Vulnerability as the Antidote to Neoliberalism in Bioethics

Vulnerabilidad como antídoto al neoliberalismo en bioética

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Abstract

The concept of vulnerability has been introduced in the bioethical debate rather recently. In philosophy, vulnerability has been a core notion particularly in Continental schools. In a sense every human being is vulnerable (although different expressions have been used to qualify the human predicament). In bioethics the concept has been introduced initially in the context of clinical research to demarcate groups of individuals or populations as 'vulnerable' and therefore entitled to special protections. With the globalization of bioethics, suffering and risk in the face of medical research, technologies and care have become global realities, so that the concept of vulnerability has emerged as one of the principles of global bioethics, for example in the UNESCO Declaration on Bioethics and Human Rights. The notion of vulnerability is in fact a criticism of the mainstream bioethical discourse, articulating that emphasis on individual autonomy is insufficient, and that attention should be directed towards the conditions for human flourishing.

Keywords: bioethics, CIOMS, globalization, neoliberalism, Potter, UNESCO, vulnerability.

Resumen

El concepto de vulnerabilidad ha sido introducido recientemente en el debate de la bioética. La vulnerabilidad es un concepto clave en filosofía, particularmente en las escuelas continentales. En cierto sentido cada ser humano es vulnerable (aunque se han usado expresiones diferentes para calificar al humano). En bioética, el concepto ha sido introducido inicialmente en el contexto de la investigación clínica para designar grupos o poblaciones merecedoras de protección especial. Con la globalización de la bioética, el sufrimiento y el riesgo de la investigación médica, las tecnologías y los cuidados son realidades globales, por lo que el concepto de vulnerabilidad ha surgido como uno de los principios de la bioética global, por ejemplo en la Declaración de la UNESCO sobre Bioética y Derechos Humanos. La noción de vulnerabilidad es de hecho, una crítica al discurso bioético predominante, denunciando que el énfasis en la autonomía individual es insuficiente, y que la atención debe ser dirigida hacia las condiciones del florecimiento humano.

Palabras clave: bioética, CIOMS, globalización, neoliberalismo, Potter, UNESCO, vulnerabilidad.

Resumo

O conceito de vulnerabilidade foi introduzido recentemente no debate da bioética. A vulnerabilidade é um conceito chave em filosofia, particularmente nas escolas continentais. Em certo sentido, cada ser humano é vulnerável (mesmo tendo sido usadas expressões diferentes para qualificar ao humano). Em bioética, o conceito foi introduzido inicialmente no contexto da pesquisa clínica, para designar grupos ou populações merecedoras de proteção especial. Com a globalização da bioética, o sofrimento e o risco da pesquisa médica, as tecnologias e os cuidados são realidades globais, razão pela qual o conceito de vulnerabilidade surgiu como um dos princípios da bioética global, por exemplo, na Declaração da UNESCO sobre Bioética e Direitos Humanos. A noção de vulnerabilidade é, de fato, uma critica ao discurso bioético predominante, denunciando que a ênfase na autonomia individual é insuficiente, e, que a atenção deve ser dirigida para as condições da plenitude humana.

Palabras Chave: bioética, CIOMS, globalização, neoliberalismo, Potter, UNESCO, vulnerabilidade.

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One of the remarkable features of contemporary bioethics is the emergence and expansion of the notion of vulnerability. This notion has been introduced in bioethical discourse recently. It was first used in the context of research ethics but later expanded in other areas of bioethical debate. The emphasis on vulnerability articulates that the human person not only is an autonomous subject but also a body that is susceptible and fragile. But the notion also calls attention to the social context in which persons are exposed to threats and harms. However, in mainstream bioethics vulnerability is construed as individual deficit.

Vulnerability as individual deficiency

The 1993 CIOMS Guidelines provide a description of vulnerability that became influential: it is "a substantial incapacity to protect one's own interest"(CIOMS 1993: 10). The Guidelines refer to several causes, such as lack of capability to give informed consent, lack of alternative means of obtaining medical care, or being a junior member of a hierarchical group. The later 2002 Guidelines reformulate the description and list other causes such as insufficient power, education, resources and strength. But the reference point remains the ability to protect your own interests. In other words, the moral principle of respect for autonomy is the framework within which the notion of vulnerability is interpreted and understood. Vulnerability is primarily regarded as an individual weakness; it indicates that certain individuals cannot protect themselves. For example, in clinical research one can assume that well-informed and free individuals will follow what is in their interest when they consent to participate. Vulnerable persons either lack decisional capacity or lack adequate information so that they need to be protected against possible exploitation. Free and informed consent can therefore eliminate the vulnerability of potential research subjects. In this perspective, vulnerability essentially is limited autonomy. Whatever the causes or conditions, it signifies that the person's capacity to make autonomous decisions is impaired or reduced. The more individual autonomy is decreased, the more vulnerability will increase (Haugen 2010:210).

Vulnerability as global phenomenon

Nowadays vulnerability is a central notion in a variety of discourses, for example in nursing science, public health and social sciences. It is also used in new fields of study concerning HIV/Aids, disasters, environmental degradation, climate change, bioterrorism and human security. The fact that the world has become increasingly interconnected and interdependent has created a sense of mutual vulnerability. In the words of the Director-General of the World Health Organization: "Vulnerability is universal." (WHO 2007: 2). Being vulnerable is often the result of a range of social, economic and political conditions, and therefore beyond the power and control of individuals. Because it is related to globalization, a broad notion of vulnerability is necessary. Processes of globalization have resulted in a world that not only creating more and new threats, but they have also undermined the traditional protection mechanisms (social security and welfare systems, family support systems) so that the abilities of individuals and communities to cope with threats are eroded. Entire categories of people are disenfranchised, powerless and voiceless (UN 2003). It is clear that this interpretation of vulnerability as global phenomenon is at odds with mainstream bioethics' framing as an individual affair.

The limitations of mainstream bioethics

When the vulnerable person is considered as a 'failed' autonomous subject, vulnerability will not only be located in the individual but will also imply a specific practical response, i.e. protection through substituting the lack of capacity through the voice of others. It is clear that this particular framing is normatively driven: it is the result of the primacy of the ethical principle of respect for personal autonomy. What is less clear is that significant dimensions of the notion of vulnerability are left out of consideration. For example, structural social, economic and political determinants that disadvantage people are not deemed relevant. The focus on individual weakness preempts a political perspective that considers vulnerability as the outcome of specific situations; that argues that people are made vulnerable in specific con-

texts; that the notion is more related to the ethical principles of justice, solidarity and equality than individual autonomy. The paradox is that the discourse of vulnerability has developed in association with increasing processes of globalization. It gives voice to today's experience that everyday existence is more precarious, that we are exposed to more hazards and threats, and that our capacities to cope have decreased. The fall-out of these processes for individual persons has correctly instigated bioethics to address the problem of how persons can be protected and empowered. But as long as bioethics does not critically examine the production of vulnerability itself it does not address the root of the problem. Framing vulnerability as deficit of autonomy not only presents part of the whole story but it also implies a limited range of options and actions. In this sense, mainstream's interpretation of vulnerability is ideological: it directs theoretical and practical attention away from the circumstances that make subjects vulnerable.

The need for global bioethics

The emergence of the notion of vulnerability is a symptom that a new approach in bioethics is unfolding, going beyond the limited perspective of mainstream bioethics. The global bioethics advocated by Van Rensselaer Potter is finally coming into existence (Potter 1988; Ten Have 2012). As stated in a recent publication: it is critical for bioethics "to incorporate the realities of a globalised world, one with increasing disparities and power differences" (Ganguli Mitra and Biller-Andorno, 2013). The notion of vulnerability is challenging bioethics to develop and expand its theoretical framework beyond the principles and approaches established in the 1970s. It also urges bioethics beyond its initial frame of reference that is heavily influenced by North-American culture and ideology. A lot of theoretical work is currently done to develop such broader theoretical frameworks based on human rights, social justice, capabilities and global care ethics. Bioethics no longer is, as formulated by Albert Jonsen, "a native grown American product" that can be exported to other parts of the world (Jonsen, 1998: 377). In this global era the product is essentially transformed. It is facing new problems as poverty, corruption, inequality, organ trade and medical tourism for which the standard bioethical responses are inadequate. The scope and agenda of bioethics are inescapably widening, and it is precisely the notion of vulnerability that calls for such broader bioethics.

The critical discourse of vulnerability

The notion of vulnerability is able to redirect bioethics debate since it has two significant implications. First, it implies the view that human persons are social beings. It challenges the idea that individual persons are autonomous and in control. Since the human condition is inherently fragile, all human beings are sharing the same predicament. Because our bodily existence is vulnerable, humans have developed institutions and social arrangements to protect themselves. This is neither an individual accomplishment nor a threat. Vulnerability means that we are open to the world; that we can engage in relationships with other persons; that we can interact with the world. It is not a deficit but a positive phenomenon; it is the basis for exchange and reciprocity between human beings. We cannot come into being, flourish and survive if our existence is not connected to the existence of others. The notion of vulnerability therefore refers to solidarity and mutuality, the needs of groups and communities, not just those of individuals. The second implication is that vulnerability mobilises a different response: if vulnerability is a symptom of the growing precariousness of human existence and is exacerbated in certain conditions, the social context can no longer be ignored in bioethical analysis. On the contrary, bioethics should focus on the distribution and allocation of vulnerability at global level. Instead of focusing on individual deficits, analysis should criticise the external determinants that expose individuals to possible damage and harm. It also means that individual responses are insufficient; what is needed is a collective response, in other words social and political action.

The neoliberal context of bioethics

How should the bioethical debate be refocused? The recent use of the notion of vulnerability in scholarly literature is fueled by the heightened sense of vulnerability at the global level. The

background is well-known. Processes of globalization are strongly influenced by neoliberal market ideology. The market is regarded as the main source of vulnerability and insecurity (Kirby, 2006; Thomas, 2007). Neoliberal policies are multiplying insecurities: less and more precarious employment, deterioration of working conditions, financial instability, growth of poverty, and environmental degradation. They also lead to the breakdown of protective mechanisms; safety networks and solidarity arrangements that existed to protect vulnerable subjects have been minimized or eliminated. Rules and regulations protecting society as well as the environment are weakened in order to promote global market expansion. As a result, precariousness has generally expanded. This is precisely what the ideology wants to accomplish: people only flourish if they are confronted with challenges, if there is the possibility of competition. Individual security is "a matter of individual choice" (Harvey, 2005: 168). It is exactly this ideological discourse that is replicated in mainstream bioethics' interpretation of vulnerability as deficient autonomy. But if, on the contrary, vulnerability is regarded as the result of the damaging impact of the global logic of neoliberalism, a different approach will emerge. It is not surprising that the language of vulnerability is often used by international and intergovernmental organizations. The devastating effects of neoliberal policies are most visible in the developing world. But nowadays, existential insecurity is everywhere. It is also obvious that market ideology has not in fact increasing human welfare. It has mainly promoted increasing inequality. It has created a world in which the 85 richest persons have as many financial resources as the 3.5 billion poorest people (Oxfam 2014). A small elite has appropriated the political process and has bended the rules of the economic system for its own benefit. Read the story of Iceland; in the 1970s and 1980s an egalitarian country with a rapidly growing economy. Neoliberal policies and privatization of the banking system in 1998-2003 resulted in fast enrichment of a small elite but massive indebtedness of the country so that in 2004 it had the highest national debt in the world (Reid, 2014).

When bioethics discourse was initiated and expanded during the 1970s and 1980s the major moral challenges were related to the power of science and technology. How can patients be protected against medical interference and paternalism? How can citizens have more control over healthcare decisions? In what ways can patients' rights be defined and implemented? These questions have shaped the agenda and methodology of mainstream bioethics, especially in more developed countries. But in a global perspective, many citizens do not have access to modern science and technology. They are marginalized in a system that is increasingly privatized and commercialized. They are exploited in clinical research projects since it is their only change to receive treatment and care. It is obvious that in this perspective, especially since 1990s the major moral challenges have changed. It is no longer the power of science and technology that produces ethical problems but the power of money. Healthcare, research, education, and even culture and religion are regarded as businesses that are competing for consumers.

The irony is that neoliberalism is not liberal at all. It is increasingly combining market language with security concerns, creating 'imperial globalism' (Steger, 2009). All citizens everywhere are continuously monitored and surveyed by a class of guardians who are not subjected to any legal regulation. A vast security apparatus has unleashed the techniques of a militarized empire. Nobody seems responsible. Accountability is absent. Political leaders deceive, deny and lie (Bamford, 2013). Secret assassination programs with remote controlled killing machines do not follow the legal standards of trial and legal hearing. Talk about individual autonomy, let alone privacy and transparency in this context seems rather vain. In many countries free market ideology is furthermore easily combined with authoritarian politics, fundamentalist religion or autocratic rule. The vast majority of the poor is shut out of public discourse. It is not want of money that makes people miserable; it is being trapped in a system that is rigged against them (Boo, 2012).

New directions in bioethics

When the major bioethical problems of today are produced by the dominance of neoliberal market ideology, bioethics should redefine itself as critical global discourse. Focusing attention on the social context will not be enough. Bioethics must argue for a reversal of priorities in policy and society: economic and financial considerations should serve the principles of human dignity and social justice, and no longer be ends in themselves. This implies specific strategies for social inclusion but also institutional support. It will be necessary to demonstrate more vigorous advocacy and activism, supplementing academic enquiry. Social inequalities and conditions that produce vulnerability are not beyond social and political control. It will also require that the voices of the disadvantaged, the deprived and the vulnerable are more often heard within the bioethical discourse, involving vulnerable groups in policy development and implementation. Global vulnerability is furthermore transforming the significance of cooperation. Forging global alliances and new networks of solidarity is the only way to address global threats. An individualistic perspective makes it impossible to address the root causes of vulnerability. Influencing and changing social conditions requires what Fiona Robinson has called “collective capacity to act” (Robinson, 2011: 60).

Conclusion

Vulnerability reflects the precariousness of the human condition and the fragility of the human species. It is also a reflection of radical changes in contemporary human existence due to processes of globalization. As a normative notion, vulnerability has implications for bioethical discourse. First, it demonstrates that emphasis on individual autonomy is inadequate; autonomy itself demands appropriate conditions to arise, to develop and to exercise. Vulnerability therefore is misconstrued as an individual attribute; rather it directs attention towards the underlying conditions for human flourishing. Secondly, vulnerability is not a negative and temporary stage that must be overcome. Since there is the constant possibility of harm, human beings need each other and must cooperate. Third, vulnerability is not merely inability or deficiency but most of all ability and opportunity. Vulnerable subjects are not victims in need of protection or dependent on the benevolence of the strong. Human capabilities will develop when inequality and structural violence have been removed, and the appropriate social, cultural, political and economic conditions for human flourishing have been created. Ethics itself has emerged through reflection on the experiences of vulnerability.

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