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Autonomy versus responsibility within bioethics and healthcare

Ph.D.thesis

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"*Finally, it is worth drawing out a crucial sense in which we (even the autonomous) are all vulnerable. The ethic of care for others is not simply a matter of protecting those who are incapable of acting autonomously (the most vulnerable forms of life). Rather, it is an ethic that builds on the premise that we are all capable of being wounded by the uncaring (and sometimes paternalistic) actions of others*."

(The Barcelona Declaration. Towards an Integrated Approach to Basic Ethical Principles)

1. INTRODUCTION

The dissertation provides the analysis of the principle of vulnerability and the justifiability of its application in bioethical discussions. Vulnerability in the present work is understood as the respect for and protection of human life. It refers to the fact that human life can be hurt wounded and killed. (As expressed in the etymology: the term derives from the Latin *vulnus* (wound). According to this interpretation vulnerability is a major feature of the *conditio humana.* By the idea of the protection of vulnerability according to the trend of bioethics the present work is affiliated with we can : ".. create a bridge between moral strangers in a pluralistic society, and respect for vulnerability should be essential to policy making in the modern welfare state." (Barcelona Declaration) The principle of the protection of vulnerability should be interpreted in the wider context of solidarity and responsibility inherent in the European tradition. This approach marks a major shift in emphasis in relation to the major trends dominant in earlier bioethical discussions in which the basic entity/unit of society is the self-determined individual towards whom our major responsibility is to prevent any hindrance which might occur on the path of his self-realization and practicing of his autonomy. It is also important that the principle of vulnerability should be interpreted in the everyday phenomenological reality of the human life world, amongst human togetherness as inter-subjective sociality. This standpoint at the same time assigns priority to human dignity over scientific progress.

The significance and gradual headway of that approach is proven by the publication of the Barcelona Declaration in 1998 on Policy Proposals to the European Commission on Basic

Ethical Principles in Bioethics and Biolaw (adopted in November 1998 by Partners in the BIOMED II Project). This document is the result of a process of discussion undertaken in a three-year EU BIOMED research project (*1995 to 1998, the European Commission supported the "Basic Ethical Principles in European Bioethics and Biolaw")* by a group of 22 partners based in different countries within the enlarged European Economic Community and coordinated by the Centre for Ethics and Law in Copenhagen. "It is unique as a philosophical and political agreement between experts in bioethics and bio-law from many different countries. The Barcelona Declaration can be considered as the most important bioethical declaration since the Helsinki Declarations. The Declaration proposes to modify the 4 principles of bioethics which prevailed in the last decades since Beauchamp and Childress published their "Georgetown Mantra" (Principles of Biomedical Ethics, 1979). According to the proposal, the four principles should be:

1. autonomy
2. integrity
3. dignity
4. vulnerability.

Thus, the respect of vulnerability has been included among the 4 most important ethical principles proposed to be applied in bioethics and bio-law emphasizing its strong presence and significance in European heritage and culture. The dissertation analyses the philosophical /theoretical background of the principle of vulnerability by referring to major philosophical contributions which developed the concept first of all in phenomenology and presents the relevance of the concept for medicine and health care by integrating it into the major events of the history of bioethics. It has also been a major intention to introduce the concept and the principle into Hungarian bioethical discussions in order to prepare a possible involvement of professionals of our field in policy proposals for health care in Hungary. In order to achieve that latter aim the dissertation describes as a background the wider social and political context of medicine health care in order to reveal those factors which justify the intensive discussion of the concept in our age, in the age of globalized market conditions. Within this globalized market biomedicine and biotechnology can (also) be considered as highly competitive business. As authors of the Barcelona Declaration emphasize, this market "involves a process of exclusion which operates at a number of

levels" which exclusion should be considered as a democratic deficit which might be compensated at least partly by special attention to those excluded. Exclusions tend to concern an ever growing number of people which is one of the major reasons behind defining vulnerability as one of the most urgent and adequate concepts within bioethics nowadays.

We should hastily add that it is not intended to question the significance of the principle of autonomy in bioethics, only to implement a better balance between the two concepts which evolves around the awareness regarding the fact that more and more patients/individuals are incapable of acting autonomously. Autonomy tends to become more and more a privilege of those "who can afford it". Besides as different schools of philosophy has shown in the second part of the 20th century, the very existence of the "autonomous subject" can be strongly questioned.

2. CHOICE OF TOPIC

The responsible research practice requires that we continuously remind ourselves of what purpose is served by the tasks we set for ourselves. Do they serve the interest of those they bear relevance on? The professionals working in the field of bioethics bear responsibility for those affected in any way by medicine, by the curing profession thus first of all for the patients and as potential patients to be, for all members of society. While examining certain issues within the practice of medicine we assess and propose values. We do normative work in order to have an effect on the processes that go on in our country, in our society. Responsible science practice also has an actuality. In our case this actuality is to be interpreted within the context of Hungarian social political conditions; a country in turmoil trying hard to catch up with the modern, developed European democracies in the globalized world constantly in change. As a determinate characteristic of this situation we must also acknowledge that we are still in the "post-regime change" period where the most important structures are under construction, democratic institutions are being developed while the democratic traditions are not very strong within our history. This is also a period of historic significance for our field, medicine and health care where the consequences of answers given to emerging questions are inestimable. Participating in providing the answers to the questions is ethically irrefutable. The professionals of the Hungarian bioethics community

should do their best to have their voice heard on higher decision-making levels. As ethicists we must also make every effort to facilitate participation in the democratic processes, namely to support participants of our democracy to have a stronger informed saying in affairs which concern them and not let the decisions to be made over their head by those in power. By calling attention to the situation of vulnerable populations we contribute to a better understanding of fairness, justice within health care.

What engraves our situation is that the Europe we were so eager to join is not as bright a perspective as it seemed some time ago. At present Europe's financial and economic crisis turned into a deepening social and political crisis. The countries of Europe still have not recovered from the financial crisis that has started in 2008. To give the detailed description of impacts of the crisis is beyond the limits of this work, one thing should be emphasized however in connection with the present crisis however. Crises have always occurred. What makes this crisis different from those in the past, what makes it longer and much deeper on different levels, is that with the present crisis the long prevailing notion that markets are self- regulating and state intervention can be reduced to a minimum level has proven false. When Hungary, together with other countries of the Eastern block was so eager to join the capitalist world of the West it was democracy, freedom and welfare of the population we wanted to have and were not aware of how big a prize we have to pay. We did not expect either that "this land of prosperity and freedom" soon after our joining it will go through its most dramatic crises in which the very pillars of that system will be crumbling. Thus on top of the difficulties of transforming the socialist system into a democratic capitalist system we – as member of the Club – go through the cataclysm like economic disaster. Obviously the weakest goes deepest the very possibility of national insolvency has threatened our country more than once since those events. (And we have in front of our eyes the drama of Greece and Spain as a threatening possible scenario). Not being too practiced either in democracy or in capitalism, the loaning ambitions of western bank reached our people without almost any constraints causing the indebtedness of a large part of the population, causing thousands of families to lose their existential stability or more. To conclude: while the process of transition has required and still requires essential structural reforms – on the way from social planned economy to market economy – we are forced to face those factors

which have appeared as a consequence of the crises. How does all that effect health-care and what implications of it can we identify to bioethics, and the bioethical discourse?
According to the KPMG Health Issues Monitor:

*"*The deepening economic crisis in the euro-zone has exposed health systems around the world, particularly in Europe, to public and private budgetary constraints. Healthcare systems currently face a funding crisis, which is adversely affecting health outcomes. High unemployment and the slow pace of recovery have further weakened the public sector and its ability to supply quality health services in Europe. The economic downturn and the consequent squeeze on public spending have significantly affected spending on healthcare in Europe… Despite signs of recovery, the economic environment remains fragile, with a strong possibility that some countries may implement further austerity measures to stabilize their finances. This, in turn, is expected to significantly affect publicly funded healthcare systems. In many countries, healthcare is likely to enter a period of extended austerity. Further, the pressures that are surfacing are likely to be a common feature of many health systems in future.*"*

3. OBJECTIVES

The difficult circumstances described above necessitate a deliberate planning of steps to be taken. In that work it is vital that we ensure that the planned or taken action is in accordance with those ethical principles that can be justified according to the scientific practice. The analysis presented in the dissertation is intended as a contribution to those considerations.

Hungary was not participating in the BIOMED II project, however the findings of the research and the proposals would probably be even more useful in our country than in lots of the 22 participating nations. Although the number of excluded is growing Europe–wide, in Hungary astonishing sociological surveys show that our new and often termed "wild" capitalism together with the ongoing crises resulted in the number of poor raising to a shamefully high level. According to the data of KSH (Central Statistical Institute) the number of people living under existential minimum has risen to 3.7 million by 2010 and on the basis of acknowledged sociologist Zsuzsa Ferge this will reach a peak of 4 million by 2014. We are talking here about the continuously widening range of those who can be considered as the

biggest losers of capitalism. As it is shown in the sophisticated analysis of sociologist Zygmunt Bauman these parts of the population are not considered "socially useful" according to the parameters of the operating mechanism, since they are hardly able or completely unable to participate in consuming which defines how strongly an individual is considered a legitimate member of these societies. As a consequence their presence within these societies is superfluous.

Thus these members of our societies appear solely as a burden, a problem to be treated if must, a pain in the back we should add in the life of the continuously narrowing group of the profiteers.

Arguing for the responsibility for the weak, fragile, superfluous fellow humans first of all within the context of medicine has been the major objective behind the writing of the dissertation. A commitment has driven the work to argue in line with the cultural heritage of Europe for solidarity and responsibility and by that compensate somewhat the „unwavering" market-rationality which seems to gain dominance within medicine and health care though I believe it should be reserved as much as possible from its rumblings as the last bastion of social responsibility/solidarity.

4. METHOD

The dissertation first of all works within the field of theoretical bioethics (chapters 1-3) and aims at applying theoretical findings in practice (chapters 4-5).

Methodologically the dissertation also applies an interdisciplinary approach by utilizing contributions of works from the fields of economics, sociology, philosophy and psychology in order to highlight the wider context of certain ethical dilemmas in medicine and health care. However the major line of investigation remains within the field of philosophy as demanded by the central topic, which is the analysis of the new bioethical principle: vulnerability. Vulnerability has been gaining a strong emphasis within the field of bioethics in the last decades and as Warren T. Reich, founding member of the Kennedy Institute of Ethics, and the founding editor in chief of the Encyclopedia of Bioethics remarked: "as the simple and most important idea that will shape both the external influence and the internal development of bioethics is the idea of vulnerability." Bioethics can easily turn to contemporary western philosophy which in several different trends is centering on vulnerability. The most important of the thinkers in whose oeuvre the concept is developed :

Emmanuel Levinas, Jürgen Habermas, Paul Ricoeur, Alasdair MacIntyre just to mention a few. The dissertation follows the development of the idea in its levinasian conceptualization, and also turns to the supportive interpretation of sociologist Zygmunt Bauman who already presents the application of it by showing their working within actual human interaction.

The integration of the concept of vulnerability as a principle of bioethics can be justified by presenting a reflective history of bioethics on the one hand and also from the analysis of certain social processes. The chosen methodology of the dissertation reflects the waldenfelsian observation presented in the quote which serves as the motto of the work, that medicine relies on an order which from essential aspects remains external to it. Waldenfels also calls the attention here to the fact that the price of the success of modern medicine thanks to new age sciences is a normative vacuum which remain the nest of turmoil in this discipline. I believe that this vacuum can be treated from outside of medicine first of all from philosophy and other social sciences which reflect upon the order Waldenfels refers to.

As part of the wider context the dissertation also presents a short history of bioethics and the use of ethical principles in the discipline and examines how new circumstances and new observations deriving from them necessitate an amendment of those principles in our present age. This is how we arrive at the emergence of the principle of vulnerability in the mid 90ies within bioethics. Methodologically this part of the work belongs to theoretical bioethics most, where concept analysis serves to support the integration of the principle. The most important concepts analised: moral responsibility, face to face encounter with the Other, the Other as a stranger, proximity, inter-subjectivity, asymmetry. The last chapters of the dissertation apply the principle to two vulnerable patient groups: the Roma and the elderly.

5. RESULTS

5.1. It is the responsibility of bioethics to develop the discourse within the discipline and society which emphasizes the character of medicine as a moral profession, and the moral responsibility of those participating in healing even though the progress of biomedicine has essentially re-shaped the context of healing and the human

relations within the therapeutic encounters, and that in globalized market oriented societies most decisions are made according to fiscal considerations.

5.2. The principle of autonomy which has played a major role for decades in the bioethical discourse from several aspects is inappropriate to deal with the actual ethical issues of medicine and health care. The dominance of the principle of autonomy disregards the fact that a human existence is primarily an inter-subjective existence and that the subject is integrated in a network of human relations which determines his/her progress in life. The exclusive application of the principle of autonomy in a lot of cases results in the abandonment of the patient within the medical encounter. The disproportionate presence of the autonomy principle also leaves out of consideration the fact that lots of people are unable to live with their autonomy. Autonomy tends to become more and more a privilege for the privileged. Thus the principle of the respect of human vulnerability should be integrated among the major principles of bioethics by stressing its significance in ethical analysis. Vulnerability is interpreted as two ideas. On the one hand it refers to the acknowledgement of the finite character of all human life, and the fact that all of us can be hurt, wounded and killed, even with the improved capacities provided by the tremendous progress within biomedicine. Thus on the first level it refers to the fragility of human existence. The second idea refers to the fact that some of us, a desperately growing number of people in the globalized world are more vulnerable than others because of specific existential or social factors. Less and less can enjoy the blessings of social security and safety. Responsibility towards them is a basic obligation deriving from solidarity which has always been a major value of European culture.

5.3. The application of the levinasian ethics of responsibility can be considered one of the most progressive and constructive initiatives of 21st century bioethics. The application of vulnerability interpreted according to the ethics of responsibility developed by the French phenomenologist as a bioethical principle might provide an answer to the exaggerated presence and function of the principle of autonomy

in earlier periods of scientific discourse and also support a more adequate reaction of bioethics to the latest ethical dilemmas of medicine and health care.

"…Levinas thought is a persistent attempt to point beyond the borders of an economy where orderly interests and ways of reasoning make us feel at home – beyond the world of needs, beyond the self, beyond politics and administration, beyond logic and ontology, even beyond freedom and autonomy". (Adrian Peperzak: Beyond)

The ethical theory developed by Emmanuel Levinas is considered one of the most significant contributions of ethics in the 20th century. According to Levinas ethics is first philosophy and his ethics essentially deals with the relationship between the Other and me, the face to face relationship which is the birthplace of ethics.

Levinas says that we are called to moral responsibility in an inter-subjective encounter with another person and we are to respond to his call. For Levinas the vulnerability of the Other evokes my responsibility which commands me to help and support him/her when in need and on the long run commands "thou shalt not kill". The face to face relation is Levinas' image on human sociality, in which the human face "orders and ordains" us. It calls the subject into "giving and serving" the other. When asked in an interview how this responsibility can be translated in actual meaning, Levinas explains the concept as follows:

"The other concerns me in all his material misery. It is a matter, eventually, of nourishing him, of clothing him. It is exactly the biblical assertion: Feed the hungry, clothe the naked, give drink to the thirsty, give shelter to the shelterless. The material side of man, the material life of the other concerns me…"(IB,52)

In the levinasian ethics *responsibility precedes freedom*, it precedes the autonomy of the subject. For Levinas responsibility for the other gives the essential structure of subjectivity : "We must therefore emphasize here the fact that freedom is not first. The self is responsible before freedom…, freedom can here be thought as the possibility of doing what no one can do in my place; freedom is thus the uniqueness of this responsibility."(GT, 181). He claims that I am not free to do according to my will as an autonomous being, but responsibility for the other comes to me and questions me

before the exercise of my freedom. The is the meaning of the “difficult freedom” (‘unedifficileliberté’) which serves as the title of his famous book.

We can easily translate those seemingly abstract observations to the ethics of the medical encounter. When turning to the Bible for the description of the possible material needs responsibility for the Other commands to relieve we talk about the hungry, the thirsty, the widowed, those who are cold or orphaned but what would reflect more perfectly the vulnerability of humans than the sick person? Levinas’ ethics shows us that by helping the sick, by relieving pain, by recovering health we are responding to the call of the other who asks for help that is, we are acting according to our primordial responsibility for him/her.

The dissertation claims that bioethics should shift its attention from the patient as a sovereign ego as rooted in the Western tradition and move out of the self and open itself to the other. By doing that the technocratic practice within medicine and technocratic discourse in bioethics could be interrupted and by that the apparently unbridgeable distance between medical professional and patients could be re-constructed and the legitimate rationalizations of that distance could be de-constructed. (e.g. At present a scientific discourse legitimates the situation in which it is not the patient but the disease that gets treated, a failure in the operation of the organism that is intended to be averted. The medical encounter often does not demand the participation of the human subject only the presence of its organ(ism).

The dissertation aims to reveal that deprivation of medicine from its moral vocation might be a dubious enterprise with tragic consequences.

5.4. The principle of vulnerability should be applied for the analysis of specific vulnerable patient groups, first of all in order to ensure that human dignity is respected in their case as well. Further studies are to be conducted to identify potential vulnerable patient groups and the analysis of their specific circumstances.

The last 2 chapters of the dissertation apply the principle of vulnerability to 2 vulnerable groups, the Roma and the elderly.

Why these two? I have chosen the Roma since I believe that present day Hungary needs to face the problem of the Roma population which on different levels has proven to be one of the most pressing social conflicts in our country. Integration of the Roma for

different reasons seems to proceed very slow, professionals are afraid that the tension between the Roma and the 'white' will explode if radical steps are not taken. The majority of the Roma population in Hungary belongs to the marginalized, seriously disadvantaged part of society.

The question of the elderly has become another significant issue all over the developed world in our aging societies. Partly thanks to the blessings of medical progress more and more people live to see a long life while at in reality these societies are not "prepared" to have them and how to live with them. Elderly people often are excluded and become part of the "superfluous populations" mentioned above.

5.5. Professional and social responsibility of bioethics. The discussion of ethical issues concerning the situation and the treatment of vulnerable patients must become part of both the professional and the social discourse. To achieve that bioethicists must assume an important role by awakening professional and social conscience. Appropriate professional forums must participate in the efforts aimed at integrating the principle of vulnerability in the state decisions concerning health care within the wider framework of solidarity compensating for the dominant fiscal considerations.

6. CONCLUSION

The last three decades in Hungary mark the transition from the socialist system to capitalism. Hungary has become part of the world of global capitalism in which market and financial consideration are accepted as legitimate regulating principles. At the same time Hungarian health care has been suffering from serious under financing which has been engraved by the ongoing financial crisis which in all over Europe and the developed world has necessitated further austerity measures. Progress in biomedicine blessing for the sick at the same time makes health care a very expensive provision. All too often ethical issues are discussed intertwined with issues concerning lack of financial resources. Any discussion aimed at the moral vocation of healing is often relegated to the domain of utopia. The same refers to arguments which deal with the

estrangement of the patient within the empire of professional expertise, the loss of the values of traditional patient physician relationship etc.

In bioethics the principle of autonomy has dominated treatment of ethical issues. The autonomy principle has stressed the contractual approach within the medical set up and operated mostly with the patient rights approach. (Obviously that had and still has an important role first of all of involving the patient in his or her treatment decisions which was not always the case). The emergence of the principle of vulnerability however seem to be the adequate task of 21st century bioethics since our age needs to stress the value of solidarity and responsibility, that is, communal values as opposed to individualistic aspects. A major task of ethics has always been the defintition of what it means to be human and how humanistic approach can be described. Within bioethics this humanistic approach is to be defined within the medical set up. The principle of vulnerability might be the adequate means of re-defining humanism within medicine which for the above described reasons has somewhat lost its content. Julia Kristeva speaks of this beautifully when arguing for adding vulnerability as a fourth term to the humanism inherited from the Enlightenment (liberty, equality, and fraternity):

"I am convinced that humanism –which has always been in search of itself, from its emergence in the past to the crises or revitalizations today and in times to come – can find a chance to revitalize itself in the battle for the dignity of the disabled by constructing what is still surely lacking: respect for the vulnerability that cannot be shared. My ambition, my utopia, consists of believing that this vulnerability reflected in the disabled person forms us deeply, or, if you prefer, unconsciously, and that as a result, it can be shared. Could this humanism be the "cultural revolution" with which to construct the democracy of proximity that the postmodern age needs?"(Julia Kristeva : Liberty, equality, fraternity and…vulnerability. In: Hatred and forgiveness. p. 30 . Columbia University Press)

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