

## The principle of vulnerability and its potential applications in bioethics

Enikő Demény

### Abstract

The principle of vulnerability is a specific principle within European Bioethics. On the one hand, vulnerability expresses human limits and frailty on the other hand it represents moral and ethical action principles. In this paper a discussion on the relationship between the concepts of autonomy, vulnerability and responsibility is proposed and presentation of some possible applications of the principle of vulnerability within bioethics. In conclusion, some potential benefits of applying the principle of vulnerability as well as possible difficulties in its application are highlighted.

**Keywords:** vulnerability, autonomy, paternalism, responsibility, bioethics, feminist approach, applied ethics

In current bioethical literature there are some valuable contributions defining the principle of vulnerability as well as several proposals for its operationalization, but there is not yet a comprehensive account of sources of vulnerability or corresponding responsibilities owed to the vulnerable (Rogers et al., 2012, p. 19). This paper aims, on the one hand, to bring into discussion some potential examples from the Central and East European context in which the principle of vulnerability would be relevant and, on the other hand, to discuss the relationship between the concepts of vulnerability, autonomy and responsibility and to highlight some potential benefits of applying the principle of vulnerability as well as possible difficulties in its application.

The marketization of healthcare, global economic inequalities, medical tourism and poverty create special types of vulnerabilities in the field of biomedicine. The research conducted, for this paper, on practices such as paid ova donation (ova selling), commercial surrogacy, or paid (illegal) living organ donation (organ trafficking) in the Central and East European context demonstrated that it is not sufficient to focus our attention only on standard issues of bioethics, such as informed consent when addressing such practices. During this research it became clear that, often, subjects who engage in the above mentioned practices as ova or kidney sellers or surrogate mothers did not see themselves as either vulnerable victims or as coerced or exploited individuals (at least until they faced the first health or fertility problems caused by their actions). Rather, in their narratives, they tend to present themselves as active agents who engaged in a certain activity (for example in “renting” their uterus) to solve a problem (in most of the cases financial) for which they could not find any other alternative solution (for example to pay back their debts, to pay their fees at university, or to buy an apartment for their family). However, relying on the subject’s perceived autonomy to act, even in a context of informed consent, and subordinating other principles such as non-maleficence, beneficence or justice to the principle of autonomy wouldn’t be an adequate approach since this would only legitimize these practices and would reinforce the “bioavailability” (Cohen, 2004, pp. 79–90) of these persons for the global market of organs or reproductive services. On the other hand, labelling these subjects as vulnerable, denying their auto-perceived autonomy and simply condemning the practice they are engaged in would be too paternalistic, since it is not the capacity of the rational decision making of these persons which is at stake, but rather the constraints of the context in which they have to make a decision. This dilemma calls for alternative approaches that can offer a sound theoretical framework for such cases.

The differences in legal frameworks, as well as the socio-cultural and economic context of a given country all impact on how certain medical procedures are applied and what implications they produce in that given context. The medical procedures in themselves might be neutral, but their applications can be empowering and beneficial in some contexts and for some persons, while in other contexts it can be sources of exploitation or of illegal profits. Similarly, the application of the same universal bioethical principles has a different impact on persons in different contexts. It will be argued that both normative and empirical standpoints have to be considered in order to make sense of how certain ‘medical/technological applications’ are working in real life, and what type of moral, ethical and political concerns they raise.

Mainstream, principlism-informed bioethical discourse based on the principles of autonomy, non-maleficence, beneficence and justice has been the dominant discourse in bioethics. These principles dominate standard ethical codes, legal documents and other governance frameworks that regulate medical practice in this field. The dominance of this approach often reduces bioethics to “a checklist” and complex ethical dilemmas to merely obtaining the informed consent form of the autonomous individuals. The principle of autonomy, one among the four basic principles, and the related practice of informed consent gained such authority due to the fact that the reflective equilibrium method that is meant to balance the four principles was rarely practised, and if it was, the other principles were subordinated to the principle of autonomy (Callahan, 2003, p. 505; Haliburton, 2014, p. 39).

However, in spite of its foundational role in the development of bioethics the principle of autonomy and/or its dominant role in bioethical theory and practice has been criticized from a variety of perspectives: feminist, communitarian political philosophy, social science, so on. One line of criticism that is relevant for this discussion is related to the concept of self on which the principle of autonomy relies and the other concerns its context insensitivity. The rethinking of the self as relational and embodied and consequently the redefinition of the concept of autonomy were important steps that facilitated the development of more nuanced ethical approaches. The feminist redefinition of the concept of autonomy is captured by the umbrella term “relational autonomy”. The focus of relational approaches is to analyse the intersubjective and social dimensions of selfhood for conceptions of individual autonomy and moral and political agency (Mackenzie & Stoljar, 2000, p. 4). Another attempt to redefine the autonomy that is relevant for the present discussion is the recognitional model of autonomy, according to which autonomy presupposes a supportive recognitional infrastructure and that agents largely dependent on this infrastructure for their autonomy are subject to autonomy-related vulnerabilities (Anderson & Honneth, 2005, p. 145).

The concern for vulnerability has been always present, in some way, in the context of health care, but mainly in the sense of avoiding harm (do not harm, the principle of non-maleficence). The concept of vulnerability, as such was used mainly in research ethics to label vulnerable persons and groups. An early attempt to reconsider the concept of vulnerability was proposed by Goodin in his theory of responsibility based on the concept of vulnerability (Goodin, 1985). While acknowledging its shortcomings, Caplan regarded Goodin’s welfare consequentialist theory of vulnerability as one with great potential for the field of applied ethics, highlighting that “in an age where selfishness and egoism have been transformed from vices to virtues” Goodin’s book is a refreshing account “that is not ashamed to transform interdependency from a source of shame to a source of moral responsibility” (Caplan, 1985, p. 47). Although the book was published in 1985 it did not have the deserved impact on ethical thinking.

More recently however, the concept of vulnerability gained more space and attention both in academic literature on bioethics and at policy level. The principle of vulnerability was

identified as one of the main principles of European bioethics (Rendtorff, 2002, pp. 235–244), and Article 8 of the UNESCO Universal Declaration of Bioethics and Human Rights also highlights the importance of the principle of respect for human vulnerability (UNESCO-IBC, 2011; ten Have 2014, pp. 15–28). There are compelling arguments formulated both from theoretical and policy perspectives that the concept of vulnerability shall be given importance in bioethical discourses and policies, and the definition and application of the concept in the field of bioethics and health care ethics, as well as the identification of various factors of vulnerability has already started. The literature focuses on the need for definition of the concept of vulnerability and operationalization of the term, as well as to its relationship with other concepts such as autonomy, agency beneficence, justice, and responsibility (Rogers et al., 2012b, pp. 11–38).

Broadly defined, vulnerability is part of the human condition's universal specificity. Vulnerable persons are those whose autonomy, dignity and integrity are being threatened (Rendtorff, 2002, p. 243). Such broad usage has been questioned by some scholars claiming that if too much is implied by the concept of vulnerability, it loses its analytic strength in the policy field. According to Onora O'Neill being "persistently vulnerable in ways typical of the whole species" is different from being "variably and selectively vulnerable" in specific circumstances (O'Neill, 1996, p. 192). While there are diverse definitions of vulnerability, many of them combine the elements of risk faced by the agents and their conditions for handling such risks. We can also speak of "vulnerability factors". The studies undertaken for this purpose operationalized the concept of vulnerability using, as a profile, a combination of predisposing risk factors (e.g. ethnicity, gender), access to permissive factors (income, health insurance, regular source of medical care), which were associated with access to health care (Shi & Stevens, 2005, pp. 148–154).

Both kinds of use of the concept of vulnerability are considered useful for the present analysis. First, the concept of vulnerability, defined as a specificity of the universal human condition is useful for making the point that, due to our intrinsic vulnerability, all of us are prone to becoming vulnerable at some point in our lives. This idea can serve as the basis for the claim that principles of solidarity and responsibility should be the framework in which ethical issues shall be approached in health care in general, and in the case proposed for examination in this paper in particular. However, while this approach is suitable to offer this basic framework, it is not specific enough to operationalize the concept for specific cases. Therefore, we also need a more specific definition of the concept. In addressing issues related to illegal ova or organ sale, or commercial surrogacy practices the use of the expression "factors/circumstances and contexts that give raise to specific vulnerabilities" is proposed.

Critical bioethics, alongside classical ethical theories, is informed by critical social science, which claims that it is necessary to understand the lived experience of real people in context. This theoretical approach is useful for us in conceptualizing how social and economic factors, as well as phenomena such as global inequalities in wealth and in access to health care influences the outcomes of biomedicine in the current context in the particular cases mentioned here. In (illegal) living organ donation, ova selling and commercial surrogacy cases studied the autonomy of the persons involved was restricted by several factors and circumstances that made those engaged in such practices vulnerable (Sándor et al., 2013, pp. 147–174; Demény, 2013, pp. 91–103). Those persons who participate in these practices such as kidney or ova sellers, or as commercial surrogate mothers are, in most cases, not patients but healthy persons who engage in the above-mentioned practices not for medical reasons but for social and economic ones. All these happens in conditions in which their relationship with "the other" participants involve asymmetries of power and financial resources, to list only a few elements of the (global) structural inequalities/injustices that create the circumstances of such practices. Under such circumstances these persons face a double burden. On the one

hand, the medical interventions put on risk these persons' bodily integrity and/or health, and on the other hand they are/might be criminalized for their acts. At the same time their benefit is some sort of economic/financial benefit, gained with the risk of physical harm and the danger of being criminalized. Their bodies are used as a mere means for the goals of others, even if they themselves consented to this. If one would prioritize the principle of autonomy and would simply claim that these persons made an autonomous decision (they gave their free and informed consent to this practice) without taking into account the circumstances under which such a decision was taken (namely the factors and circumstances that seriously limited their choices and pushed them into situations in which they "choose" to sell their kidney, ova or rent their uterus) it would mean to agree that it is morally acceptable for one to take advantage of someone else's unjust situation for promoting his/her own goals, providing that the other person consented to this. It would also mean to accept that once consented, the kidney or ova sellers/surrogate mothers ("donors") are responsible for the consequences of their actions, while the signed informed consent form or/and the official (but false) declaration that no money was involved in the transaction would take away the responsibility from all the other actors involved in the practice.

Taking into account the principle of vulnerability, and acknowledging the vulnerability of the "donors" would not mean however that their capacity for rational decision making is questioned. It would only mean that we need to apply the concept of autonomy that allows us to take into consideration the contextual elements that might pose limitation to their autonomy, since if we neglect the context in which they make moral decisions we would reinforce further injustices against them. We also need an adequate conception of autonomy too, to avoid, on the one hand, the critiques of victimization, labelling or paternalism formulated in relation to the use of the concept of vulnerability in some other contexts, and on the other hand to give an account to the perceived autonomy of those persons who engage in oppressive practices. Since the term relational autonomy has been defined as an umbrella term (Mackenzie & Stoljar, 2000, p. 4) we can adopt it to express the idea that even if subjects in vulnerable situations perceive that they made an autonomous decision their autonomous decision making capacities are limited by factors and circumstances (low education, poverty, emotions and relatedness, dominant discourses about gender, global social injustice, asymmetrical power relations, so on) that give rise to specific vulnerabilities.

The principle of vulnerability should work in an integrative way in balancing the competing interests and shaping the legislation and policies, along with the other basic principles of bioethics in order to promote responsibility, solidarity and social justice in these particular fields of health care, too. It seems necessary to find the right balance between hard paternalism and a total shift of responsibility to the "donors" based on their free and informed consent. Actions seeking to protect vulnerable individuals or groups might be regarded as paternalistic, and therefore questioned by those for whom protection is sought. In order to respond to this challenge, it is necessary not only to acknowledge that certain individuals or groups are vulnerable under specific circumstances but to examine the factors and contexts that give rise to their specific vulnerabilities, to identify the harm/wrong caused to these individuals or groups, to identify the agents who have a role in and responsibility for this and then to take responsibility for changing these conditions, when possible, rather than simply forbidding these practices and criminalizing those who, due to their vulnerable situation, engage in such practices. If we regard these subjects as persons in especially vulnerable situations, whose autonomy is limited by several factors and circumstances, and point out the wrongs/harms they are exposed to due to their involvement in the above discussed practices we can approach their situation in a different way. First of all, we can identify those agents that contribute to/have a role in causing harm and then examining to what extent and for what exactly they are responsible. A more detailed ethical analysis is necessary, however, to offer

an account on what exactly their responsibility can be based on, and to decide if and when their responsibilities/duties shall take the form of negative or positive obligation. The aim in this paper was to highlight the importance of the concept of vulnerability in addressing practices such as (illegal) paid living organ donations, ova selling or commercial surrogacy and to highlight that the use of the concept has policy implications, too.

**Enikő Demény** is Associate Research Fellow at the CEU Center for Ethics and Law in Biomedicine, Budapest, Hungary and was Visiting Lecturer at the Babes-Bolyai University, Cluj, Romania (1998–2009). She received her Ph.D. in Philosophy in 2006 at Babes-Bolyai University, Cluj. Her research interest includes: the social, ethical, legal and policy impacts of new converging technologies; gender and bioethics; social science and bioethics; gender and science; responsible research and innovation in the field of biomedicine.

#### **Corresponding author:**

**Enikő Demény**, Center for Ethics and Law in Biomedicine, Central European University, Nádor str. 9, HU-1051 Budapest (Hungary)  
Email: demenye@ceu.edu

#### **References**

- ANDERSON, J. & HONNETH, A. (2005): Autonomy, Vulnerability, Recognition and Justice. In: J. Christman & J. Anderson (eds.): *Autonomy and the Challenge to Liberalism: New Essays*. Cambridge: Cambridge University Press, pp. 127–149.
- CALLAHAN, D. (2003): Individual Good and Common Good: a Communitarian Approach to Bioethics'. In: *Perspectives in Biology and Medicine*, 46, pp. 496–507.
- CAPLAN, A. (1985): Our Brothers' Keepers (book review). Robert Goodin, *Protecting the Vulnerable: A Reanalysis of Our Social Responsibilities*. Chicago: University of Chicago Press. In: *Hasting Center Report*, 15(6), pp. 46–47.
- COHEN, L. (2004): Operability, Bioavailability, and Exception. In: A. Ong & S. J. Collier (eds.): *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*. Oxford: Blackwell, pp. 79–90.
- DEMÉNY, E. (2013): Medically Assisted Reproduction: Challenges for Regulation in Romania. In: J. Sandor (ed.): *Studies in Biopolitics*. Budapest: CEU Center for Ethics and Law in Biomedicine, pp. 91–103.
- GOODIN, R. (1985): *Protecting the Vulnerable: A Reanalysis of Our Social Responsibilities*. Chicago: University of Chicago Press.
- HALIBURTON, R. (2014): *Autonomy and the Situated Self: A Challenge to Bioethics*. Lanham: Lexington Books.
- INTERNATIONAL BIOETHICS COMMITTEE (IBC) (2011): Report of IBC on the Principle of Respect for Human Vulnerability and Personal Integrity. Paris: UNESCO.
- MACKENZIE, C. & STOLJAR, N. (eds.) (2000): *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. Oxford: Oxford University Press.
- O'NEILL, O. (1996): *Towards Justice and Virtue*. New York: Cambridge University Press.
- RENDTORFF, J. D. (2002): Basic Ethical Principles in European Bioethics and Biolaw: Autonomy, Dignity, Integrity and Vulnerability: Towards a Foundation of Bioethics and Biolaw. In: *Medicine, Health Care and Philosophy*, 5(3), pp. 235–44.
- ROGERS, W., MACKENZIE, C. & DODDS, S. (2012): Why Bioethics Needs a Concept of Vulnerability. In: *International Journal for Feminist Approaches to Bioethics*, 5(2), pp. 11–38.

- SÁNDOR, J, BEŠIREVIĆ, V., DEMÉNY, E., TUDOR FLOREA, G. & CODREANU, N. (2013): Organ Trafficking, Organ Trade: Recommendations for a more Nuanced Legal Policy. In: F. Ambagtsheer & W. Weimar (eds.): *The EULOD Project: Living Organ Donation in Europe: Results and Recommendations*. Lengerich, Berlin, Bremen, Miami, Riga, Viernheim, Wien & Zagreb: Pabst Science Publishers, pp. 147–174.
- SHI, L. & STEVENS, G. D. (2005): Vulnerability and Unmet Health Care Needs: The Influence of Multiple Risk Factors. In: *Journal of General Internal Medicine*, 20(2), pp. 148–154.
- TEN HAVE, H. (2014): The principle of vulnerability in the UNESCO Declaration on Bioethics and Human Rights. In: J. Tham, G. Miranda, & A. Garcia (eds.): *The principle of human vulnerability in bioethics: Religious perspectives*. Dordrecht: Springer, pp. 15–28.