that we have any duty to stop the act from occurring or preventing it from happening again.²⁰

Awareness that less developed countries have a high prevalence of susceptible citizens should make outsiders understand that deprivation and weakness are conditions that require special and selective care, and that if the affluent wish to conduct business in these countries, they come under moral obligation to develop the social virtues due to the susceptible: to shed their indifference and neglect by benefiting the people they want to negotiate with. In biomedical practices this means letting research subjects benefit in a substantial and not only temporary and circumstantial way, and to avoid harming the host population by introducing practices that are disallowed at home.

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²⁰ Ibid. p. 443.