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Quo Vadis, Bioethics?

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[Abstract] The paper outlines an alternative approach to bioethical issues to replace the present dominant approach which tends to be too abstract and ignores the concrete contexts of the bioethical issues faced by the contemporary world. This new approach, called “the humanistic narrative approach”, attempts to make the best of the insights of Wittgenstein, his followers such as Cora Diamond and David Cockburn etc., Feminists such as Hilde Lindemann Nelson and Eva Feder Kittay, and the Christian theologians Gilbert Meilaender and Jean Vanier. After outlining a moral vision of human animals from the vantage point of the humanistic narrative approach, the author discusses organ transplantation from brain dead persons, prenatal testing, and selective abortion, including a criticism of Peter Singer’s position on the last issue and an explanation of Jean Vanier’s entirely different attitude towards disability.

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A great number of books and papers are published in the field of bioethics. In that sense bioethics is thriving. There is, however, a conspicuous imbalance in the kind of topics and the kinds of approaches to the topics in those books and papers. Many bioethicists discuss the matter of life and death. Nevertheless, they do not discuss life or death itself, and their significances in concrete and substantive ways. Their discussions tend to be abstract and do not give attention to the concrete contexts surrounding individual lives. Ironically, then life and death in bioethical discussion is often not life and death in real lives. Bioethicists tend to deprive life and death of the real significance which they have for real human beings, who are social beings with flesh and blood. It goes without saying that real life and death are full of rich nuances and meanings. Bioethics, which is supposed to deal with matters of life and death, must never fail to discuss those concrete nuances and significances in a substantive way. Otherwise, bioethics does not deserve its name. Bioethics which does not look at life and death with their rich nuances and meanings squarely is not an ethics of life but an empty shell of ethics of life. As Clifford Geertz says, “Believing, with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in

search of law but an interpretive one in search of meaning.”¹ Bioethicists must pay more attention to the concrete meanings of life and death of cultural animals. Furthermore, as Peter Winch says, our conceptions of good and evil are necessarily connected with our understandings of birth, sexuality and death.² We, as cultural animals, have spun and are spinning the webs of significance surrounding the nodes of life and death. One of the major jobs of bioethics, therefore, must be the concrete and substantive discussion of those significances of life and death. Those discussions are sine qua non of bioethics worthy of its name. Hence, I would like to see the increase of the efforts in this direction on the part of bioethicists in the near future.

The fact that bioethics is often regarded as a field of applied ethics might be a reason for this unfortunate tendency. This view of bioethics as a branch of applied ethics, however, is wrong-headed because it implies that applied ethics is treated as just an application of those ready-made abstract theories produced by more general, ethical inquiry. This way of understanding the relationship between ethical and applied ethical inquiries and hence ethics and bioethics is wrong and impoverishes both inquiries. In fact, these inquiries cannot be productive apart from each other. They must interact with each

¹ Clifford Geertz, *The Interpretation of Culture*, Basic Books 1973, p. 5

² Peter Winch, "Understanding a Primitive Society" in his *Ethics and Action*, Routledge 1972

other and enrich each other. The difference between ethics and applied ethics must be just one of emphasis. Hence, bioethicists cannot afford to ignore the need to think deeply and carefully about the more basic moral issues armed with a detailed and concrete understanding of the issues in question. Without this kind of interaction, bioethics cannot contribute to the deepening of our understanding of life and death which is necessary for the deepening of bioethical discussion. For the rest of this paper I would like to explain some results of my own efforts in this direction which are greatly indebted to Wittgenstein and those philosophers who try to develop Wittgenstein's insights to apply them to broader moral issues, such as P. F. Strawson, Peter Winch, Cora Diamond, David Cockburn and Richard Norman.³ But my position depends not only on Wittgensteinian insights but also on Christian theologians such as Gilbert Meilaender, and feminist philosophers who emphasize the importance of focusing on the particular features of individual moral issues in order not to lose sight of crucial details by using an excessively abstract and universalistic approach.⁴ In the section one, I will explain

³ P. F. Strawson, "Freedom and Resentment" in his *Freedom and Resentment and Other Essays*, Methuen 1974; Peter Winch, *Trying to Make Sense*, Blackwell 1987; Cora Diamond, *The Realistic Spirit: Wittgenstein, Philosophy and the Mind*, MIT Press 1995; David Cockburn, *Other Human Beings*, St. Martin's Press 1990; Richard Norman, *Ethics, Killing & War*, Cambridge University Press 1995

⁴ Gilbert Meilaender, *Body, Soul, and Bioethics*, University of Notre Dame Press 1996; Hilde Lindemann Nelson, *Damaged Identities, Narrative Repair*, Cornell University Press 2001; Eva Feder Kittay, *Love's Labor: Essays on Women*,

the basic claims about human morality gleaned from my Wittgensteinian and feminist inquiry. In this paper I will not give detailed arguments but rather outline a vision of human life and morality. Then, I would like to discuss the issue of brain death and Peter Singer's position on prenatal testing from the viewpoint based on the vision outlined by me. The general conclusion of this paper is that bioethicists must make greater efforts to look at human life and death with more compassionate regard which pays loving attention to concrete and particular features of the issues, and that bioethicists must learn more assiduously from moral philosophy, philosophy of mind, anthropology, ethnography, literature, sociology and theology as well as the natural science.

I. The Basis of Human Morality

a) Attitude Towards an Embodied Soul

The starting point of my moral inquiry is Wittgenstein's famous passages in *Philosophical Investigations*, "My attitude towards him is an attitude towards a soul. I am not of the opinion that he has a soul.... The human body is the best picture of the

Equality, and Dependency, Routledge 1999 and "When Caring is Just and Justice is Caring" in Eva Feder Kittay and Ellen K. Feder (eds.), *The Subject of Care*,

human soul.”⁵ In addition, Simone Weil's following words also provide insights into this basic feature of human morality.

The human beings around us exert just by their presence a power which belongs uniquely to themselves to stop, to diminish, or modify, each movement which our bodies design. A person who crosses our path does not turn aside our steps in the same manner as a street sign, no one stands up, or moves about, or sits down again in quite the same fashion when he is alone in a room as when he has a visitor.⁶

We human beings are disposed to take a distinctive attitude towards other human beings. Clearly our attitude towards other human beings is different from those towards stones and rocks. We respond to the former as someone who has a soul. I take it that a soul has an embodied being and includes heart and mind. Without clear awareness we take a distinctive attitude towards other human beings. We are innately equipped with this disposition. Strawson points out that we respond to other human beings' actions with gratitude or approbation, resentment or indignation etc., responding to their good will or ill will or indifference toward us or others. These attitudes imply that other

Rowman & Littlefield 2002

⁵ Ludwig Wittgenstein, *Philosophical Investigations*, Macmillan 1963, p. 178

⁶ Simone Weil, "The Iliad, Poem of Might", in George A. Panichas (ed.), *The Simone Weil Reader*, p. 157 quoted by David Cockburn in *Other Human Beings*, St. Martin's Press 1990, p. 5

human beings are beings which can be held responsible for their actions. They are entirely different from rocks and stones. Strawson calls these attitudes “reactive attitudes.” As he thinks, “this network or system of attitudes and feelings is so deeply rooted in our human nature...”⁷ This kind of distinctive response to other human beings is not mediated by any reasoning. The innate quality of such an attitude does not, however, imply that we have no clues to use. In fact, as Wittgenstein says, we have the body and use its subtle and complex behavior as clues by means of which to detect humanity in other human beings. Human animals do not consist of two distinctive entities, mind and body, but rather have an organic unity with mental and physical features. In short, human beings are essentially embodied beings. Human animals can recognize each other as such and, weaving the web of meanings, convey and receive even subtle messages via complex behavior patterns in particular contexts. They can behave very cruelly and, hence, immorally. But even then still they treat other human animals differently from rocks and stones. In this limited but significant sense we respond to other human beings in such a way that we recognize the humanity in others. This is the basis of human moral sensibility which could develop to become a mature moral sensibility with proper training and life experiences.

⁷ P. F. Strawson, "Reply to David Pears" in Lewis Edwin Hahn (ed.), *The Philosophy of P.F. Strawson*, Open Court 1998, p. 259

That is, the vision which I wish to propound is that human beings are embodied beings which have an innate capability of recognizing each other as such by means of distinctive behavior patterns, that is to say, we are equipped with the potentiality of becoming mature moral beings. This picture of human beings has rich implications as follows.

b) Human Being as a Prototype

As indicated in a), we respond to other human beings in a distinctive way with others' bodily behavior in a particular context as the clues. But there is no necessary and sufficient condition of being a human being. What we have is a proto-type of human being and respond to others in accordance with the degree of the difference from the prototype. As Wittgenstein says, "Only of a living human being and what resembles (behaves like) a living human being can one say: it has sensations; it sees; is blind; hears; is deaf; is conscious or unconscious."⁸ This resemblance is exactly what Wittgenstein calls family resemblance. Even among human beings our response depends upon the prototype of a human being. In borderline cases, there is room for discretion and debate. What I can say here is that the decision is not an all or nothing matter. We must carefully take into consideration every

⁸ Ludwig Wittgenstein, *Philosophical Investigations*, Macmillan 1963, p. 97

aspect of a case in question. In this kind of problems, the narrative approach, which I will explain later, is needed.

c) We Live in the Moral Space: We Come into Being as Moral Animals.

In order to fight with the dehumanizing force and scientism in the present world, the following points must be emphasized. First of all, we are already in, as it were, the moral space from the outset. We do not decide to adopt a moral viewpoint by choice through some inference from the non-moral background. We just find ourselves in the moral space when we become aware of the world. Hence, the gap between fact and value is jumped over during the developmental process through which the innate disposition develops and becomes more sophisticated. Thus, the perennial moral philosophical question, why be moral, is not answered but rather pushed aside as a question not worth asking. We, human animals, are constitutively moral animals which live in the moral space. The question of 'Why be moral' reaches the bedrock of the moral nature of human animals and is turned down by that. The moral justification game just stops there. Whatever reason and causal mechanisms may exist (and certainly evolutionary mechanism must be involved), we happen to be moral animals.

d) The Moral Training of Political Animals

We happen to be born into the moral space. Our basic distinctive attitude towards other human beings is innate, but that does not mean we behave always in a morally appropriate way. Obviously, the innate disposition is not sufficient for us to become a proper moral being which can make proper moral judgments. Potential moral sensibility requires training in order to realize its full potential. That is to say, we need to learn how to be a proper moral being in addition to possessing the potentiality to become one. Human beings need a training consisting of complex mutual interactions in order to acquire a proper kind of responsiveness. One's society and, especially, one's parents as representative of the society's culture train one's moral sensibility. Consequently, there exist cultural differences in our moral sensibility. Our attitude towards other entities has a great variety in accordance with different socio-cultural training. The existence of racial and other kinds of discrimination shows that the basic moral attitude or disposition can be distorted and undermined during cultural training. Indeed, our moral sensibility needs constant nurturance.

e) The Need of Constant Nurturance

Our moral sensibility, which evolves constantly, needs nurturance

not only in the beginning but also throughout life in order to realize its full potentiality. Here, I would like to make a claim that our moral sensibility grows in relationship with other human beings, that what is necessary for the moral growth is the recognition by others of us as beings with dignity, or worthy of respect.

First of all, we have to remember the undeniable fact that we become moral beings in relationship with others, in other words, in mutual responses to each other. During childhood, especially in early stages of our development, our sheer survival entirely depends upon other human beings, usually our parents. Furthermore, our basic and primitive trust in life in general, the sense that life is good enough to stay in it, is the achievement of our parents' labor of love. Innate moral nature without being nurtured by a primary care giver's labor of love can be distorted and not be manifested fully and properly.

After the basis of our moral sensibility is established, our moral nature still needs constant care, nurture and refinement. Our moral sensibility evolves constantly. It can not only grow but also deteriorate. We are complex animals who have a critical need of recognition by other human beings. We need to be recognized by others as beings with dignity. Without the recognition by others we cannot establish a stable and positive self-image, which is the buttress of the stable self. One needs here to think of the dehumanizing treatment of people, such as persons subjected to torture: their personalities as well as moral

selves eventually collapse. Fortunately that process is sometimes reversible. In fact, the autonomous self cannot be established without basic self-esteem. Hence, autonomy and self-determination in the authentic sense can exist only in a healthy relationship with other human beings. The notion of autonomy entirely separated from other human beings is a fiction which has exerted a pernicious influence upon our understanding of ourselves and our relationship with others and, as I will discuss later, can offer cover for hidden oppression and, hence, stand in the way of the full realization of autonomy and self-determination. Primo Levi's following words nicely express the crucial importance of recognition by others. "Part of our existence lies in the feelings of those near to us. This is why the experience of someone who has lived for days during which man was merely a thing in the eyes of man is non-human."⁹

Human beings need each other to grow as moral beings. The quality of responsiveness to each other is the key to the moral growth of each other. Human morality is deeply rooted in the fact of human interdependency. In our world divided by class and cultures, however, what Levi calls non-human experience and the distortion of moral sensibility by that experience is not rare. Unfortunately, our moral nature is not a robust and adamant set of characteristics. Indeed, we human animals are complex

⁹ Primo Levi, *Survival in Auschwitz*, Simon & Schuster 1996, p. 172

beings which sometimes shows incredible robustness and other times great fragility in our physical and mental aspects. Therefore, all the more we need mutual support from each other. We must keep watch for the negative features of our culture in order to curtail the pernicious effect of them in the early stages of their development.

f) Fragility of Our Moral Sensibility: The Slippery Slope

Despite our innate attitude towards others as embodied soul and the vulnerability of our moral sensibilities that need constant reinforcement, we have a tendency to harden our regard towards other human beings. We have a tendency to become accustomed to using other human beings merely as means to our aims, in other words, we have the tendency to reify, especially in our capitalistic society to commodify other human beings. The ultimate expression of this tendency is Nazi's atrocities during the World War Two. Nazis treated people's lives merely as things to be efficiently used for their purposes. This historical fact still warns us what could happen unless we always bear in mind the fact of our fragility, and are vigilant for signs of trends towards reifying human beings. In fact, our moral sensibility can be coarsened and worn out and begin to descend on a slippery slope. Although extreme historical events, such as The Nazi Holocaust, are examples of events that destroy moral sensibility, we need

not resort to such aberrant cases; familiar, everyday events in our private lives may also coarsen or corrode our moral sensibility. I will discuss in greater detail later in this paper a crucial structural problem in modern medicine, the fact that many medical doctors tend to regard the self as separable from the body and, hence, deny the fact that our existence is essentially an embodied existence. So there is a large gap between lay people's ideas of their own bodies and selves, and the doctors' approach to these. One plausible explanation of this gap is the influence of the medical school education. During the process through which medical students become medical doctors they become desensitized to the humanly meaningful aspects of the human body. Although not all medical doctors completely lose that sensibility, the fact that some retain such a sensibility shows the malleability of our moral sensibility. Students' sensibilities can be shaped in a clear direction by medical school training. Medical school's cultural training reinforces 'the objective view' and ignores the ordinary view of the human body. Certainly for their professional activity doctors need an objective view of the human body as a complex machine to be manipulated and repaired. Patients on the operation table wish their surgeons to acquire that distanced attitude towards their bodies at the time of the operation. The problem is, however, that that kind attitude can transgress into the sphere where personal and moral sensibility must dominate our thinking. In other words, it is not

always easy to separate the sphere of where one kind of sensibility properly functions from a different sphere where a different sensibility is required. One kind of sensibility can become dominant in more spheres than it properly should. Moreover, that kind of process can be very subtle and gradual so as to evade recognition. But this problem is not confined to the professional training of a small number of elites. It has a much more threatening form: the tendency to encourage commodification of human beings exists in contemporary capitalist, market-centered society where everything is a possible commodity, an object of market exchange, and hence a source of profits. These cultures can infiltrate and contaminate our moral sensibility. Hence, constant vigilance and nurturance of moral sensibility are required.

g) Life as a Narrative or Story

If we look at history of human beings and look around us, we find that we share a common fate. We share a basic trajectory of our life: conception, birth, childhood, adolescence, youth, middle age, old age and death with various admixtures of happiness and unhappiness. In this sense we are all fellow travelers in life. We are embodied beings and inevitably share the fragility and vulnerability of bodily existence. Human trajectories with their complex structure, whether individual or the collective one of a

society as a whole, are best understood by means of the concept of narrative or story. Each of us, who is a node of the web of tremendously complicated causal connections, weaves a complex story of one's own in which many human beings and things are involved in the developments of the plot. As Dostoevski said, there lies behind an article on a newspaper an entire life of a human being. We add our stories to the entire history of the world. By adopting the narrative approach we can more easily understand our fellow humans and ourselves as concrete, specific human beings, not generalized, abstract stereotypes. The focus upon the specificity of each case, each human being, is what narrative approach aspires to. We are interested in specific stories, not abstract outlines. From this vantage point the irreplaceability of each human being can also be easily recognized.

h) Irreplaceability of Each Individual

When we adopt the narrative approach to other human beings, by means of which we can imagine the whole life story of an individual behind our glimpse of each other, we understand better the irreplaceability of them. Each of us is a particular individual with an unique story, in other words, a unique and irreplaceable individual. Our moral sensibility is nurtured by personal relationships involving particular individuals close to us. Their life stories and ours overlap significantly. The more we

share life's experiences together, in other words, the more our stories and theirs overlap, the more the irreplaceability of each other increases. Having a particular story as one's own, each human being is unique and irreplaceable. We tend, however, to forget that the irreplaceability is a universal property, and that it is applicable even to a complete stranger whose culture seems completely alien to our sensibility. But the experience and recognition of the irreplaceability of person closest to oneself provides the basis for proper moral sensibility, which can be extended to others who are less close to us.

To recapitulate the vision I am offering, the vision of human beings which appears from the above discussion is as follows. Human beings are embodied souls who have an innate disposition to take a distinctive attitude to each other as a soul by means of bodily behavior as clues. In this sense they are born into the moral space. Human beings are constitutively moral beings. Their moral disposition, however, needs constant nurturance in order to grow into mature moral sensibility. Otherwise, the innate moral disposition might not express its potentiality fully, or might express itself in a severely distorted form. Human beings need to be recognized as worthy of care and respect throughout life in order to maintain moral sensibility in its proper place. Human beings are animals with boundless aspirations and inescapable finitude which exist in the midst of tremendously intricate, multi-dimensional causal connections.

Therefore, the concepts of narrative and story can help to understand human beings as they are, and hence I will argue, the complexity of particular bioethical issues and concrete meanings involved in them. Each particular human being with each own particular story is irreplaceable. Since human moral sensibility is fragile and easily degenerates, when we discuss bioethical issues, we have to take into consideration the fragility of our moral sensibility and the irreplaceability of particular human beings implicated in bioethical issues, relying in part on the help of the concepts of narrative or story.

II. The Issue of Brain Death

In this section I will apply the ideas explained in the first section to concrete bioethical issues, organ transplantation from brain-dead donors and prenatal testing, and especially, Peter Singer's position on the selective abortion of disabled fetuses.

a) The Concern Raised By Organ Transplantation from A Brain-Dead Donor

1) Dropping the Dead-donor Rule

Japan is notorious for the delay of legalizing the organ

transplantation from brain-dead donors. Now about six years after the proclamation of the organ transplantation law in Japan, there is still a small but vocal minority against the organ transplantation from brain-dead donors. They claim that a brain-dead person is still alive and, hence, an organ transplantation operation involves the killing of the donor for the benefit for the recipient. For them the organ transplantation from brain-dead donors means the sacrifice of the life of a brain-dead but living human being for the recipient, the consequent devaluation of the former, and ultimately the instrumentalization of human life. For these critics the fact that a brain-dead donor is still alive means that organ transplantation from that person is morally forbidden because killing a living donor for organs is not morally acceptable. There is, however, a very interesting trend in the field of the organ transplantation in the West, that is, the non-negligible move towards dropping so-called “dead donor rule,” the requirement of the death of a donor for organ transplantation of vital or non-paired organs. R. Truog, one of the major supporters of this move, in his seminal paper¹⁰ points out the problematic aspects of the concept of brain death and suggests that we in the United States had better abandon the concept of brain death as the death of a person. Truog differentiates three levels of the concept of brain death: definition

¹⁰ Robert D. Truog, Is It Time to Abandon Brain Death?, *Hastings Center Report* 27 no. 1, 1997

of death (the permanent cessation of functioning of the organism as a whole); criterion for death (the permanent cessation of functioning of the entire brain); and tests for death ((1)cardiological standards and (2) the neurological standards). According to him, a person who satisfies the tests of brain death does not satisfy the criterion of brain death and, hence, is still alive. While the definition of brain death says that brain death is the cessation of all the functions of brain, a person who satisfies the criteria of brain death still has indications of the presence of remaining functions of brain. Truog points out that there are inconsistencies even between the definition of death and the criterion for death. Because of the sophistication of ICU treatment, brain death does not necessarily mean the cardiac arrest and hence death within a short time. Therefore, in so far as we are loyal to the definition of brain death we must not operate on a person who satisfies the criteria of brain death, hence is brain dead in this sense. Instead, Truog suggested that we had better abandon the concept of the death of a donor as the necessary condition for organ transplantation and allow the killing of a living person for organ transplantation. Truog chose to loosen up the dead donor rule in order to increase the number of transplantable organs. For him it is acceptable to kill a person who is still alive, in so far as that person gave prior consent. This is, in a sense, the understandable development of one strand of the logic of organ transplantation driven by the severe shortage

of organs.

The purpose of organ transplantation is to save a recipient who otherwise would die. The image of organ transplantation is that of returning back to life a recipient otherwise doomed to death. It is a magnificent feat to be celebrated by everyone. People use biblical phrases, such as the “raising the dead,” or “raising Lazarus.” On the other hand, the life of a donor and a donor's family does not receive enough attention and appreciation. They are not main characters in this popular scenario. They may be appreciated for their generosity to donate organs and their benevolence is praised. The phrase such as “the gift of love” is used. Nevertheless, they are treated just as donors, an abstract category. I wonder whether supporters of organ transplantation, especially doctors of the organ transplantation team, are seriously concerned with what kinds of deaths donors die and what kinds of experience the families have at the time of the death of their beloved one. I am not so sure that such a concern has a significant place in their mind. I am afraid that the focus upon a recipient outshines the life and death of a donor and the meaning of his or her family's experience of the death of their loved one. Especially when the death of a donor is imminent, the donor's life could be taken lightly because of the comparison with the future life of a recipient after a successful operation, and the experience of the donor's family could also be marginalized. Yet, family members, facing the imminent death of their loved one,

are having a difficult and meaningful experience which could be deeply important. This description of the attitude towards a donor and its family is, at least with respect to the attitude of the organ transplantation team, a reasonable speculation on the basis of a critical examination of the early cases of organ transplantation from a brain-dead donor in Japan. Later cases are not covered by mass media, and hence people do not know critical details of those cases. The life of a donor and his or her family are not treated with the same care and attention paid to the life of a recipient. Given this tendency, Truog's bold suggestion that donors may not be required to be dead is not really so surprising.

2) The Market Approach to Organ Procurement

The severe shortage of organs produces more problematic proposals. People in persistent vegetative state are mentioned as possible donors. Moreover, the legalization of the organ market is now discussed as a legitimate and morally unproblematic way of dealing with the organ shortages. This trend surely leads to a coarsening of moral sensibility, the proverbial slippery slope mentioned above. Bit by bit, our moral precaution is being undermined. We have accepted organ transplantation from a brain-dead donor as a legitimate way of saving lives. Then, we have found that the shortage of usable organs prevents organ transplantation from expressing its full potential. The realization

of the purpose, which justified the organ transplantation from a brain-dead donor, is thwarted by the obvious obstacle, severe shortage of organs. Furthermore, there are effective ways to deal with the problem. Why not increase the opportunities for harvesting usable organs by adopting a market approach?¹¹ But in the market system what matters is that an agreement is made between supposedly independent players equally capable of consent to the bargain, and the personal reasons or the cause for making a particular agreement can be ignored as irrelevant. Why a particular donor decided to agree to sell, say, a kidney for money need not be a matter of concern for recipients. Recipients who buy organs from poor donors need not care about the well-being of the donors. The acceptance of this kind of organ procurement system which devalues the life of the sellers of organs signifies a subtle degradation of moral sensibility. Here, our moral sensibility is off balance. The life of recipient is cared about and celebrated but the life of a donor while it might not quite be slighted, at least does not receive enough care and attention, and, in the worst case, may be treated just as a source of repair materials. People initially accept with some hesitation and then come to take it for granted buying another person's organ as just another precious commodity, without caring much

¹¹ For recent moves towards the introduction of market mechanism see Donald Joralemon and Phil Cox, "Body Values : The Case Against Compensating for Transplant Organs," *Hastings Center Report* 33 no. 1, 2003

for donor's well-being. Buying an organ becomes just another commercial transaction. In the society which allows the organ market to exist, the value of the life of poor donors is not properly appreciated. This kind of trend may thrust into the open the problematic aspect of organ transplantation, the devaluation of a donor's life, which was felt but not properly focused on and was eventually pushed aside into the corner of the collective consciousness of society.

This kind of unequal treatment of recipients and donors, however, is not acceptable. The life of a dying person is still a life and to be respected as much as any other human life except under extreme circumstances such as when triage is imperative. Although the organ transplantation team may claim that they really appreciate donor's generosity and kindness and respect the life of a donor, I cannot eliminate my suspicion. The requirement of a donor's consent is important, but it is not beyond doubt that it could be used as a defensive disguise, a mere gesture towards the requirement of showing respect for the donor.

When we accept the idea that the shortening of the life of a donor as justifiable, do we really think carefully what that decision means concretely? Do not we move too breezily from the idea of a dying person to the idea of shortening of that person's life in order to rescue and resurrect another person? Are not our imagination and emotion deeply involved in that movement of our thought? Do we imagine in a concrete way the

situation with its full force of emotional impact? If we think more concretely about the significance of the death of a person and the importance of the time around the death of that person, we may think more carefully and seriously about the treatment of donors and their families. The fact that the medical system does not make a best effort to ensure the donor and his or her family have a quiet and meaningful time shows the tendency to be partial to the well-being of recipients, ignoring the well-being of donors and their families.

The kind of balance in, as it were, the moral economy, which I have discussed, is delicate and fragile. Members of a society must always be vigilant for the possible imbalance which coarsens the moral sensibility of the society as a whole. Especially in the contemporary world where the technological imperative, market mentality and a narrowed vision of life acquire dominant power, we must all the more jealously protect our fragile moral sensibility by never forgetting that the death of a particular human being is an inescapable part of organ transplantation. In the next section, I would like to discuss two major obstacles against the more concrete and meaningful discussion of life and death in bioethics.

b) Scientism and The Shadow of Cartesian Dualism: Two Major Obstacles Against Concrete and Meaningful Talk about Life and Death in Bioethics

When the issue of brain death is discussed, the focus is often on the clinical definition and criteria of death; the concrete meaning of death tends to be ignored. But death is the final part of a particular life story, hence, one of the most important parts of the story. Moreover, many other human beings are involved, because human beings are social animals; the death of a human being is not a utterly private event but a social event in the midst of the web of a variety of relationships with other human beings. Without doubt it is desirable for the story to end on a positive and life-affirmative note, and make a kind of a coherent whole to be inherited somehow by the next generation. As for the significance of the death of another person, the time of facing the dying process of a loved one is an important occasion for us to recognize all the meaning of lives and deaths of human beings, including our own life and death. We squarely face our own mortality and hence reflect on the stories of our own lives, and appreciate both the fragility and preciousness of our lives. It can deepen our appreciation of life and those people and things which support our life. Moreover, we can understand the fact that all of us share the common fate of finite mortal beings and, thereby, the sense that we are members of the community of living things can be reinforced.

But this kind of richer approach to death is not prevalent in contemporary bioethical discussion. It tends to be too abstract and dry, in other words, lacks concrete and substantive

appreciation of the significances of death.

One major reason for the lack of a richer discussion of death seems to be the influence of scientism, which rules out more humanistic or interpretive approach to life and death. Moreover, Cartesian dualism still shapes the contemporary medicine where the mind has been replaced by the brain. Hence, the contemporary version of Cartesian dualism is the brain/body dualism in which the brain is the seat of the subject that owns and controls the rest of the body. This remnant of Cartesian dualism is still dominant in contemporary biomedicine. Although natural science and scientific technology dominate our culture, we as bioethicists need not be cowed by simple-minded scientism and the remnant of Cartesian dualism. Science and scientific language are good tools for the purpose of control and prediction, but we need an alternative language and approach for dealing the issues related with moral meaning and significance. We need both kinds of languages and approaches. We are complex animals indeed and we must not be afraid of being taunted as “unscientific.” Science cannot deal with all the problems which human animals face in coping with life in the world.

c) The Humanistic Narrative Approach and the Need for a Synoptic View

We have an alternative position which takes the living human being as the basic unit and regards life as a complex narrative. That is the Wittgensteinian approach combined with narrative approach, which I discussed above. I will call this approach “the humanistic narrative approach.” If we adopt the humanistic narrative approach to life and death, we will be more sensitive with respect to the kind of the death experienced by a donor and the lives of the donor's family, and the wider (socio-politico-economic) contexts surrounding donors and their families. Thus, the humanistic narrative approach both widens our vision and provides greater sensitivity to the details of the situation surrounding organ transplantation from a brain-dead donor. As complex animals, we need both the scientific and the humanistic narrative approach, to understand and discuss bioethical issues of life and death more concretely and meaningfully.

From the humanistic narrative approach, the death of a person is the final part of that person's story that started at the time of the conception. We are animals who spin the web of significances and live not just by food alone but also by significances. It goes without saying that any human life is a tremendously complex and unique story; any person is a product of infinitely intricate causal processes and exists as a node of complex web of causal connections and meanings. From this approach, the lives of human animals are morally worthy, unique and irreplaceable. By adopting this approach, we can remind

ourselves of the fact that life is a tremendous enterprise full of meaning and that the death of each living human being is quite as tremendous an event as the final chapter of an unique and complex novel. It is the disappearance of one view of the world. On the other hand, from the objective and scientific approach, a human life is one minor character in the vast and hugely complex story of the universe. Every human being without exception dies somehow. Moreover, human beings die everyday in the world, hence, the death of a single human being is nothing exceptional. If we hew solely to a scientific approach to death, death loses its existential significances: it is just another biological event. But if we look at death from both approaches simultaneously, it looks quite different. The death of a person is a tremendous trifle, to borrow G.K. Chesterton's memorable phrase.¹² It is an event that is dramatic and mundane at the same time. Each of the two approaches is valid in its proper function. What we need is the well-balanced combination of these approaches which constitutes the synoptic view of life and death of human animals. We must adopt both of them and manage to combine both of them simultaneously in a balanced way. We should thereby learn the virtue of humility from the scientific, objective approach, while we appreciate the intrinsic value of life from the humanistic narrative approach. These two approaches to life and death

¹² G. K. Chesterton, *Tremendous Trifles*, Dodd, Mead and Company 1909.

should be incorporated into the synoptic view of life and death of human animals in the world. As Chesterton suggests, the paradoxical combination of humility and a keen awareness of one's moral worth is the proper attitude towards one's own and other people's lives and deaths. Moreover, this picture corresponds exactly to Pascal's idea that human beings are thinking reeds, which are tremendous trifles.

Wilfrid Sellars defines philosophy as the project “to understand how things in the broadest possible sense of the term hang together in the broadest possible sense of the term.”¹³ Bioethicists, especially those with philosophical training can make a significant contribution to the enrichment of bioethical discussion by following Sellars' exhortation and correcting the narrowing of the bioethical discussion, i.e. the explicit or implicit dominance of scientism. To create and refine what Sellars calls the stereoscopic vision of the scientific image and the manifest image of man in the universe is what is needed in order to find better ways to have a more balanced and realistic view of life and death.

d) The Concepts of Autonomy and Self-Determination as Effective Tools for Social Reform

¹³ Wilfrid Sellars, "Philosophy and the Scientific Image of Man" in his *Science, Perception and Reality*, Routledge and Kegan Paul 1963, p. 1

Finally, I would like to discuss how the humanistic narrative approach can contribute to the guarantee of authenticity of self-determination or autonomous decision-making and why autonomy and self-determination are effective tools for social reform. As mentioned before, the concept of self-determination plays an important role in bioethical discussions. The field of organ transplantation is not an exception. The donor's self-determination plays the role of a trump card in discussions of organ transplantation from brain-dead donors. But if we pay attention to a story behind the apparent self-determination, we would find much more complex elements involved. Promotional efforts by governments and other institutions, including withholding crucial information from the public, moral pressure from society and family, etc., contribute to shape one's decision. Hence, the right to self-determination could be a precious tool for a person vulnerable to oppression for various reasons. Some people criticize the concept because it can be easily turned into the tool of oppression by the powerful. That is, the decision made under hidden and subtle pressure that seems to be an autonomous decision may be used as the justifying reason for whatever is wanted by the powers that be. For example, someone's decision to be euthanized might be caused by the social pressure to reduce the medical expenses or the lack of social support network. The decision to be euthanized voluntarily is the exercise of the right to self-determination, no one is supposed to be able to object or

intervene in the process, if voluntary euthanasia is legal in that jurisdiction. But apparently autonomous decisions may be the result of an unnecessarily narrow set of options, due to a bad allocation of resources by a society, such as a lack of good hospices. Certainly there is a danger of subtly coerced “decisions” that are taken to override any criticism in the name of “self-determination.” Hence, we must carefully examine the whole story behind a decision in question. The possibility of such a coerced “autonomous decision” is not, however, a good reason for denigrating the concept of autonomy itself. On the contrary, that kind of situation must be exposed and corrected in a systematic way to guarantee the authenticity of the self-determination. The core of the right to self-determination is the respect for person's dignity to decide his own life. So we should use the concept with the proviso that the authenticity of the exercise of the right must be jealously pursued and guaranteed. The concept can be used not just as the means of the increasing the authority of the self-determination but also as the means of criticizing and thereby reforming oppressive social environments. The story of self-determination cannot be separated from the story of social reform, including the moral and cultural aspects of a society.

Thus, the humanistic narrative approach can make a contribution not only to the deepening and enrichment of bioethical discussion, but also to social reform by encouraging a

focus on both the particular and also the wider aspects of each case. In the next section I would like to use the humanistic narrative approach to life and death in order to criticize Peter Singer's approach to the treatment of a fetus with a genetic disability.

III. Peter Singer's Approach to Disability and Selective Abortion

In this section I will argue that the approach which I recommend can give a better and enriched approach to the issue of disability and prenatal testing.

In his article "Shopping at the Genetic Supermarket" Peter Singer argues that disability is negative element in one's life which reduces the moral worth of a human animal with disability, and that hence the abortion of disabled fetuses and the killing of infants of up to 28 days old might be justified. There he claims homosexuality as one example of disability among others; he agrees with Stephen Macedo's idea that homosexuality is a disability because the shared participation in pregnancy and new life is not fully available to homosexual couples.¹⁴ Singer thinks

¹⁴ Peter Singer, "Shopping at the Genetic Supermarket," in *Asian Bioethics in the 21st Century*, Proceedings of the Fourth Asian Conference of Bioethics, 2002, pp. 181-183

this fact is sufficient reason for a justifiable abortion. I basically agree with him that the claim that disability is not a negative element at all is unreasonable. This does not necessarily imply, however, that life with disability must be worse than life without disability, in other words, that the quality of life with disability is less than that of life without disability.

I claim that Singer makes a literally fatal error of forgetting the familiar truth that the whole is more than mere sum of parts applies to life, which has an organic and dynamic unity. In the first part of his paper Singer argues successfully, I think, that disability is a negative factor. Then, he makes a claim which implies that the general quality of life, or even the value of life, with a given disability is lower than that of life without disability. Here he makes a big inferential jump. The fact that disability in itself has negative value does not entail that the general quality of life with a disability, or even the value of life with disability is lower than that of life without disability. Life is not that simple. From the vantage point of the humanistic narrative approach, the core of the problem of Peter Singer's attitude towards disability is that he evaluates disability in itself apart from the context of the life as a whole of a human animal with a disability. Human beings' stories are very complex and some of them can be dramatic enough to defy the stereotype. Indeed, disability is one characteristic of a human being and has a certain value in itself, albeit often a negative value. As a human being's feature,

however, it acquires a value in the context of the whole life story of that human being. Because human life is a complex story which can develop in unexpected ways due to the tremendously intricate causal connections, we cannot tell how one's life turns out. That is why disabled person whose life is expected to be miserable, or at least very hard, can turn out to be happy and feel his or her life is full of meaning. The life of people with disability cannot and must not be evaluated apart from the context of those people's personal and social environment. The idea that we can do that is an expression of prejudice and a narrow and abstract vision of life in general. That prejudice often seems to be due to the basic premise accepted deep down in one's basic image of life. It says that the life of a competent, sophisticated and wealthy middle-class person who fares well in the present, capitalistic society is the standard of normal life. Fortunately, there are more things in life than dreamt of in professional philosopher's abstract speculation. In real life's arithmetic or alchemy minuses can create huge pluses through intricate causal connections. The lives of disabled people could be quite rich and worth living. Harriet McBryde Johnson's and Helen Keller's life are just a hint of the wider range of meaningful lives of people with disabilities. Obviously as many disability advocates persuasively claim, it is the environment which greatly affects the quality of life of a person with disability, and that can be ameliorated to a considerable extent if the society

is willing to make adjustments to improve the lives of individuals with disabilities. The quality of life of people with disabilities is not fixed but malleable, improving in proportion with the increase of proper social support. Therefore, to evaluate the value of life with disability apart from the context of personal and social context of each person is not just impossible but also creates a pernicious influence on people's attitudes towards life with disability. Hence, we had better not adopt the approach to life that encourages people to evaluate disability separate from its social environment. Instead, we must adopt the humanistic narrative approach towards life.

When we think about bioethical issues, for example when we have to deal with the issue of how to treat the issue of disability, we must consider what kind of society we would like to create and live in. We had better direct our efforts towards reforming every aspect of our society in such a way that there is a rich variety of options for people with disabilities, which enable them to choose their own ways of leading a meaningful life. Since human beings are fragile, the society which supports the efforts of people with disability to lead meaningful life can give the sense of security to other, “temporarily abled” members of the society, which in turn reduces the survivalist mentality that contributes greatly to the coarsening of our moral sensibility. There is a choice we can make. One option could lead to the vicious cycle in which the lack of social support leads to the

worsening of life with disability, hence, apparently verifying the Singer's judgment and furthering the reduction of the support. The other option could lead to the virtuous cycle in which the social support could lead to the improvement of life with disability and the increase of the sense of security of all people in the society and a furthering of social support.

Singer and others who share a similar way of thinking use the kinds of examples which magnify the problematic aspects of disabilities. Their examples are designed to make people focus on disability in exclusion of other aspects of life, including the possible positive result of life's alchemy that can come from a life with disability. For example, Singer mentions Jonathan Glover's claim that "if we do not have enough resources to treat all the sick, when it comes to tough decisions about saving their lives, some of the sick are less equal than others."¹⁵ In another example, Singer uses another hypothetical situation, that is, "there are two infants in the neonatal intensive care unit, and we have the resources to save only one of them," in order to show that "there is a clear sense in which we do not value both children equally."¹⁶ The contexts of these examples are all hypothetical impoverished ones where there is no personal and social supports which could improve the life with those disabilities, in other words, in their examples disabilities are

¹⁵ Peter Singer, "Shopping at the Genetic Supermarket," p. 175

¹⁶ Peter Singer, "Shopping at the Genetic Supermarket," p. 176

separated from real life contexts with its multiplicity of different possibilities. There is no room for life's alchemy, which may produce meaningful life out of negative elements, such as disability. Furthermore, his premise also plays the role of drawing out into the open our survivalist mentality. But fortunately our situations surrounding selective abortion in the present world are not so desperate as to accept the survivalist attitude as a reasonable one. There are other options. But Singer's examples tend to divert our attention from factors of life which could be reformed or ameliorated in the direction of increasing the options for human beings with disabilities and of increasing the sense of security of these people. Hence, the humanistic narrative approach to life and death is much more preferable than Singer's abstract, over-simplified approach.

In addition, the humanistic narrative approach to life and death has another merit when we think about abortion on the basis of genetic disability. That is, that approach can make it easier for us to understand our common fate, which we share as fragile and vulnerable animals with an irrepressible desire to relationship with other human beings. Jean Vanier, the founder of L'Arche,¹⁷ says that he learns from mentally handicapped people. Those people who are free from social conventions express freely their desire for human relationship. Vanier and other caretakers at

¹⁷ The community for mentally disabled people founded by Jean Vanier

L'Arche learn the presence of unmistakable desire for human relationship in the depth of those people's beings and their own beings. I presume that this kind of learning can make care-givers acquire the compassionate regard towards those people suffering mental disturbances. The compassionate regard is based on heartfelt recognition of the fact that people with mental handicap and their caretaker share the common fate as human beings, that all of us fragile and vulnerable animals have a deep desire for human relationships. Jean Vanier says the following.

I came to visit them. I was embarrassed, not knowing quite how to communicate with people who couldn't talk very well, and wondering, even if they could, what we would talk about. But I was touched by these men. By some word or gesture or through the look in their eyes they seemed to be saying to me, "Do you love me?" At the time, I was teaching philosophy at the University of Toronto, where my students were interested in my intelligence, in what I could teach them so that they could pass their exams. But these men didn't care about what was in my head; they were interested in my person, in my heart and in my capacity to relate.¹⁸

Vanier also tells us on the basis of his experience

¹⁸ Jean Vanier, "Understanding Our Brokenness" in *Spiritual Journeys*, 15 quoted by John F. Kavanaugh, S. J., *Who Count as Persons? : Human Identity and the Ethics of Killing*, Georgetown University Press 2001, p. 157

When people with disabilities sense that they are accepted and loved just as they are, when they are seen as someone of value with a gift to give, when they feel appreciated for their creative activities and work, they blossom forth. Energies are awakened in them. Life has meaning. This acceptance and respect is not just the work of professionals but of the whole local community---every one of us. A society where those who are “different”---weak and less autonomous---can find their place, is a society that is becoming more fully human, a society where together we can celebrate life.¹⁹

The quality of life of human animals is not static but fluctuates with the quality of their relationship with other people and the society in which they live. The attitude of unconditional acceptance and respect towards people with mental handicaps shown by Vanier is similar to the parent's love for their child, which is the basis of human morality. The kind of experience of being accepted and loved is the bedrock of human morality. On this kind of basis, each of us comes to be able to cope with the world. Our basic trust in life and society originates from this childhood experience. Hence, this kind of unconditional acceptance is the essential for the maintenance and enrichment of any decent society. Society should not only maintain but also

¹⁹ Jean Vanier, "A Gift to Give," *Transition Magazine* Spring 2002, Vol. 32 No. 1 <http://www.vifamily.ca/tm/321/2.htm>

foster and expand this kind of attitude towards each other. Our humanistic narrative approach to life and death can make a significant contribution to fostering this kind of attitude by making us more sensitive to concrete aspects of our life as fragile and vulnerable human animals with reason and heart.

On other hand, if we pay attention to the complex aspect of life in a concrete way, it is not easy to agree with those people who demand the complete ban of prenatal testing which can lead to selective abortion. With life is as it is, there must be that kind of option. But the presence of the option and the fact that people adopt the option should give more reasons and resolution to change the society and people's attitude and its correlated conceptual framework. People who oppose selective abortion on the basis of disability had better focus their efforts on changing people's attitudes towards life with disability and ameliorating a variety of institutional structures in the society to help improve the quality of life with disability. Especially in the aging societies of the developed nations, there are political opportunities to mobilize people to participate in their movement. That kind of activity would be far more productive than a campaign with accusatory rhetoric for the total ban of prenatal testing. Bioethicists can contribute to this effort by providing the theoretical framework in terms of which people can discuss issues more open-mindedly, free from the remnants of Cartesian dualism. These efforts cannot change the situation quickly, but

can change the vantage point from which people discuss the issues. Bioethicists can especially help to create and propagate what Michael Berube calls “a more capacious and supple sense of what it is to be human.”²⁰

Thus, Peter Singer's position on disability and selective abortion suffers from the abstractness and narrowness of his regard with respect to human beings with disability. A more compassionate regard towards them supported by the humanistic narrative attitude can make it possible for bioethicists to discuss issues in a concrete way with a proper understanding of the complexity of particular cases. The main focus must be on a particular human being with a particular story on the particular historical stage of the society. For example, the question such as whether someone's wish to be an organ donor is reasonable in light of his life story as a whole. Even general discussion should be underwritten by the insights that result from this kind of focus on the particularities of issues.

Conclusion: Against the Dehumanizing Force

However, the present reality is far from the ideal.

²⁰ Quoted by Martha Nussbaum in "Disabled Lives: Who Cares?" *The New York*

“Children with disabilities are over-represented in families with low-income for two reasons: first, because the extra time required for care leaves less time for the parents to do paid work, and second, because these families face higher out-of-pocket expenses.”²¹

In spite of the efforts of people like Jean Vanier, people with disabilities are still struggling with prejudices and the lack of social support. In the contemporary world, not only persons with disabilities but even temporarily-abled people are struggling in their everyday life with the harsh reality of a world where competition for material wealth and power is encouraged and celebrated. In Japan, many children have to go to cram schools after regular schools to get into prestigious schools which are supposed to give them a ticket to success. Children in Japan tend to get subjected to control by school authorities. For example, intrusive monitoring their daily activities all year round occurs in certain regions. In addition, recently the number of suicides in Japan has risen to over thirty thousand a year. Especially after the economic bubble broke and so-called restructuring started, the number of suicides by middle-aged people increased. Workers and small business owners are abandoned by companies and

Review of Books, January 11, 2001 p. 37.

²¹ Judith Maxwell of The Canadian Policy Research Network, quoted in Donna McCloskey, *Transition Magazine* Spring 2002 Vol. 32 No. 1, <http://www.vifamily.ca/tm/321/notes.htm>

banks without a decent, social safety net. Japanese society needs to change its attitude towards human life; otherwise, there will be even more suicides. And Japan is just one example. In the contemporary world you can see the overwhelming power of dehumanizing forces. Our life is full of fear, such as fear of losing in competition, being neglected, etc. Fear of disability is one of our fears and one of major causes of prejudice against persons with disability. We must fight with those fears by recognizing the humanity of each other, our common fragile humanity. Spinoza says that man is the best thing for man. We have to remember repeatedly this basic fact of human life. We should make our best effort to foster the kind of attitude towards human life that gives a proper respect for particular human beings, each with a particular story of one's own.

This paper is one which recommends a more concrete discussion of bioethical issues without giving many concrete examples. This paper is just a mere suggestion of the direction to be pursued by bioethics. I give only a vision of human life on the basis of which we can pursue bioethical inquiry which tries to be more loyal to the concrete and multi-dimensional reality of human life. Ethnography, sociology, religious doctrine, literature, etc., we have to avail ourselves of anything which can help to understand the real situations of particular human individuals. But what is most important is to keep a compassionate regard for the fellow human beings. A character in Arthur Miller's "The

Death of a Salesman” says “But he's a human being, and a terrible thing is happening to him. So attention must be paid. He's not to be allowed to fall into his grave like an old dog. Attention, attention must be finally paid to such a person.”²²

Not only a salesman who lost in the sales race but all of us are fragile and vulnerable and need attention to be recognized as human being with equal dignity. Iris Murdoch also uses the phrase “the idea of a patient, loving regard, directed upon a person, a thing, a situation”²³ and “the word ‘attention’ which I borrowed from Simone Weil, to express the idea of a just and loving gaze directed upon an individual reality”²⁴ ---the attentive regard towards human individuals in the present world, their tremendously complex stories. I yearn for the development of the kind of bioethics that deals with bioethical issues with a kind of loving and compassionate attention toward particular individuals caught in the tragic dilemma that originated from the boundless aspirations and inescapable finitude of human animals.

²² Arthur Miller, "Death of a Salesman" Penguin Books 1961, p. 44

²³ Iris Murdoch, "The Idea of Perfection" in her *Existentialists and Mystics*, Chatto & Windus 1997, p. 331

²⁴ *Op. cit.*, p. 327