BIOETHICAL EDUCATION ON DELIBERATION: THE VIEWS OF A NOVEL

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ABSTRACT

Ethics is the study of the moral basis of human behavior that aims to determine the best course of action. Bioethics, as a transdisciplinary area, based both on ethics and on life sciences, reflects upon the ethical problems raised by new technologies and scientific research. One of the main tools to tackle bioethical problems is deliberation, a procedure that attempts to analyse problems, weighing up the principles and values involved as well as the context of each case. Due to the complexity of deliberation, educational projects should be promoted, providing the practice necessary for correct deliberation and raising awareness of the current ethical issues.

It is our purpose to present a framework for ethical deliberation throughout the use of literature. Literary texts are essential, since they show human beings acting in space and time and they give the readers an opportunity to deliberate on ethical issues. Based on a literary text, we will reflect upon a controversial ethical issue - Preimplantion Genetic Diagnosis (PGD).

Keywords: *Bioethics, ethical deliberation, Literature, Preimplantation Genetic Diagnosis*

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1. A model for deliberation

Ethics reflects upon human conduct *aiming at the good life with and for others, in just institutions* (Ricouer, P.,1992,p. 172). The issue we have to address is how we can decide the best way to act, choose the most prudent course of action, when we face conflicting principles/values as alternatives that exist precisely because we are free human beings. The imperative to decide and act is therefore inscribed in a context of free will, which is nonetheless determined by individual and social influences: 1) individual influences, such as age, character, natural talents, circumstances; 2) social influences, such as education and society. According to Aristotle, who taught deliberation as the main procedure of ethics, (moral) wisdom and (moral) knowledge originate from reflections on and within concrete situations, being thus impossible to separate moral truth from experience. Moral decisions, Aristotle further emphasized, are not a product of instrumental reasoning, calculation or logic, but flow from wise judgment, perceptiveness, imaginative understanding and an engagement with practice. In a nutshell, the meaning and construction of morality is inherently contextual and temporal.

Consequently, the first step to promote solid deliberation is to make individuals aware of the different factors that intervene in this process, of the different steps to be followed, and most importantly, of the situational nature of deliberative procedures. Moreover, one should also provide them with the opportunity to develop second-degree virtues, i.e. virtues that allow one to consider moral problems carefully and to act according to the results from the ethical reflection previously done. It is not enough to be compassionate, brave or benevolent (first-degree virtues), because when it comes to act, the second-degree virtues are the ones that make the bridge between the moral judgment and the intention to choose a course of action that respects this judgment. We think that this bridge can only be built by educating the future citizens who will have to decide upon controversial issues affecting their own lives and the lives of the next generations.

Different models have been designed to describe the ethical decision making process, being one of them by T.M. Jones (1991) – *An issue contingent model,* which is based on the idea that the moral intensity of a particular situation influences the way the individuals perceive that situation and the way they decide to act. There is thus a correlation between the moral intensity of a situation and the perception and ethical intention of the subject. In Jones' model moral intensity is defined according to six components: **magnitude of consequences**; **probability of effect**; **temporal immediacy; concentration of effect**; **proximity**; **social consensus**. A person's collective assessment of these characteristics results in a given situation's moral intensity. In general, issues with high moral intensity will be recognized as ethical dilemmas more often than those with low moral intensity, leading to a positive relationship between **moral intensity** and **perception** of an ethical problem. Furthermore, issues with high moral intensity have a positive relationship with an individual's **intention** to behave in an ethical manner. The fact that moral intensity is a key component in ethical decision making underlines the need previously mentioned of educating individuals on potential consequences and implications of ethical problems, so that their perception and decision making skills can be sharpened, when they encounter ethically sensitive situations. Other authors have proposed different models of ethical decision making, which share some items with Jones' model:

- Dawson W. Carlson et.al. (1997) have analyzed the impact of concentration of effect, probability of effect and proximity on the ethical decision making process and they added a variable that is not considered by Jones in his model – **Orientation.** This variable refers to the role played by the decision maker as the subject of the action, as an external advisor or as an element of an organization.
- Susan J. Harrington (1997) has also tested two of Jones's model steps (moral judgment and moral intent), by analyzing the strength of **social consensus** and of the **seriousness of consequences** on these steps. Moreover, the study goes further and examines different levels of social consensus and how they interact with important individual characteristics of **rule orientation** and **denial of responsibility** (how the former influences moral judgment and how the latter influences moral intent). Based on Jones' model, Harrington states that social

consensus, i.e. the degree of social agreement that a proposed act is evil or good, influences ethical behavior: the stronger the social consensus against some unethical behavior is, the more likely it will act as instructions for behaviour. However, Harrington says that moral orientation and moral judgment do not give full explanation to moral behaviour, since this one is also related to moral intent – what the individual intends to do in an ethically controversial situation. Possible reasons for the gap between moral judgment and moral intent are: considering other personal values more important than the moral ones at stake; lack of recognition of an ethical issue or previous exposure to the issue, thus responding with less deliberate thinking; or neutralizing moral judgments by **denying responsibility (RD)** for the results. **RD** mediates between self standards (moral orientation and moral judgment) and ethical behaviour: i.e. RD acts to neutralize self standards. Therefore we can say that whenever there is lack of social consensus against a particular type of behaviour, it will be more likely that those high in RD will agree with an unethical behaviour.

Jones' model (1991) as well as other models of ethical decision making (Gracia, D., 2003; Rest, J.R., 1984; Trevino, L. K., 1986; Vitel et. al., 1993) - see references to other models - usually include four basic stages: 1) **recognition** of the **moral issue**; 2) **moral judgment** about which course of action is morally right; 3) formation of a **moral intent**, that may not accomplish the moral judgment made before if this one collides with the individual's previous desires; 4) **moral behaviour**, which requires the motivation to act according to the moral intent.

2. Bioethics and Literature

Nowadays ethical decision making plays a key role in response to the dizzying advances in technology and the profound socio-political changes in a world caught up in globalization and multiculturalism. Therefore, it would appear to be of paramount importance that this new area of knowledge be properly disclosed and explained to civil society in order to seek their engagement. In fact, it is more and more important that students and society in general understand the need of well-reasoned judgments, combined with respect and empathy for other approaches.

It should go without saying that the transdisciplinary nature of bioethics demands different perspectives when dealing with ethical issues. These varied points of view are usually grouped under two kinds of approaches, mainly the *wide-range approach* and the *in-depth* one. The former is mainly related with the global and extensive view of ethical issues by responsible politicians, mass media, inter-disciplinary research groups and opinion makers; the latter is the basis of the research carried out by philosophers, religions and ethicists. Both approaches require educating the way we see the world, the way we speak about it, the way we reflect upon it and the way we act (hopefully) according to the steps taken before. Choosing the most prudent and the most appropriate course of action in a particular setting, with and for the others, considering not only the individuals directly affected by the decision, but also their community and the biosphere, was also the project outlined by Van Rensselaer Potter in his papers "Bioethics: the Science of Survival" (1970) and "Bioethics: Bridge to the future" (1971). Potter had a global perspective of Bioethics as a discipline that could set up the bridge between the ethical values of Humanities and the biological facts of Life Sciences, which he considered to be indispensable to guarantee the survival of Human Kind. Therefore, global bioethics is a concept coined by Potter, which he later included in the title of one of his works: "Global Bioethics: Building on the Leopold Legacy" (1988). Only by educating our sight can we fully understand the concept of global bioethics, focusing our reflection not only on the individuals, but also and most importantly on the Other that is part of each individuals' sense of their own identity. Moreover, education can provide citizens with the tools to participate in ethical deliberation on issues that concern not only the nature of scientific research and doctor/patient relationship, but also the survival of Human Kind with a human sense. Actually, these days Bioethics is considered by many experts as a civic ethics, i.e. as an ethics shared by the members of a community who see themselves as co-authors of the narrative of that society. According to M. C. Patrão Neves and W. Osswald (2000), the three main reasons for the current role of Bioethics as a civic ethics are: the lack of universal moral foundations, which can either lead to deep relativism or to the search for rules and guidelines applied to the particular setting under analysis; the Death of God, of the Author, of the unified subject, which has also led to the need

of wide deliberation procedures, from different perspectives, that can be achieved by Bioethics due to its transdisciplinary nature; furthermore, the fact that Bioethics has been organized in institutions has also contributed to its functional role in our days. As applied ethics, Bioethics has a public dimension that has a strong impact on public opinion, providing the citizens with information and formation about the ethical issues underlying different areas of human action. The wide range of resources available in bioethics education provides different tools that can be explored according to the topic under discussion, the subjects participating in the ethical deliberation procedure and the kind of approach used to analyse the ethical issues. Choosing literary texts as a resource for Bioethics education means that this approach must be anthropological, bio-cultural, a revision of ethics as a dialogical search and not as a source of ready-made answers or recipes:

Today there are logocentric habits and an educational philophy focused on conveying information and training experts, which highlights the pragmatic and the scientific, the efficient and the instrumental dimensions of human life, but forgets the key role of imagination and memory. In fact,memory and imagination were the basis of a free, critical and creative thought of the greek civilization (Clavel, 2004, p. 77, our translation)

The metaphorical structure of literary texts – which implies a reading strategy of suspending the literal reference and locating the meaning between the world of the text and the text of the world – gives them the power to release a second-degree reference that provides the reader with the opportunity to see something in a certain way, thus shedding new light on the world and increasing human knowledge. Umberto Eco (2002) conceives of Literature as an enlightening source, which contributes to the building of language and cultural identity, while disclosing the vulnerable trait of humanity: literary texts reveal the impossibility of changing the course of their story, even if it is against the readers' will. Literature shows human beings acting in space and throughout time, making the readers aware of the limits and of the conditioning of their existence together with their freedom of choice. David Lodge (2009) adds to the ideas outlined by Eco that literary texts also express the uniqueness of each human being, since they are written in a singular and unrepeatable way, even when they recycle stories or import characters from other stories. It is this singularity together with a universal dimension that makes literary texts the place where experience can be deeply represented, making the reader see what characters tell, even when they tell it in the first person:

There is no ethically neutral narrative. Literature is a vast laboratory in which we experiment with estimations, evaluations, and judgments of approval and condemnation through which narrativity serves as a propaedeutic to ethics. (Ricoeur, P., 1992, p. 115)

It is important to notice, that the knowledge provided by literary texts will only be achieved through hermeneutics, i.e. through interpretation, which gives the reader an important role in this linguistic process rooted in the objective facts of the world and in the subjective interpretation of the individual who interprets them. It is precisely this hermeneutic process that sets up a bridge between narrative and identity:

By narrating a life of which I am not the author as to existence, I make myself its coauthor as to its meaning (…) It is precisely because of the elusive character of real life that we need the help of fiction to organize life retrospectively, after the fact, prepared to take as provisional and open to revision any figure of emplotment borrowed from fiction or from history. (Ibidem, p. 162)

2.1 The views of a novel
My Sister's Keeper, a novel by Jody Picoult (2004), makes us see this process of building identity through narratives told by the different characters that *attest* the Self that states *here is where I stand*, the Self that remains as time goes by, the Self that keeps the promise of being *Oneself as Another*. All the narratives embedded in Picoult's novel are thus linked by the hermeneutical process that created them, that is represented by them and that they in turn ask from the readers.

As Ricoeur points out in *The Rule of Metaphor* (2006, p. 6), the work of interpretation involved in understanding a metaphor is itself part of the knowledge provided by metaphorical language, which, in the case of Jodi Picoult's novel, could be translated as follows: the different

perspectives from the characters given to the reader are part of the reader's interpretation and they underline the role of the very process of building a way of seeing the world.

I was born because a scientist managed to hook up my mother's eggs and my father's sperm to create a specific combination of precious genetic material. (pp. 7-8)

The Fitzgeralds (Sara and Brian) have a two-year old daughter, Kate, who has acute promyelocytic leukemia and are informed by the oncologist -- Dr. Chance -- that, since Kate's brother, Jess, is not a genetic match, they have to find an unrelated donor in the national marrow registry or have another child, a savior sibling (Anna). Interestingly, the slippery slope argument related to the use of IVF (medically-assisted reproduction) is part of a conversation between the reporter for the newsmagazine, Nadya, who interviews the Fitzgeralds, and this couple:

Nadya looks down at her notes. 'You've received hate mail, haven't you?'
Brian nods. 'People seem to think that we're trying to make a designer baby.'
'Aren't you?'
'We didn't ask for a baby with blue eyes, or one that would grow to be six feet tall, or one that would have an IQ of two hundred. Sure, we asked for specific purposes – but they're not anything one would ever consider to be model human traits. They're just Kate's traits. We don't want a superbaby; we just want to save our daughter's life. (pp. 102-3)

According to the slippery slope argument, by allowing savior siblings, which may be morally acceptable, we will start a slide towards other practices that are ethically unacceptable, such as creating designer babies. In bioethical discussions of PGD and Prenatal Diagnosis, eugenics and slippery slope are key concepts that refer to the potential danger of opening the lid of the Pandora's box, leading to a perception of humanity based only on Utilitarianism. This utilitarian attitude could range from treating the other as an Object to assuming the right to create tailor-made human beings (eugenics, the science of improving the human stock according to Francis Galton's definition in 1883). On top of this, PGD is ethically controversial because of the surplus embryos, that may be destroyed in spite of being healthy:

The doctor was able to screen several embryos to see which one, if any, would be the ideal donor for Kate. We were lucky enough to have one out of four – and it was implanted through IVF. (p. 102)

In *My Sister's Keeper*, the IVF is used as a technical procedure to find out an HLA matched donor, combined with PGD to select the embryo that would save Kate and it is precisely this saviour trait that seems to efface the identity of Anna, who is born with the purpose of giving life to her sister:

Although I am nine months pregnant, although I have had plenty of time to dream, I have not really considered the specifics of this child. I have thought of this daughter only in terms of what she will be able to do for the daughter I already have. (p. 100)

Considering Kant's principle of humanity, *which states that one should act in such a way that you always treat humanity, whether in your own person or in the person of another, never simply as a means, but always at the same time as an end*, Sara's statement quoted above can be read as the disclosure of the potential utilitarianism underlying some procedures of IVF. There are a number of fallacies misguiding the reflection upon the use of IVF, and one of them is the conviction that couples have the right to have a child, as if the child could be considered a commodity, something that one can possess, the object of another's power. Autonomy is often used to justify the translation of the *wish* to have a child into the *right* to have one, which is also fallacious, because autonomy can only be ethically acceptable when it is applied to oneself or to the respect for the other, never as a claim for the other, in this case, a claim for the child to be born. (Patrão Neves, M.C., 2008)

When the Fitzgeralds decide to have another child to save Kate, they act out of the assumption that they have the right to choose between having another child or letting Kate wait for a donor and probably die. From a Kantian perspective, autonomy is the intrinsic characteristic of the Will

that makes it rule for itself according to a maximum that should become a universal law. Therefore, freedom and morality are dependent upon each other, and the community built on these principles is open to the respect for the person seen as an end in him/herself and not only as a means. The recognition of one's dignity by the others is undermined by a narrative that reduces Kate to her disease and her siblings to *stereotyped* figures in a plot:

'Don't mess with the system, Anna,' he (Jess) says bitterly. 'We've all got our scripts down pat. Kate plays **the Martyr**. I'm **the Lost Cause**. And you, you're **the Peacekeeper**.' (our highlights, p. 15)

The isolated individualism, where duty is replaced by the right to have and to be according to the individual's wish, is the result of seeing autonomy as the quality of being free from all external coercion (negative meaning), which contrasts with the respect for autonomy defined by Beauchamp and Childress:

To respect an autonomous agent is, at a minimum, to acknowledge that person's right to hold views, to make choices, and to take actions, based on personal values and beliefs. Such respect involves action, not merely a respectful attitude. It also requires more than non-interference in other's personal affairs. It includes, at least in some contexts, obligations to build up or maintain other's capacities for autonomous choice, while helping to allay fears and other conditions that destroy or disrupt their autonomous actions. (Beauchamp, T.L.; Childress, J.F., 2001, p. 63)

To enact this respect for autonomy, one should not take this principle as an isolated one, ruling over the other bioethical principles, as if it were autonomous from beneficence, nonmaleficence, integrity, solidarity and vulnerability. In fact, individuals are *emotional, embodied, desiring, creative, and feeling, as well as rational, creatures (Mackenzie, C.; Stoljar, N., 2009, p. 21)*, and only by acknowledging these features, do we respect each individual's autonomy, the capacity to choose their course of action, as well as their own communities, the so called *communities of choice*:

[T]o value these communities is to reject the strong descriptive claim that we are so constituted by social relations and shared values that we are unable to reconsider our attachment to them. (ibidem, p. 68)

Interestingly, relational autonomy and the agent's freedom of choice imply human features that are also worked out by reading literary texts, namely *memory, imagination and emotional disposition and attitudes* (ibidem, p.21).

Reading *My Sister's Keeper* in search for Anna's identity - *the sister's keeper* referred to in the title - we are faced with a narrative about *invisibility* and *ready-made scripts*, with characters looking forward to having their autonomy/identity respected/recognized:

My throat closes like a shutter of a camera, so that any air or excuses must move through a tunnel as thin as a pin. I'm invisible (…) (p. 54)
My father looked right at me, but he didn't answer. And his eyes were dazed and staring through me, like I was made out of smoke. / That was the first time I thought that maybe I was. (p. 245)
Parents control everything, unless you are like Jess and you do enough to upset them that they'd rather ignore you than pretend you actually exist. (p. 302)

By acting according to one's values, we actually give value to the Value and this could stand as the main argument for being against the use of PGD to save an existing child: the act of having a child for utilitarian reasons withdraws the value of the dignity that we apparently address to the life we are trying to save. The deliberation process that leads to the decision of *giving birth to a saviour* does not focus on the context where the decision will be acted out, but only on two elements of the context –the sick child and the parents. Therefore, we could say, that the ethical issues of *My Sister's Keeper* are raised by a deliberation model supported by a linguistic structure, which is based on a substitution theory or the theory of making one term invisible while putting the other on the stage. This linguistic structure or trope, which fosters the

invisibility of some characters and the excessive visibility of others, is metaphor considered as the trope that allows us to see a familiar thing in a new light. For Aristotle, metaphor – e.g. *Achilles is a lion* - borrows from one domain (that of animals) and is a substitution for a word belonging to another domain (that of people), creating an alien effect and providing the reader with new information. The substitution theory underlining this concept of metaphor on the level of the word is related to the reasoning strategy used to decide whether to have a savior sibling for Kate. In fact, if one deliberates by considering the individual meaning of a certain human action (PGD as an instrument used to have a matched donor, a medicine embryo, a saviour) and its consequences, without taking into account the values underlying it and the narratives of the different individuals involved, then we could say that the deliberation process would be ruled by a metaphorical/substitution theory. This is the main reason why Anna tells her story against a narrative that tries to efface her; the reason why this novel is made up of different narratives, each one trying to build up their own identity - the narrative identity that bridges the gap between the *Ipse (who I am)* and the *Idem (what I am)* (Ricoeur,1992); the reason why Anna sees herself being looked at as a word replacing another word – Kate. Paradoxically, Kate's voice is never heard except for the echo of her words in other people's mouth and after Anna's death. It is ironical that the one whose life is being kept at the expense of respecting the others' autonomy is not given her own voice until her sister's death.

On the other hand, we could consider metaphor as a trope based on tension and not substitution, on interaction and not on replacement. For Ricoeur metaphor works not on the level of individual words, but at the level of the sentence and of the discourse, thus it does not work by substituting a *deviant* term for another *proper* term, but by the interaction between the focus (Anna) and the frame (Kate) within the context of the whole sentence (the family). *Anna is Kate* is the metaphor that should not have been accepted by the family at the moment they considered having a child that was not part of their parental project and that was born for purposes other than giving life to her. The other metaphorical proposition – *Sara and Brian are Kate* – should also have been eliminated if the deliberation process had been carried out by considering all the elements that are actually affected by it: Sara, Brian Kate, Jess and Anna. The first step in this deliberation procedure should be to analyse *the context*, the *conflicting values/principles at stake*, to reflect upon the *situational factors* that influence the ethical decision making: life stage, cultural background, general knowledge and specific information about the issues being discussed, peer pressure, social consensus, seriousness of consequences and individual characteristics, such as rule orientation and denial of responsibility. By applying this framework of analysis to each character's course of reflection and decision making, we are allowed to actually practise the ethical deliberation process, becoming aware of the key role played by **Orientation**, i.e. the role played by the decision maker as the subject of the action (the characters of the novel), as an external advisor (the readers, when they step out of the novel and perceive it from the border line between reality and fiction) or as an element of an organization (the characters of this novel who play the role of doctors in hospitals, geneticists in labs, judges in courts). Moreover, by getting inside the story as readers who see from the characters eyes, we are also faced with the impact of moral intensity on ethical decision making, mainly the impact of **temporal immediacy, probability of effect and proximity**. On the other hand, moving out from the plot of the novel to our own *story*, we can now have a wider and at the same time deeper view of the ethical issues at stake, which provides us with the possibility of producing an answer and yielding a choice or decision, but not of finding **the** right answer, since, as we stated before, this is not the aim of ethical deliberation.

Let us focus now on Anna's decision to stop being a donor to Kate and on Kate's decision to stop being submitted to medical procedures aimed at finding the cure at all costs. Anna builds her own narrative based on key concepts developed throughout the story, mainly the concept of otherness, utilitarianism and invisibility. It is a narrative written both by Anna's experience and by her parents' version of their family's life. Anna decides to stop to stand up for her autonomy and integrity. On the other hand, there is Kate, whose narrative is mostly conveyed by other characters' voices, thus making us read it as a narrative about an identity that has been reduced to one single trait: cancer. Her decision to stop is thus motivated by the same principles that justify Anna's decision: autonomy and integrity. If we go back to the moment when Sara and Brian are faced with the choice of using PGD to have a matched donor for Kate, they also claim the same principles underlying their ethical judgment, their ethical intent and consequent behaviour: in fact, they also act out of respect for their reproductive autonomy and to protect Kate's integrity. By following the ethical deliberation path of these

characters, as if we were them, not only do we feel the urgency to reach a decision, but we also perceive the situation as ethically challenging due to the moral intensity conveyed by the literary text. We also become aware of the fact that principles and theories are only meaningful when they are located in time and place, affecting the lives of subjects whose deliberation procedure is supported or weakened by individual and social circumstances. Not every route is ethically permissible, but there is surely more than one path that can be followed when deliberating upon controversial ethical issues.

The novel's adaptation to the cinema (directed by Nick Cassavetes, written by Jeremy Leven and distributed by New Line Cinema, Warner Bros. Pictures) has worked as the search for a different perspective of the deliberation process on the ethical issues of using PGD to have a saviour sibling and of knowing when to start palliative care. It is interesting to notice that the use of a different artistic medium has given back the mystery that vanished from the fictional text. In fact, the movie gives Kate the voice that the book does not let us hear and keeps both Kate and Anna in a constant tension. Therefore, Anna is portrayed as the one who keeps Kate alive and the one who helps Kate keep her dignity till the end. Death is present from the beginning of the novel and of the movie, but the former fights against it and the latter makes it part of the narrated lives of the characters, thus making them and the viewers aware of everyone's vulnerability. By keeping Anna alive at the end, the film argument introduces a significant twist in the story, which can be interpreted as an expression of respect for autonomy. It is this twist that makes us finally catch the magic eye picture: we can only see Kate from the background of the picture if we let Anna become visible; we can only see Anna when Kate is allowed to tell her own story; we can only see ourselves by narrating our own story to the *Other*, with and for the others:

> *Between the imagination that says 'I can try anything' and the voice that says 'everything is possible but not everything is beneficial (understanding here, to others and to yourself)', a muted discord is sounded. It is this discord that the act of promising transforms into a fragile concordance: 'I can try anything', to be sure, but 'here is where I stand!* (Ricouer, P. 1992, pp. 167-8)

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