



**HELENA MARIA  
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**ÉTICA E RELAÇÕES FAMILIARES EM *MY SISTER'S  
KEEPER* DE JODI PICOULT**

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Dissertação apresentada à Universidade de Aveiro para cumprimento dos requisitos necessários à obtenção do grau de Mestre em Estudos Ingleses, realizada sob a orientação científica da Dra. Maria Aline Ferreira, Professora Associada do Departamento de Línguas e Culturas da Universidade de Aveiro.

To my husband and my boys

## **o júri**

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I'd like to thank my teachers for the support; I'd like to thank Dra. Aline, who never let me give up, and a word to some colleagues who always encouraged me, when I began feeling I wouldn't succeed.

## Palavras-chave

família, amor, relacionamento, engenharia genética, “saviour sibling”, decisões, dilemas, ficção científica.

## Resumo

Desenvolvimentos recentes na área da biotecnologia e pesquisa genética levantam complexas questões éticas relacionadas com o legítimo alcance e limites da intervenção genética. Com a possibilidade de intervir no genoma humano com o objectivo de evitar doenças, a comunidade científica entende que a espécie humana poderá em breve ter controlo sobre a sua evolução biológica. “Playing God” é uma expressão frequentemente usada para classificar esta auto-transformação das espécies, a qual parece cada vez mais vir a tornar-se realidade. A literatura, vivendo lado a lado com estes avanços científicos, tem a possibilidade de “brincar” com temas que vão desde o espaço, ideologia, raça, etnia, futuros utópicos ou criaturas de laboratório criadas para desafiar, ou talvez ser reflexo da nossa própria humanidade, antevendo mudanças que as novas tecnologias possam trazer. E, uma vez que vivemos num tempo em que os avanços tecnológicos levaram as nossas capacidades para lugares antigamente só imaginados na ficção científica, a literatura tem também a oportunidade de explorar questões levantadas pela clonagem humana, inteligência artificial e engenharia genética, ou outras questões bioéticas.

Jodi Picoult, escritora Americana, tem dedicado a sua escrita a assuntos do dia a dia e a temas actuais e controversos, como por exemplo a engenharia genética e a perspectiva de “saviour siblings” com todas as implicações éticas, tema do livro *My Sister's Keeper*, que me proponho analisar neste trabalho.

**Keywords**

family, love, relationship, genetic engineering, 'saviour sibling', decisions, dilemmas, science fiction.

**Abstract**

Recent developments in biotechnology and genetic research are raising complex ethical questions concerning the legitimate scope and limits of genetic intervention. With the possibility of intervening in the human genome to prevent diseases, the scientific community feels that the human species might soon be able to take its biological evolution in its own hands. "Playing God" is an expression commonly used to refer to this self-transformation of the species which, from the evidence, might soon be a reality. Living side-by-side with these advances, literature has the chance "to play" with themes such as outer space, ideology, race and ethnicity, utopian futures, or laboratory beings created to defy, or perhaps reflect our own humanity, dealing with changes that new technologies might bring about. And as we are living at a time when technological advances have moved our capabilities to places previously only imagined in science fiction, literature also has the opportunity to explore questions raised by human cloning, artificial intelligence and genetic engineering or other bioethical issues.

Jodi Picoult, an American novelist has been devoting her writings to several present-day events and controversial issues such as genetic engineering and the prospect of "savior siblings" with all its ethical implications, dealt with in *My Sister's Keeper*, the novel I will be presenting in this work.

# Table of Contents

Introduction .....	8
Chapter 1	
1. Late 20 <sup>th</sup> century fiction and bioethics – a survey .....	14
2. Technological advances and the meaning of life in literature .....	19
3. Jodi Picoult, an American novelist and her fiction .....	26
Chapter 2	
1. Ethics and Human Relationships .....	32
2. Habermas and <i>The Future of Human Nature</i> .....	37
Chapter 3	
<i>My Sister's Keeper</i> , human relationships and decisions.....	42
Final Remarks .....	62
<i>My Sister's Keeper</i> - The movie .....	66
Bibliography .....	70
Other books mentioned.....	73
Consulted Articles .....	73
Films .....	74
Online Articles .....	74
Other Online Resources .....	76

## Introduction

The first Picoult I read came to my hands by chance, when I was just browsing in a bookshop. The title, *My Sister's Keeper*, first published in 2004, made me read the synopsis and I immediately decided I had to read the whole book. I believe it didn't take me a week to do so, because this is the sort of narrative you just want to keep reading, not only because the next chapter is giving you more and more detail, but also because it makes us question a lot of things. As for me, it brought to my mind the early months of my elder son, twenty-eight years ago, when he was diagnosed with Diamond-Blackfan anemia, a very rare condition that usually occurs as a spontaneous genetic mutation. It is impossible to describe what one feels when something is wrong with someone we love, especially our own child and at a time when medicine was ages away from what it is now. That is why I was so impressed by Picoult's book. What wouldn't a family do in order to keep their beloved, at a time when science and technology are advancing so quickly? Besides, Picoult writes in an extremely vivid way and, even though what she writes is fiction, her stories are always based on something real, to what she adds an extremely important question: "What if", as she states in some interviews about her work.

The idea for this work came exactly from that reading. I thought I would like to study the way the writer deals with topics such as family relationships, especially as far as a nuclear family is concerned, and in the novel referred to above, mainly because it deals not only with the relationship inside the Fitzgeralds' family but also because it emphasises the problems and the dilemmas that may arise when one of the family members is so "powerful" as to make all the others live around her/him, thus ignoring other members' rights, even as far as what is basic: the decisions about the right to your own body. I guess we all know that we are born due to someone's wish (our parents) but that certainly gives no one the right to decide what is better for you, especially when those decisions mean invading your own (and in this case, healthy) body. Those considerations made me do some research in relation to the evolution of the family in the last one

hundred years, the philosophical ideology behind the new post-human condition and the way writers have been dealing with subjects such as genetic engineering and cloning, or the creation of new beings to be used as spares. There is no doubt that as David DeGrazia points out in the introduction to his *Human Identity and Bioethics*, “future technologies will enable doctors to modify a fetus’ genome, either to prevent some disease or impairment or to enhance certain traits.” The question is that these possibilities truly give origin to other worrying issues as he also mentions: “But would such interventions, by changing an individual’s genes, effectively eliminate that individual and create a new one? Or would it merely change a persisting individual in a way that importantly affects her later self-story?” (2). All these uncertainties provide fundamental topics for philosophers to study and are at the same time the basis for speculation in literature.

Writers such as Picoult often use the new ideas from science and scientific research and develop them, creating situations that may be possible in a near future. Those situations raise complex questions as they frequently give origin to dilemmas which are of difficult solution. That is what happens in the book under study: the Fitzgeralds are a normal family with a stable life, until the moment when their daughter is diagnosed with leukemia, at the age of two. When the parents hear about the possibility of a sibling to be a donor, Sara, the mother, doesn’t hesitate; the question is that her elder son doesn’t have Kate’s characteristics. This is the reason why the couple takes the hard decision of having another child, genetically programmed to be a perfect donor for Kate. This now seems to be no fiction, as Picoult explains in an interview about *My Sister’s Keeper*: “I heard about a couple in America that successfully conceived a sibling that was a bone marrow match for his older sister, a girl suffering from a rare form of leukemia. His cord blood cells were given to the sister, who is still (several years later) in remission.”<sup>1</sup> This would be what we can now see as a normal procedure, since advances in genetics allow many infertile couples to have their own baby, or to prevent certain diseases in future children, but the question is that the problem wasn’t of such easy solution. Kate’s condition made her totally dependent on Anna, who became

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<sup>1</sup> <http://www.jodipicoult.com/> (accessed on 19/02/2009)

a sort of “source for parts”. Anna wasn’t allowed to have an independent life, as she had to provide all sorts of blood compounds every time Kate got worse, till the moment she was almost obliged to give her sister a kidney...

The topic Picoult chose is very complex and I guess it’s difficult for us to take a pro or against position. Besides, the reader is confronted with the unusual situation of a thirteen-year-old girl suing her parents. If one thinks thoroughly about such a situation, we can say that Anna is not a normal thirteen-year-old; she is very young but when reflecting upon what this girl has already gone through, her attitude is perfectly understandable. Despite being so young, her experience of life is much stronger than the one of many adults; in the course of events her father admits that “Anna’s only thirteen - is that too young to stay alone in a house? Social Services might say so, but Anna is different. Anna grew up years ago” (145).

Throughout history philosophers have devoted themselves to the study of complex problems and the way people face them and we assume that everything that deals with religious beliefs, human life, health, human dignity or human rights is very controversial in every society. The advances in medicine as far as genetic engineering is considered, for example, have numerous advantages, as they allow people to improve the quality of their life or to live longer and avoid or treat numerous diseases.<sup>2</sup> But at the same time they can have disadvantages, if there are no regulations or if people misuse the new techniques. As John Ancona Robertson points out in his book *Children of Choice*,

there is something profoundly frightening about technological control over the beginning of human life. Anxiety over these techniques abounds, even as a growing number of persons seek them out. We are both fascinated and repelled by surrogate motherhood, in utero fetal surgery, prenatal genetic manipulation, the latest frozen embryo case, and the other technologies now on the menu of reproductive choice. They present a series of dilemmas. Individuals must decide whether to use novel means to achieve their reproductive goals despite the ethical and social uncertainties involved. (...) they must also learn to use them in

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<sup>2</sup> Other medical cases are mentioned by David Prentice, William Lee Saunders and Michael Fragoso in the Article “Adult Stem Cells Successful Stories”.

responsible, constructive ways that minimize harmful effects on participants and offspring. (...) At the same time society must decide whether to permit these techniques to be developed and used. (Robertson; 1996: 3)

Organ transplantation has been possible for some years, but not rarely do we hear about unscrupulous people taking advantage of that; let's just remember the news on July, 23, 2009, about the traffic of organs where one can read: "State of disgrace - Mayors, rabbis charged in New Jersey's latest corruption case. (...) The probe also uncovered Levy Izhak Rosenbaum of Brooklyn, who is accused of conspiring to broker the sale of a human kidney for a transplant. According to the complaint, Mr. Rosenbaum said he had been brokering sales of kidneys for 10 years" (Honan: 2009). News such as this is certainly a matter of concern for many of us. And with this we don't mean to be against organ transplantation, if the procedures are ethically correct and when used for the benefit of patients.

It is also possible today to distinguish two kinds of parenthood, as it is possible to separate sexuality and conception, procreation and fertilization in what Norbert Rouland calls the "denial of nature". In the article "Cultural Dimension of Kinship" he mentions the decision of the Creteil Court which allowed the insemination of a widow with the frozen sperm of her husband who had already died. Situations like this one seem odd, especially because the husband is not alive, but also because that decision will allow the birth of a child who will be brought up in an already existing mono-parental family. This situation also emphasises what Hans O Tiefel argues in his article "Human Cloning in Ethical Perspectives". According to him, "children have always been in the hands of parents, for better or for worse. But now parental hands hold so much more power. We can not only call a human being into life, but can determine its genetic identity" (199).

That is also what David DeGrazia points out when he mentions that "today's parents routinely face reproductive decisions in light of information provided by genetic and other medical tests" (2). But is it right? Shouldn't we allow nature to follow its course? This attempt to "play God" gives origin to what we would dare

call bizarre situations as the one described by Linda Nielsen in her article “The Right to a Child versus The Rights of a Child” and that we will transcribe:

Consider the well-known case from the USA where seven embryos were frozen, the mother and the father were divorced and the father wanted the embryos to be destroyed while the mother wanted implantation and birth. One of the arguments used by the father was based on division of property rights. Although the argument was not accepted, (...) the fact that it was raised indicates the issues that are at stake. (...) Commercialisation will increase dehumanisation as contracting of semen, egg, surrogacy, etc. will become similar to other purchases. (Nielsen; 1993: 219)

Situations as the one described create a whole range of questions and doubts, some of which are dealt with in Rollin’s book *Science and Ethics*; we shall mention but a few, since we believe they are of major concern for many of us: “What effects will (...) technology have on our lives? Will benefits outweigh costs, harms outweigh goods? (...) How likely is it to be misused? (...) Will it promote justice or injustice? Is it something benign or beneficial, something to be curtailed or allowed to soar? Will things be better or worse in virtue of its existence?” (Rollin; 2006: 129). These are questions to be discussed but one mustn’t be so naive as to think they might have straight answers, which does not mean that society should not worry about them and try to figure out possible future scenarios. We believe those issues should be widely discussed and legislation should be defined so that bad practices can be avoided.

It cannot also be denied that parents want the best for their kids, and according to the law, have the right to plan their own family; as individuals and as a couple they have the right to decide freely and in a responsible manner whether and when to become parents and on the number of children they want to have. As M. Kirilova Eriksson reminds us in the article “Family Planning as a Human Rights Issue”, “the right to choose on matters related to procreation is an inherent right in itself. (...) since it affects a person’s entire life it is to be considered as a fundamental civil human right” (194). But when one decides to have children, the fundamental rights of the newborn must be observed, since a new being with its

own characteristics and personality will arrive and will want to live its life according to its desires and expectations.

# Chapter 1

## 1. Late 20th century fiction and bioethics – a survey

For centuries humankind has struggled to understand its own existence, trying to make sense of what we are and how we relate to the world around us. With technological advances the human being realised that he/she could gain control over the forces around him/her but at the same time that feeling is being challenged by technology itself: the threat to human existence from what one cannot control or doesn't understand. According to Robert Pepperell in his book *The Posthuman Condition*,

as we enter the technological era, which is marked by increasing automation (...) we can see that the perceived relationship between nature and human is changing. (...) The tendency towards the development of artificial life, synthesised intelligence, instant telecommunications and virtual reality means that we are now aware of the disappearing barrier between 'natural' and 'human—made' phenomena.(...) The Post-Human era begins fully when we no longer find it necessary, or possible, to oppose human and nature" (165).

To this list I would also add genetic manipulation.

Using these ideas and experience, not only writers but also men and women of science have used much of their knowledge and devoted their time to discussing, writing about, foreseeing and imagine situations and even fictional and utopian/dystopian worlds. That is the case of mainstream fiction writers such as H. G. Wells with *The Island of Dr Moreau* (1896), Aldous Huxley with *Brave New World* (1932), George Orwell with *1984* (1949), Nevil Shute with *On the Beach* (1957) and Margaret Atwood with works such as *Oryx and Crake* (2003) among many others, who achieved great success and inspired not only other writers but also various cinematic adaptations.

Science fiction as a genre was accepted after Hugo Gernsback, the editor of *Amazing Stories*, in 1926, had described it as “a charming romance intermingled with scientific fact and prophetic vision” and referred to Jules Verne, H. G. Wells and Edgar Allan Poe as some important authors. But science fiction is not easy to define, since in the 1993 *Encyclopaedia of Science Fiction* one can find about twenty descriptions of ‘sf’ or ‘SF’ along with several different theories to define it; there are also divergent opinions about ‘sf’, commonly accepted as a genre connected with myths and legends from other times, according to Lester del Rey, or, following Broderick’s argument, “as a modern genre, since the technologies with which it is chiefly preoccupied are relatively new” (Johnson-Smith; 2005: 16).

According to Kathryn Cramer, cited in *American Science Fiction TV*, ‘sf’ originated in a “desire to create and predict the possibility of a better world. In ‘sf’, this better world will be created and predicted through science and technology; scientific exploration and technological innovations are political acts leading to world salvation” (ibid.: 17). Many authors often use heroic quests, epic explorations and the human search for knowledge as their themes.

Because many people are intrigued by the future and are curious about what life might be like in a few or many years, science fiction has also done a good job of predicting some of the elements of a likely future. Along with this, the rapid pace of change in science and technology provides ‘sf’ authors with new opportunities; these rapid changes, in some cases, make the “What ifs” from older stories seem dated today. Scientific developments have also increasingly begun to invade an area traditionally understood as religious and moral, such as the concerns surrounding human origins, genetic manipulation, euthanasia and gender reassignment. This can be seen as a sign of the genre’s vitality.

In these fields we have not only literature but also films dealing with the concept of genetic manipulation and human cloning, reflecting the technological advances along with the world’s concerns about those advances and the consequences one might have to face.

Films dealing with the concept of human cloning generally divide into three different categories: first, there are films where a particular person (usually a historical figure) is replicated down to the last detail. We can here refer to films such as *The Boys from Brazil* (1978) directed by Franklin J. Shaffner, in which there are ninety-four copies of Hitler placed into homes similar to his own to simulate his upbringing in the hope that at least one of them would repeat the original's "achievements". The second category of clone films are those where an evil super-villain wishes to build an army composed of exact duplicates of himself, as in *Star Wars Episode II: Attack of the Clones* (2002). The third category is where the rich and the elite create clones to use as their own personal organ banks. That is what happens in the film *The Clonus Horror*, also known as *Clonus*, from 1979, a science fiction horror movie about an isolated community in a remote desert area, where clones are bred to serve as a source of replacement organs for the wealthy and powerful, an elite which includes a candidate for the presidency of the country. The story surrounds one clone who begins to question the circumstances of his existence and eventually escapes from the colony. Top government officials are aware of what is happening and support the super secret project because they are also cloning themselves to live longer at the expense of their clone counterpart, a "slave", as far as human rights are concerned.

The same idea was worked on by Michael Bay when he agreed to direct *The Island*, released in 2005. The film delivers a striking look at a strange world of the future. Midway through the 21st century, a large community lives in a confined indoor environment, after ongoing abuse of the Earth has rendered most of the planet uninhabitable. One of the only places still capable of sustaining life is an idyllic island where citizens are chosen to live by a lottery. Or at least that is what "people" there are made to believe. Those people are actually clones who are expected to provide needed organs when the person who "paid for" them falls ill or to provide infertile couples with a child, killing the surrogate clone mother when the baby is born. Both the clones and their sponsors live deceiving situations, the first because they are told that they are survivors who have been rescued from a contaminated world and who are expect to be selected to go to the outside , to the island; the sponsors, because they have paid for a kind of life insurance (a spare),

hoping to live longer, but believing that his/her spare is in a vegetative condition and not alive. As some of the clones develop intelligence, contradicting the wishes and expectations of the responsible, the situation gets extremely complicated.

Michael Bay has been criticized because of the huge similarities between his film and the already mentioned *The Clonus Horror*, since both share the main theme and the way it develops: the secret community, the creation of clones as spares, the escape, as well as the chase; these situations follow the same pattern and reflect the widespread concern about controversial issues such as the creation of “spares”. These films update early fictional concerns with creation and deal with the worries around genetic engineering and the alterations that technology seems to impose on both the self and our world.<sup>3</sup>

Along with worries about the creation of life, rapid technological advances may also lead to a dominance of machines, another issue raised in several films. We can take the example of *Equilibrium*, written and directed by Kurt Wimmer, in 2002; the plot is set in the futuristic and dystopian city-state of Libria, following the destruction of World War III. Convinced that it is the cause of all war, human emotion has been outlawed, along with anything that might provoke emotion, such as books, art, pets and perfume. To keep the citizens in line, everyone is forced to take doses of Prozium—a drug that dampens human feelings—three times a day. To enforce these laws, the dictatorship government has created a special police unit made of trained killers, who control everything.

Another thought-provoking example comes from Canadian director David Cronenberg’s *Existenz*, released in 1999; Cronenberg has long been fascinated by the ways new technology shapes and manipulates the human beings who believe they are its masters. His film *Existenz* is a futuristic thriller which combines elements of science fiction, horror and action-adventure. According to the glossary Cronenberg put together for this film, *Existenz* is a new organic game system that, when downloaded into humans, accesses their central nervous system, transporting them on a wild ride in and out of reality. Besides, it changes every time it is played, by adapting to the individual user (you have to play the game to

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<sup>3</sup> Other examples of similar thematic concerns in fiction are Michael Marshall Smith’s *Spares* (1996) and Kazuo Ishiguro’s *Never Let Me Go* (2005).

find out why you are playing it). More than one person can plug into the same game and set out on a series of bizarre and surrealistic adventures together. The narrative takes place some time in the near future, when game designers are worshipped as superstars and players can organically enter the games.

Even though these seem nothing but fictional situations, they should make each one of us reflect upon the possible scenarios that, one day, might become reality and I believe that scientists and society as a whole are also aware of what our future might be in scientific terms. But as Cronenberg once said: "If you admit to the possibilities of the most horrific things, then maybe they won't happen. It's what I do when I make movies. You're hoping it's going to stay on the screen and not come into your life" (Dee; 2005). In a certain way that's what Jodi Picoult feels when she writes about such controversial topics as teen suicide, child abuse, etc, as we will see in the third part of this chapter.

## 2. Technological Advances and the Meaning of Life in Literature

“It is an obvious truth that scientific and technologic innovations produce changes in our traditional way of perceiving the world around us. (...) Yet it is not only perceptions but also conceptions of the familiar that become altered by advances in science and technology.” – Ruth Macklin, “Artificial Means of Reproduction and Our Understanding of the Family” (612).

We are living in a time when scientific advances are happening at hyper-speed and, taking into account the developments which we have been hearing and reading about in the news, some of the predictions or the intentions might well be a reality in 15 or 20 years' time. Scientists are now able to clone animals and some are working to clone human beings; bioengineers, cell biologists and clinicians are working together to build replacement body parts. Since the 1950s scientists have known that the chemical basis of life is DNA, a discovery that increased the hope that life itself could be controlled; in 1971 James D. Watson<sup>4</sup>, co-discoverer with Francis Crick<sup>5</sup> of the double-helical structure of DNA, predicted that one day human cloning would be possible and urged that as many people as possible should be informed about the new ways for humans to reproduce and their potential consequences, both good and bad. As a consequence of Watson and Crick's achievement, it was possible to decode the way DNA reacts with other chemicals and determine what each part of it does, what gives a great possibility for the genetic manipulation of the human species. This reduction of humans to a series of codes means that such codes can be “re-mixed” in a series of ways to produce a variety of offsprings.

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<sup>4</sup> American molecular biologist, one of the co-discoverers of the structure of DNA (Nobel Prize in Physiology or Medicine in 1962).

<sup>5</sup> British molecular biologist, physicist and neuroscientist, one of the co-discoverers of the structure of DNA (Nobel Prize in Physiology or Medicine in 1962).

*In Vitro Fertilization* has also been possible for decades; *In Vitro Fertilization* Pre-Embryo Transfer (IVF-ET) is a fertility procedure which first succeeded as recently as 1978, performed by Dr. Edwards (an embryologist)<sup>6</sup> and Dr. Steptoe (a gynecologist) in England. This technique, which Dr. Edwards had been studying since the early 50s, aims at helping infertile couples to have their own children and it has been used since 1978, when the first “test tube baby” was born in England. Despite great opposition at the time, Dr. Edwards, together with Dr Steptoe, developed IVF from experiment to practical medicine. Since then the technology has been further refined and developed by physicians and embryologists, with over 20,000 babies born worldwide, some of which have already become parents themselves. The possibility of a continuing pregnancy being achieved by IVF has improved from practically nil to one chance in 4 to 6 at IVF centers worldwide. While there are a number of assisted reproductive technologies (ART) available to infertile couples, *In Vitro Fertilization* is by far the most utilized of these methods. In fact, IVF accounts for more than 95% of all ART procedures.

Studies and experiments on cloning have been attracting scientists and it is well-known that on February 23, 1997 the world came to know that Dolly, the lamb, had been cloned from the non-reproductive tissue of one adult female sheep, which made it genetically identical to its sole progenitor. This extraordinary and at the same time frightening event was made possible by Dr Ian Wilmut, an embryologist and his research team at the Roslin Institute in Edinburgh, Scotland; their achievement, considered a symbol of modern science, raised strong debate and gave light to a series of worries about the prospect of human cloning and consequently about its implications. This big step in science opens the way to new forms of human reproduction and their potential consequences.

Even with legislation trying to regulate such procedures, “on Tuesday the 26 November, 2002 in Rome, Italian embryologist Severino Antinori announced that the first cloned human would be born in January 2003. (...) On 28 December 2002, Clonaid, a biotechnology company set up by the Raelians (a religious group

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<sup>6</sup> Dr. Robert G. Edwards was awarded the Nobel Prize in Physiology or Medicine in 2010, for the development of *In Vitro Fertilization*.

who believe that human beings were originally genetically engineered by aliens), announced that 'Eve', the first cloned child had been born. Both (...) received a very sceptical reception from the scientific community" (...) and whether their "claims are accurate or not, the possibility of human reproductive cloning is raising serious debates on ethical issues and morality" (David and Kirkhope; 2005: 367).

Many of those issues are debated in the article "Cloning/Stem cells and the meaning of life" and its authors cite Lewontin when he claims that "science, like other productive activities, is a social institution intermeshed with and influenced by the structure of all other social institutions" (ibid.: 375). The two authors consider that "science is moulded by society because it is a human productive activity and it can be argued, putting fears aside, that human reproductive cloning has a place in a society such as ours" (ibid.). One can say that this is based on speculation but it surely opens up a space for debate around the ethical issues surrounding human reproductive cloning. On the other hand, there is also the concern within science that fear may not only produce policy preventing scientific advance in this field but also an open debate not just on whether human reproductive cloning is safe and possible but actually on the ethical and moral considerations it raises. Besides, when reflecting upon questions such as human embryonic stem-cell research, one can also come across the question: what about the spare embryos from fertility treatment? This is indeed another powerful issue as science may speak with many voices, although some voices are more powerful than others. In this area we can refer to organized religions, patients' associations, bioethics committees, regulators, parliaments or even the mass media, where we have the Catholic Church and many governments calling for a ban on human cloning experiments, while scientists sign petitions to carry on more research.

Leon R. Kass<sup>7</sup>, an opponent of human cloning, strongly criticizes unrestrained technological progress and embryo research; he considers himself a humanist who is broadly concerned with all aspects of human life, not just ethics. He welcomes biotechnology for its therapeutic promise (to cure disease, relieve

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<sup>7</sup> Leon R. Kass is an American physicist, scientist, educator and public intellectual. He was the chairman of President's Bush Council for Bioethics.

suffering and to restore health and wholeness) but he worries about its uses for enhancement. In a lecture he pointed out four specific objections to cloning:

“Human cloning involves unethical experiments. Most cloning experiments result in fetal deaths or the birth of deformed infants.” And he raises a strong question: “Shall we just discard the ones that do not meet expectations?”

“It threatens identity and individuality.”

“Cloning would transform the making of a human being into the building of a manufactured product.”

“Parents of clones would have an unreasonable set of expectations for their children. If created from someone gifted, such as a famous athlete, the clone would live his entire life with comparisons to the person from whom genetic material was harvested”<sup>8</sup>.

In the book *Human Cloning and Human Dignity – an Ethical Inquiry*, the American Bioethics Committee show their concerns about cloning, mentioning that “one possible result would be the industrialization and commercialization of human reproduction” (Kass; 2003:107). In the same book, it is stated that “cloning is a human activity affecting not only those who are cloned or those who are clones but also the entire society that allows or supports such activity” (ibid.: 112) and that “with cloning, parents acquire the power, and presumably the right, to decide *what kind* of a child to have. Cloning would then extend the power of one generation over the next – and the power of parents over their off springs – in ways that open the door, unintentionally or not, to a future project of genetic manipulation and genetic control” (ibid.: 105). It is thus clear that, if it were to become a reality, cloning “would be an experiment in family and social life – altering the relationships within the family and between the generations, for example, by turning ‘mothers’ into ‘twin sisters’ and ‘grandparents’ into ‘parents’, and by having children asymmetrically linked biologically to only one parent” (ibid.: 98).

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<sup>8</sup> [http://www.law.duke.edu/features/news\\_kass.html](http://www.law.duke.edu/features/news_kass.html) (last accessed on 01/04/2009)

Neil J. Cooper and Simon Jonathan Hampton in the article “Reproductive Technology in the Context of Reproductive Teleology” reflect on “some of the major concerns that appear to underlie the disquiet regarding designer babies within the context of current reproductive choices and parenting behaviors. (...) There’s concern that we are violating our proper place by ‘playing God’”, and they go on citing Fukuyama when he emphasises the fact that “there is a concomitant concern that we are in danger of altering human nature and, in the process, of destroying ourselves as humans” ( 499).

It is easy nowadays to come across news such as that published in *Sábado* (a Portuguese magazine) under the headings (my translation): “Choice. To have children with a different skin colour”; “Black couple wants white baby”. The article is about two black couples, one of them being a couple of lesbians who, in Spain, asked to be pre-implanted with white embryos. This is something unusual, and even more unusual are the reasons they presented for such a request, which was refused because it would be a violation of the Spanish law on medical assisted reproduction.

We also know that research with human embryos for the purpose of obtaining stem cells that can help in finding effective treatments for some of the major diseases prevalent in our society, like diabetes, cancer, Alzheimer’s or Parkinson’s, to name but a few, makes many people uneasy. In fact some of those diseases may be healed or even prevented if more research is permitted. Besides, there are already surveys and studies being carried out in order to know people’s opinions on such controversial issues, even though one must agree that, as Rafael Pardo and Félix Calvo point out:

Despite the intense debate over stem-cell research, it is clearly a highly complex issue that is hard to grasp for the majority of individuals lacking scientific training. Yet, at the same time, it touches on core aspects of the ‘moral landscape’ of society (15).

Controversial issues such as this one have been studied for a long time and dealt with by various authors, as we can read in Ferreira’s *I Am the Other*:

Our contemporary world is fascinated with the fantasy of human cloning, which since the birth of Dolly, the cloned sheep, on July 5, 1996 (...) has fired the popular imagination and gradually permeated popular discourse, proving to be an endless source of inspiration for the media, advertisements, literature and film (Ferreira; 2005: 4).

In literature, versions of fantasies like human cloning or the creation of other genetically programmed creatures appear in, for example, Mary Shelley's *Frankenstein*, considered the founding text of science fiction, H.G. Wells's *The Island of Dr. Moreau* (1896) or Aldous Huxley's *Brave New World* (1932), in which the issues of genetic manipulation and cloning are raised. According to Jeremy Rifkin, who is "one of the earliest and most vocal secular critics of genetic engineering" (Rollin; 2006: 138) and author of several bestselling books on the impact of scientific and technological changes on different aspects of society,

*Brave New World* was greeted more as a metaphor, a compelling parody of the modern condition than as a very real possibility. ... Today, Huxley's vision is fast becoming commonplace. (...) The genetic code has been broken and scientists are rearranging the very blueprints of life. They are inserting, deleting, recombining, editing, laying the foundation for a second creation – an artificial evolution designed with marked forces and commercial objectives in mind.<sup>9</sup>

More recently Kazuo Ishiguro wrote *Never Let Me Go* (2005), a novel in which Hailsham, a private school, exists to raise cloned children who have been brought into the world for the sole purpose of providing organs for other "normal" people. Those children don't have parents, they cannot have children, they don't even have a surname, just an initial, "H", for Hailsham. Can this be our future, the future of humankind? What will happen to our family ties, our culture, our moral values?

Such writings can be seen as a sign of the world's awareness and, in a certain way, the fear of what our post-human society may have to face but there is

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<sup>9</sup> Jeremy Rifkin, quoted in *Cyborg Citizen, Politics in the Post-Human Age*, by Chris Ables Gray, 124.

surely a clear consensus that reproductive cloning has social, moral and ethical implications.

### 3. Jodi Picoult, an American novelist and her fiction

Jodi Picoult was born on May, 19th, 1966 in Long Island, New York. She had a happy childhood, with her younger brother, Jonathan, in Nesconset, New York. She began writing stories when she was very young.

When she was at Princeton University, she studied creative writing and published two short stories in *Seventeen* magazine, still as a student. After her bachelor's degree in English, which she took in 1987, Picoult had several jobs: she worked as a technical writer for a brokerage firm on Wall Street, as a copywriter in an advertising agency and as a textbook editor. While teaching creative writing at a Massachusetts middle school, she earned her master's degree in education from Harvard in 1990. She left her post as a teacher in 1991 to focus on writing. She began writing her first novel, *Songs of the Humpback Whale*, when she was pregnant with her first child; it focuses on the idea of love and was published in 1992. *Harvesting the Heart* (1993), her second novel, was based on her experiences as she tried to balance her children's needs with her writing.

Picoult had a normal childhood; her mother was a nursery school director and her father worked on Wall Street. At school she was eager to learn; in an interview she gave to *The Observer*, published on Sunday, April 15th 2007, she says: "I am very 'Type A' – organised, overachieving, fiercely motivated". When she was in college she dated and married her husband, whom she met on the rowing team; they have three children. Despite having started writing at such a young age, it was difficult for her to start selling her fiction. In the same interview, she reflects upon the fact that "most people in America want an easy read. I call it McFiction – books which pass right through you without you even digesting them. (...) We are more of a TV culture" (ibid.).' That made her think of giving up writing. Only when she had five or six books written, did people start to know her; when she had about nine novels published, she hit the bestseller list.

The author continued to write novels regularly as her children grew older. After *Harvesting the Heart* (1993) dealing with postpartum depression, she

published *Picture Perfect* (1995); social issues seem to be one of her great concerns - in this case, spousal abuse – and she began receiving significant critical attention. More recently she wrote about childhood sexual abuse in *Vanishing Acts* (2005) and date rape in *The Tenth Circle* (2006), a Columbine-style school shooting in *Nineteen Minutes* (2007), which has been at the top of the New York Times fiction bestseller list.

Picoult's work is the result of a vivid imagination but also accurate research; for example, she spent a considerable amount of time exploring suicide pacts for the failed agreement at the center of *The Pact* (1998), the molestation of children by priests and related legal issues for *Perfect Match* (2002), as well as ghost hunters for *Second Glance* (2003); to write *My Sister's Keeper* (2004) – to be studied in the third chapter – she spoke to children who had cancer, as well as their parents, “to better capture what it felt like to live day by day, and maintain a positive attitude in spite of the overwhelming specter of what might be just around the corner”.<sup>10</sup>

She has also spent time in an Amish community, in a Hopi reservation and for her fifteenth novel *Change of Heart* (2008) she visited Death Row. This novel is about a death row inmate, Shay Bourne, an uneducated, marginal man who's been convicted of a double homicide, who decides that, to redeem himself, he must donate his heart post-execution to the sister of his victim – a little girl who needs a heart transplant. In the official site for the novel Picoult explains how this theme came to her:

I've explored religion and spirituality before in books – it's a topic I could plumb many times and still raise more questions than answers. And I've looked at legal issues that, when pushed, are less than fair. But right now in America, it feels to me like the country's being broken apart on the fault line of religion. All the big controversies – like abortion and gay rights and capital punishment seem to boil down to religion, and the weird thing that's happened to religion. Although historically it was a way to unite people, it's become divisive – because beliefs

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<sup>10</sup> “A conversation with Jodi Picoult about *My Sister's Keeper*”, in <http://www.jodipicoult.com/> (accessed on 19/02/2009)

In the same interview she mentions her son's physical problem, which made him undergo several surgeries, also because it might have become much worse and might have killed him.

have become absolutes. People think, “I’m right, so you MUST be wrong.” I found myself asking why we believe what we believe. Is it because it’s right? Or because it’s too scary to admit we may not know the answers? And suddenly, I started to come up with the story for *Change of Heart*.

According to the same source,

research for this book was two-pronged. I began by learning about the death penalty. America’s the only first world country that still uses capital punishment. According to polls, 70% of Americans support it, but that number drops to 50% if the choice is between death or life imprisonment without parole. In New Hampshire, where I live, the death penalty is on the books but hasn’t been used since 1939. (...) Clearly, I needed to see a working death row – so I scheduled a visit to Arizona to see the facilities and to talk to a death row inmate face to face.

Picoult usually chooses a subject which is controversial and develops the story through a rotating cast of characters; in a certain way that is what she did with *My Sister’s Keeper*. When doing research about genetics for a novel, she came across the successful case of an American couple who had a genetically programmed child to be compatible with their older daughter suffering from a rare form of leukemia. In an interview in her official site she explains how impressed she was with the case and how a set of questions and doubts came to her, considering that “it’s always hard to imagine a scenario where a family is dealing with intense grief.”<sup>11</sup>

She loves using fiction as social commentary and at the same time raising social awareness for several issues as she explains in the same interview: “I believe that we’re all going to be forced to think about these issues within a few years ... so why not first in fiction?”. She became better known as a writer after her New York Times Bestseller *My Sister’s Keeper* (2004) was selected for the Richard & Judy Book Club in 2005; in 2007 she was nominated Author of the Year in the 2007 British Book Awards.<sup>12</sup>

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<sup>11</sup> “A conversation with Jodi Picoult about *My Sister’s Keeper*” in <http://www.jodipicoult.com> (accessed on 19/02/2009).

<sup>12</sup> Other Honors and Awards:  
Winner of the 2007 Virginia Readers’Choice Award;

Her novels have been translated into dozens of languages and have made her the bestselling female adult author in Britain. Despite her huge popularity, she is ignored by literary critics, not only in England but also in the USA. She does not seem to worry much about that, as she explains in the interview referred to above: “I am fortunate to write commercially marketed books that still manage to get review coverage – too often in this industry books are divided by what’s reviewed and literary, or what’s advertised and commercial. (...) I never write a book thinking of reviewers (...)” Her fiction might not be elegant or literary but it is thought-provoking and controversial. Her next novel, *Handle with Care*, published in March 2009, was strongly criticized even before its publication due to the extremely complex issues it raises: Willow, a smart and charming five-year-old is born with a bone disease called osteogenesis imperfecta. Over her lifetime, Willow suffers hundreds of fractures and her mother does everything to give her the best life possible. When facing financial problems, Willow’s mother thinks about suing her doctor due to the fact that she hadn’t diagnosed the baby’s condition in time to allow the pregnant mother to consider an abortion. The money would mean life insurance for Willow but at the same time it would mean she would have to sue her best friend. This is another emotionally complex novel, charged with thought-provoking questions about medical ethics, morality, parenting and honesty.

Even though this is fictional, similar cases from real life are coming to light like that of a young Spanish boy, born in 2004 with Down’s Syndrome; his parents demanded compensation because the doctors who assisted the pregnancy didn’t diagnose the condition their child would suffer from, due to a mistake made by the laboratory when the mother, aged 39 at the time, decided to have the tests to check for abnormalities or malformations. The parents claimed that they would have considered an abortion had they known the baby’s future condition. The case was recently on the news because the Supreme Court ordered the University

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Winner of the 2006-2007 Maryland Black-Eyed Susan Book Award in the High School Division;  
The Abraham Lincoln Illinois School Book Award (2007);  
Vermont Green Mountain Book Award Master List (2007);  
Winner of the Margaret Alexander Edwards Award (the Alex Award ) given by the American Library Association;  
Best Book of the Year (2005);  
Nominated for an IMPAC Dublin Literary Award.

where the tests had been carried out and the Local Health Authorities to pay the boy a pension for life.

It can be argued that attitudes such as that of the Spanish couple are hard to understand; there is a contradiction in these parents' attitude since they state that they love their son but at the same time they argue that the mother's right to decide if he should be born or not was violated.

These kinds of controversial situations imply moral and ethical dilemmas that aren't difficult to imagine and it can be also pointed out that these parents' main concern might not have been the compensation for their suffering but to ensure that the child would have a kind of insurance for his future, as Picoult evokes in the above-mentioned novel.

Her next work, *House Rules*, was published in July 2010 and there is no doubt it will be a major topic for discussion; it revolves around a young boy who is unable to understand social codes or rules or to express himself to others, but like other kids who suffer from Asperger's Syndrome, he focuses all his attention on a subject, in his case, forensic analysis. He is of great help in some crimes but one day the police questions him because his tutor was found dead and he turns into a suspect. This novel to quote Picoult's official site, "looks at what it means to be different in our society, how autism affects a family, and how our legal system works well for people who communicate in a certain way – but lousy for those who don't."

When Picoult is questioned about what makes her write about controversial issues, she explains: "Fear. Superstition. The feeling that if I write about it I won't have to live it. Sometimes readers ask me why I am so hard on my moms in my books, I think it's because it's got to be the hardest job in the world and maybe if I write about these awful moms, I'll look so much better" (Bertodano; 2008).

Some of her books have already been adapted as films, as is the case of *The Pact* in 2002, about two teenagers who agree to kill themselves at the same time, *Plain Truth* in 2004 dealing with a very intricate and richly detailed tapestry of Amish life and a court case that shocked the small town of East Paradise Township as well as *The Tenth Circle* in 2008 about parental vigilance gone

haywire, inner demons and the emotional risks of relationships. According to Picoult's website, the film adaptation of *My Sister's Keeper* was released in 2009.<sup>13</sup>

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<sup>13</sup> In Portugal, it was released in the course of this work, in September 2009, and will be briefly analysed at the end.

# Chapter 2

## 1. Ethics and Human Relationships

“Ethics is the branch of philosophy that deals with values relating to human conduct with respect to the rightness and wrongness of actions and the goodness and badness of motives and ends. (...) It involves how individuals decide to live, how they exist in harmony with the environment” (Pozgar and Santucci; 2004: 388).

This quotation comes from the book *Legal Aspects of Health Care Administration*, which addresses some of the issues at stake in the novel under study. The novel is about human conduct, values, what is wrong and what is right and the goodness and badness of motives and ends. It deals with the way a family lives, the way the members relate to each other, what they expect from the other members. A family is supposed to be there for its members when they need it, a family is supposed to laugh together and to work for the welfare of all its members.

It is not easy to define family. According to Don Edgar from the Centre for Workplace Culture Change in Australia in the book *The Family on the Threshold of the 21st Century*, “the family is a unit in which men, women and children who care enough about one another to combine their various skills, property and other resources produce through work enough to meet their combined needs, consume and distribute the rewards and benefits of that labor and care for one another as well” (Edgar; 1997: 149). At least this is the way we envisage a family, an integral part of the human experience. The family is where we gather our traditions, where we learn our culture and where we seek emotional and physical support. As human beings we have great difficulty in feeling fulfilled without the support of our own family and the contact with our origins.

In a liberal society parents are free to transmit their own values to the children and they are free to make certain choices and guide their children's lifestyle. It is true that the role of each member of the family has been changing, from the father who was the provider for all its members and the mother who everyone expected to be at home taking care of a whole bunch of children, to what we see today: now, family can consist of single parents, remarried parents, and very distant relatives raising the children. As Laura Oswald mentions in her article "Branding the American Family", "instead of measuring families against a universal family myth, experts such as Linda Rubinowitz<sup>14</sup> (...) measure family in terms of intangibles". She cites Rubinowitz "who counsels traditional families as well as gay parents, stepfamilies, racially mixed families, and divorced families" when she reassures us that "today there are more ways to define family than the two-parent married couple. ... I like to think of family in terms of intangibles such as commitment, mutual support, personal growth and health." Laura Oswald points out that "today family configurations include traditional two-parent, one-career households; dual career households; single-parent households; gay and lesbian households; merged families; and a variety of kinship arrangements" (Oswald; 2003: 323).

Also with the changes in society, it is not rare to find single parents, lesbian and gay couples who want to have their own children, which is possible not only through adoption (depending on the countries) but also due to the advances in genetic engineering. Several examples can be found in the Portuguese magazine *Visão* number 863, under the heading (my translation) "Stories of almost impossible children". Genetic engineering, as we can conclude from the article, is of extreme importance for couples who have difficulties in having their own children by what we can call natural methods, but is increasingly becoming a way of changing traditional society: in the article, we have the cases of a couple whose husband would never be able to be a father but who accepted as natural his wife's pregnancy thanks to an anonymous donor. Now they have a lovely daughter. There is also the case of another couple whose embryos would never survive due to a problem of incompatibility. Thanks to PGD (Pre-Implantation Diagnosis) they

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<sup>14</sup> Professor and Counselor at the Family Institute at Northwestern University.

overcame that problem and they already have their own daughter. According to the same article, in countries such as France, Denmark or Belgium, it is already possible to remove and preserve the ovaries from women who suffer from cancer in order to allow them to get pregnant after their cancer is cured, by reimplanting them.

The advances and the new techniques also take us to other examples, which I guess are slightly difficult to accept or even to understand: in the above mentioned article there's the example of Vasco and Alexandre who, being a gay couple, managed to have their own child, in a process involving not only a woman who gave her egg but also a surrogate mother, who carried the baby for nine months and received her own payment. What seems even more complicated is the fact that the gay couple intended to have "twins", one from each father, but the circumstances didn't allow it. If in the first cases things do not seem that odd, this one is more thought-provoking: shall we say that the newborn is being brought up by two fathers? Who is the mother? Will the little boy accept this as natural when he is old enough to question his own existence? In such cases, how will the child feel and how will he/she integrate in society? How will society accept him?

Another thought-provoking case is presented in *Notícias magazine* from the 6th December 2009 under the heading (my translation) "Rubén Noé – I'm transsexual and I want to get pregnant"; a transsexual has been making changes in her own body because, despite having been born a girl, she has always felt that she would be a man. (S)He looks like a man now, but (s)he has not made the final surgery to change sex, as (s)he wants to be a mother. (S)he has already been pregnant but had a miscarriage and (s)he wants to have a child before undergoing the final changes; for that (s)he will use *In Vitro Fertilization*. What is somehow strange is that, if (s)he manages to be a mother and changes sex afterwards, will (s)he be the mother or the father of the newborn? How will (s)he explain to the child the whole process?

Issues such as these cannot be avoided nowadays and there is evidence that organizations around the world are concerned about the new family landscape

and the implications it has in today's society. According to Ruth Deech and Anna Smajdor in their book *From IVF to Imortality*,

(...) the idea of deliberately bringing a child into the world with only one parent -- of whatever sex -- is viewed by some as being obviously socially and morally wrong. (...) A mother and a father jointly bringing up children may provide an example of complementary roles, the interaction between the two sexes, a role model of each sex, and two sets of relatives. There is exposure to adult conversation, and to an adult relationship that does not centre solely on the child. (...) In sum, there is give and take to be witnessed, a micro-society of which the child is just one member. (169)

Scientists are eager for knowledge and at the same time to give hope to those who have problems in having their own family, but for those who have been brought up in a catholic family, it is sometimes hard to understand some of the changes in science and society.

But here we are expected to discuss issues such as Ethics and Human Relationships, which seems a hard task since these are very broad subjects. What can surely be pointed out is that the evolution in scientific terms and the changes that have been occurring in society also mean huge changes in the way people relate to each other. Constant different scenarios related to the work force, women who want to define their own career and decide to have children at a later age, the high rate of divorce, unmarried women who want to be mothers are some of the reasons why the family landscape is getting different. Here we can take as an example the case of a single woman from Mourão, a small village in Alentejo who, in her late thirties, decided she wanted to be a mother as a way of escaping her own loneliness but she didn't want to have a man involved, fearing that the baby would have to be "divided". She travelled to Spain where she managed to get pregnant through *In Vitro Fertilization* and she already has her daughter. The small community where she lives accepted the situation well.<sup>15</sup>

The number of couples who are together but who have already come from other relationships, with the children from their former marriages and now have

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<sup>15</sup> In *Visão*, number 863, edition from 17<sup>th</sup> to 23<sup>rd</sup> Sept. 2009, "Histórias de Filhos Quase Impossíveis".

other children in common is also growing. We guess that in many cases it must be tough to balance such a family as each individual has his/her own personality and not rarely do their interests collide and cause serious problems. The truth is that the sort of life modern society imposes on us also determines the bonds that we establish with each other and it cannot be denied that children need stability in order to grow up happy and healthy; despite the turmoil that technological advances can impose on us, not only do children still need parents' support, but they also seek it.

Many countries are now showing their concerns since the changes that have been occurring in terms of the family are having strong consequences on society as a whole. We cannot forget the problems with drugs and alcohol faced by young people today, the unemployment rate that quickly gives origin to theft, the incidence of suicide among young people, just to mention a few. Laura Oswald points out some of the reasons why societies have changed so much and why families are so "isolated and fragmented", but at the same time she is eager to show her hope that things will change, since "they (families) are also being encouraged to reach out and participate in the broader community" (Oswald; 2003: 328). In the article mentioned above, she cites the book *It Takes a Village*, written by Hillary Clinton and published in 1996, considering that it "effectively calls for the community and perhaps the government, to take on the tasks of parenting and family support that used to be a domain of the nuclear family." That is probably the reason why it is considered a controversial book. Oswald cites Clinton when she states that:

To many, this brave new world seems dehumanizing and inhospitable. It is not surprising then, that there is a yearning for 'the good old days' as a refuge from the problems of the present. However, by turning away, we blind ourselves to the continuing, evolving presence of the village in our lives, and its critical importance for how we live together. The village can no longer be defined as a place on a map, or a list of people or organizations, but its essence remains the same: it's the network of values and relationships that support and affect our lives. (ibid.: 329)

## 2. Habermas and *The Future of Human Nature*

Habermas' main concerns revolve around the criticism of technicism and science and he develops that criticism defending three main ideas: the theory of communicative action, the defense of a true democracy, in which every citizen may present and defend his/her ideas and the notion that natural science observes straight patterns while human sciences observe interpretative patterns, based on symbols.

He was 16 when World War II ended and he knew what happened under the Nazi regime, when about six million Jews, as well as millions of other innocent people died because of the Nazi eugenic idea of creating a pure race.

What started as an attempt to basically create a master race by discouraging reproduction with people with genetic defects and other undesirable traits, also using sterilization, turned into a genocide. The idea of introducing measures like prohibition and later birth control in order to avoid problems such as the rising population among poor people, bad public hygiene as well as mentally ill people, had already been fiercely implemented by developed countries such as Great Britain and the USA. As Edwin Black observes, "the concept of a white, blond-haired, blue-eyed master Nordic race didn't originate with Hitler. The idea was created in the United States, and cultivated in California, decades before Hitler came to power" (Black; 2003), although in both countries the policy never reached the extent it did in Germany, especially in the period of the Second World War.

The German experience with the use of eugenics, "the racist pseudoscience determined to wipe away all human beings deemed 'unfit,' preserving only those who conformed to a Nordic stereotype" (Black; 2003) created in Habermas a sense of revulsion towards the Nazi's' inhumanity. He was in shock and horrified with the events, which was one of the reasons that led him to defend ideas such as the emancipation of every citizen from arbitrary social constraint.

In 2001, Habermas publishes *The Future of Human Nature*, a collection of texts previously introduced at some conferences between 2000 and 2001. In this book he presents a series of topics to be studied, showing his concerns about what society and scientific experiences are doing to humankind, to which his above mentioned knowledge of the Nazi procedures has a crucial importance. He underlines the difficulties in defining a frontier between the use of science as therapy and as eugenics, even though he is aware of the fact that scientific evolution means better health and living conditions, as he notes: “The perceived, and dreaded, advances of genetic engineering affect the very concept we have of ourselves as cultural members of the species of ‘humanity’ – to which there seems to be no alternative” (Habermas; 2003: 39, 40).

Taking into consideration the importance of eugenics which, according to the *Cambridge Advanced Learner’s Dictionary*, is “the study of methods of improving humanity allowing only carefully chosen people to reproduce”, Habermas points out the need to distinguish between a negative eugenics (“assumed to be justified”), and which is aimed at lowering fertility among the genetically disadvantaged using techniques such as abortions, sterilization, and other methods of family planning, and a positive or liberal eugenics (“still considered problematic”) aimed at encouraging reproduction among the genetically advantaged. The question is that the divide between the two is not well defined, which might give origin to less clear situations.

The new techniques, such as *In Vitro Fertilization* or PGD (Preimplantation Genetic Diagnosis, “a reproductive technique by which early human embryos are genetically screened and then discarded or placed in the uterus”, [Robertson; 2003: 465]) represent a great option not only for infertile couples but also for the prevention of children with congenital diseases, for example, but the question is that in their eagerness to use those new technologies, people might become unable to distinguish what is right, or a necessity and what is a liability. As Habermas remarks, the problems arise when scientists “play God”, by creating new beings thus fulfilling the parents’ desires. As he remarks,

(...) as soon as adults treat the desirable traits of their descendants as a product they can shape according to a design of their own liking, they are exercising a kind of control over their genetically manipulated offspring that intervenes in the somatic bases of another person's spontaneous relation-to-self and ethical freedom. (Habermas; 2003: 13)

Despite defending that techniques such as PGD should never be used for genetic enhancement but only with the aim of preventing serious health conditions, Habermas is perfectly aware that negative eugenics is a way of "hiding" its positive use.

Another important issue in his book is the study of "human dignity" and the "dignity of human life"; the author defends that "prepersonal life that has not yet reached a stage at which it can be addressed in the ascribed role of a second person still has an integral value for an ethically constituted form of life as a whole." He considers that "the genetically individuated child in utero is by no means a fully fledged person 'from the very beginning'" (ibid.: 35). This position goes against the "pro-choice" ideology, which defends the mother as the one who can make choices about her pregnancy or about the future of the spare embryos; at the same time he calls attention to the discussion of important issues and the defense of moral values. The paragraph in which he emphasises that "application of preimplantation technology is bound up with the normative question 'whether the fact that one was conditionally created and had one's right to existence and development depend on genetic screening is consistent with the dignity of human life'"<sup>16</sup> is of great importance as it points out doubts about the way one envisages genetic intervention. He shares his concerns:

May we feel free to dispose over human life for the purpose of selection? A similar question is raised by the perspective of 'using' embryos with the vague prospect of some day being able to breed (...) and to implant transplantable tissues. (...) To the extent that the creation and destruction of embryos for the purposes of medical research are extended and normalized, the cultural perception of antenatal human life will change, too. (...) Today, we are still sensitive to the obscenity of this

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<sup>16</sup> In *The Future of Human Nature*, by Jurgen Habermas, 20 (citing R. Kollek, *Praimplantationsdiagnostik*, Tübingen: A. Francke, 2000, 214).

reifying practice and wonder whether we want to live in a society which is ready to swap sensitivity regarding the normative and natural foundations of its existence for the narcissist indulgence of our own preferences. (ibid.: 20)

Habermas also defines what he considers “the grown” and “the made”, that is, the person conceived in the common way, and the other who is genetically engineered to have certain characteristics and develop certain traits. He underlines the dangers that such a selection can introduce, not only in the shape of society but also in the newborn, since he/she will be expected to act in a way that might not be the one he or she in fact does. His/her own self might also be at risk, as the child knows he/she was conceived under certain circumstances and might pretend to be someone he/she in fact isn't, just to fulfill the parents' expectations. In his opinion “eugenic interventions aiming at enhancement reduce ethical freedom insofar as they tie down the person concerned to rejected, but irreversible intentions of third parties, barring him from the spontaneous self-perception of being the undivided author of his own life” (ibid. : 63). He defends that “in liberal societies, every citizen has an equal right to pursue his individual life project ‘as best he can’ “ (ibid.: 60), which does not necessarily mean that his aspirations are different from what his parents imagined. He also mentions the fact that even the children naturally conceived are expected to have certain characteristics or develop according to their parents' wishes.

Still according to Habermas, the development of genetics tends to blur the distinctions between what is subjective and what is objective, the grown and the made, and this “instrumentalization of pre-personal life” (ibid.: 71) gives origin to a series of moral questions. He also emphasizes the fact that pre-programmed children will have difficulty in being themselves and in relating to others as it will be hard for them to come to a self-understanding as persons, adding that people might also change their attitude towards society and moral values might be put aside. He believes that a genetically programmed person will find it hard to accept that someone else has made the choices for him or her, thus interfering in his/her own future. At the same time he goes further and questions: “But why – if biotechnology is subtly undermining our identity as members of the species –

should we want to be moral?" (ibid.: 73). I'll quote his answer in full giving that it is of extreme importance for the understanding of his philosophy:

Without the emotions roused by moral sentiments like obligation and guilt, reproach and forgiveness, without the liberating effect of moral respect, without the happiness felt through solidarity and without the depressing effect of moral failure, without the 'friendliness' of a civilized way of dealing with conflict and opposition, we would feel, or so we still think today, that the universe inhabited by men would be unbearable. Life in a moral void, in a form of life empty even of cynicism, would not be worth living. This judgement simply expresses the 'impulse' to prefer an existence of human dignity to the coldness of a form of life not informed by moral considerations (ibid.).

Habermas strongly defends the ideas of moral values and of the dignity of human life, where each one of us should have the right to make free choices and live his/her own life, even if that means suffering and facing less enjoyable situations.

Feeling conscious of the complexity of the issues related to genetic manipulation, Habermas believes that every citizen should be well informed and an enlarged discussion should take place, along with regulation of the process, so that in the future we won't have to regret not having legislated accordingly.

When analyzing *My Sister's Keeper* (in Chapter 3 of this work) some of the concerns Picoult shares with her readers will be enlightened by Habermas's ideas about the future of humankind.

## Chapter 3

### *My Sister's Keeper*, human relationships and decisions

*My Sister's Keeper* by Jodi Picoult was published not long ago, in 2004. The impression given by the first chapter is that an adult is remembering a far-away childhood but one does not have to read much to be surprised by the fact that it is being narrated by a young teenager; and I say surprised also because of the topics she is speaking about and the way she expresses herself. And then, let us say, astonishment increases as a thirteen-year-old girl speaks about the way she was conceived in the way she does. She reveals she had always been curious and wondered why babies were born, till the day her parents told her the reason why she was there, as one of the Fitzgeralds: Sara, a stay-at-home mom, who gave up her job as a lawyer to take care of her two children Jesse and Kate because, as she says: "I am much better at being a mother than I ever would have been as a lawyer" (Picoult; 2004: 27); Brian, a career firefighter who wants to protect his family at all costs; Jesse, who turns into a delinquent as we will see and Kate, around whom the story evolves.

Anna was informed early in her life that she had been specifically conceived to try to help her sister. The Fitzgeralds led what can be called a normal life, but it seems that the old Portuguese saying "a little rain must fall into each life" is scarcely adequate to describe the storm that breaks over their heads. When Kate is two years old Sara notices what seems "a line of small blue jewels" (28) down her spine which later the tests reveal to be "APL ... a subgroup of myeloid leukemia. ... The rate of survival for APL patients is twenty to thirty percent, if treatment starts immediately." (33)

Kate survives the treatments but, about five years later, cancer cells threaten her body again; if she cannot have a bone marrow transplant she will die. Sara wants desperately to save her daughter and she will try everything to keep

her alive, which leads her to convince Brian to have another child; that child would have to be genetically programmed with the adequate characteristics to fit Kate's needs in medical terms because as Sara explains in an interview, they had no time to keep having other children hoping that one would be the ideal match for the sick child. About nine months later Anna is born, in time to help Kate, who manages to survive thanks to the newborn's donation. So why does Anna, at the age of thirteen, go to a broker, "sell" the locket her father gave her when she was six, after a bone marrow harvest for her sister and look for a lawyer's help, in order to sue her parents? Anna loves her sister and understands why she was conceived, but she also starts feeling that she must have rights over her own body. Apart from the cells from her own cord-blood, a procedure she obviously cannot remember, she has already undergone other procedures in order to heal Kate's suffering. She has been in hospital several times. She has even felt that she is not treated by her mother in the same way as Kate; for example, when she has to give bone marrow and cannot stay with Kate, she wants her mother near her; she is just a child and she is in pain after the procedure, but Sara "prefers" to remain with Kate. It must have been extremely difficult for a young child to understand why, with such suffering, her mother does not keep her company, especially when she is used to seeing her mother being with Kate all the time. Now that she is required to donate Kate a kidney, she starts to wonder why her life has to be so different from the other kids of her age; she resents never having been asked if she wanted to endure painful procedures and extended hospitalizations when she was healthy and decides that she must do something: she wants to have medical control over her own body.

*My Sister's Keeper* is narrated by each of its major characters, from the parents to each of the children, the lawyer that Anna "hires" and the guardian that the court mandates to study the family and their family life, and it revolves around Anna and the life-altering consequences of her very adult decision. From the beginning she looks quite sure of what she is doing but there are moments in which she is in doubt about who she is and if what she is doing is the right thing. At the same time it is difficult for her to conceive losing the person who has defined her from the beginning. As she said "it made me wonder ... what would

have happened if Kate had been healthy. ... I'd still be floating up in Heaven ... Certainly I would not be part of this family" (8). There's a sort of lack of identity and Anna is perfectly aware of that; all her life has been lived according to Kate's illness and she resents for instance that it is almost impossible for her to have friends or to go to camping-sites with other people of her age. That is what she explains to her guardian *ad litem*, "a person independent of the local authority, whose prime duty is to safeguard the interests of the child. The appointment of GAL and their duties are defined in the Children Act 1989" (Head; 2003: 355). Julia was indicated by the court to study the case and accompany Anna during this process; when she asks about her friends, she replies: "Friends?" and shakes her head. 'You can't really have anyone over to your house when your sister needs to be resting. You don't get invited back for sleepovers when your mom comes to pick you up at two in the morning to go to the hospital'" (111). Anna cannot even pursue her intense interest in hockey because it would mean being away from Kate. Indeed, she cannot pursue any interests that would take her away from Kate. The reason is that she always has to be ready for what Kate needs, or for what Sara decides for her. On the other hand, Anna strongly believes she would be completely lost if her sister died as she says after having a small argument with her, about friends: "I can't stand the idea of losing her" (57). On another occasion, when reflecting upon her life, she imagines herself as someone different but she cannot help considering that "Kate and I are Siamese twins; you just can't see the spot where we're connected. Which makes separation that much more difficult" (92).

In this novel Picoult uses several examples of the need to have a balance between giving to others and not forgetting yourself. Anna is happy to give to her sister but she has come to a point in which she also starts thinking about herself. Sara is also giving, giving all her attention and energy to one of her siblings, but isn't she forgetting her husband, her son, her other daughter, even herself?

It may be pointed out that this is a typical American family. In *The American Ways: An Introduction to American Culture* it can be read that: "Americans view the family as a group whose primary purpose is to advance the happiness of individual members. The result is that the needs of each individual take priority in

the life of the family” (Datesman and al; 1997: 221). The point is that with the Fitzgeralds the needs of one member are the main focus, or rather, they are the only focus of this family. Brian is often worried about Anna, but he admits to being a coward, for not defending her and especially for not being able to save his own family. Jesse has been forgotten from the moment her sister got ill; Anna was conceived for a specific purpose and can't be forgotten because she is expected always to be ready for the welfare of her sister.

Still according to the same authors “the American desire for freedom from outside control clearly extends to the family. Americans (...) want to make independent decisions and not to be told what to do (...)” (ibid.). Can't Anna's lawsuit be the way Picoult found to emphasise this characteristic of the American society? When Anna is five years old she lies about her mother's job, which infuriates Sara; she tells Anna to “Stop acting like a five-year-old!” (172), just because the little girl could not understand why she had to leave the party where she was with some kids her age. She had to be taken to hospital, again because of Kate. Sara seems to forget that the little girl was in fact five. Maybe the only occasions when she can feel like herself and act as a child, is when she goes with her father to the station and feels at ease with the other firemen, helping them with their cooking.

The reader also knows Jesse exists but only gets to know him better after page 93. Jesse's reflections are extremely important to understanding how this family functions; he starts by remembering an episode in which he was playing with matches and the way Anna reacted, because it surprised him; he then recognizes that “Anna is the only proof that I was born in this family” (93) and makes a series of confessions about what he does. He is a delinquent who lives by himself in a small apartment above his parents' garage, drinks too much, drives his jeep at high speed and is later revealed as an arsonist. Even Kate, who rarely “speaks” in the course of events, confesses to Julia when she visits her in hospital that Jesse “gets into a lot of bad stuff he shouldn't” and she adds that “I don't really think it's something he does on purpose. It's the way he gets noticed, you know?” (161). These are hints that all the members of this family share the same feeling, the feeling that one of the children is the main focus of everything and the other

members are just there because they happen to belong to the family or, as in the case of Anna, because she has to be there whenever necessary.

Jesse admits he would like to be killed in a car accident because he feels it would solve a lot of problems. He feels alone and lost: "I drive toward the warehouse I've been watching. I look for places like me: big, hollow, forgotten by most everyone" (95). He knows the reason why he has been forgotten (by his parents), which suggests that Sara and Brian are not necessarily capable of considering Anna's best interests, which is what the novel is about. At the same time when Jesse sees Kate suffering, he would do anything to help her. He wanted to give his sister a kidney for the transplant because in that way he might feel useful even though he does not want to admit it to his mother: "It wasn't like I was volunteering, I just wanted to, you know, know." (...) "But inside, I'm burning ... What made me believe I might be worth something even now? What made me think I could save my sister, when I can't even save myself?" (98).

Later in all this process, Brian finds out that Jesse has been the person that started all of the recent fires that he and his men have been putting out. When Brian confronts Jesse in his own apartment, the boy tries to lie but he then admits that he feels immense guilt due to the fact that he was not a donor match for Kate. Brian realizes that Jesse's behaviour was a way for him to convince himself that since he could not rescue, he had to destroy. At this moment Brian has to face another dilemma: should he tell the authorities or should he protect his own son?

This is another reason why the life of this family is so difficult to handle but, at the same time, the way the novel develops gives the reader another reason to go on reading. The truth is that a large part of the book revolves around the question of whether Anna's emancipation would really be in her best interests were Kate to die as a result. Anna was born for a specific purpose which, in my opinion, is a serious ethical concern. As ethicist Samuel D. Hensley points out in the article "Designer Babies – One Step Closer", "this is a serious ethical concern. Should a child be created specifically to save another person's life, or should a child be welcomed and loved unconditionally regardless of his or her instrumental value in helping someone else? This is important not just from a Christian

perspective” (Hensley). In the same article he adds: “Immanuel Kant, the prominent philosopher of rationalism, felt that human beings should always be treated as ends in themselves and not as the means for another person to attain his or her ends” (ibid.).

This is surely a topic for discussion: the Fitzgeralds want to save Kate, but do they have the right to keep demanding that Anna be a spare part for her sister? This is exactly the way Anna feels in this family, a spare part, and she often confesses that feeling in the novel, as when she says that: “I used to pretend that I was just passing through this family on my way to my real one. (...) there’s Kate, the spitting image of my dad; and Jesse, the spitting image of my mom; and then there’s me, a collection of recessive genes that came out of the left field” (49).

At certain crucial moments both parents have different opinions about what to do, but it is as if Sara’s opinion is stronger than Brian’s. Brian is capable of understanding what Anna feels and why she looked for a lawyer to help her gain control over the decisions about her own body; in the course of events he considers defending Anna’s position in court, even being aware that it would give rise to a huge problem between the couple. Sara is unable to understand, let alone accept this position; she considers it something crazy but Brian has a different opinion as can be seen from the following excerpt: “This is Jesse, all over again. (...) She’s doing it for the attention. (...) Maybe we need to take her somewhere, alone. (...) Make her see that she doesn’t have to do something crazy to get us to notice her. What do you think?’ (...) My father takes his time answering. ‘Well (...) maybe this isn’t crazy’” (58). He also states to Anna’s lawyer that he will testify on her behalf, but when in court he is not able to maintain that decision. The dilemma that he lives is too strong and he would probably lose his wife, if he took such a decision. He has already experienced a similar situation when he was almost sure that Kate was dying and wanted to convince Sara to bring her home from hospital in order to ‘let her go’. He was aware of Kate’s bad condition and thought that there was nothing else to do when he told Sara that “she wants your permission to leave” (217). His wife believed there was something else they could do, and in fact she was right because Kate recovered. So why shouldn’t she be right this time? This doubt makes him change his mind in court;

he is not able to defend Anna's demand because he knows that it would mean losing Kate.

Sara is almost hysterical when Anna tells her parents she has a lawyer to help her. She even slaps Anna for not peacefully agreeing to give her sister a kidney for transplant. As we can read in the *Textbook of Medical Ethics*, chapter 9: "The idea of transplanting organs is not new, even though the reality of doing so is. (...) the transplantation of kidneys from one identical twin to another was first done in the middle of this century. (...) A kidney as well as blood and bone marrow can be taken from a live donor leaving the donor substantially unimpeded". (Loewy; 1989: 109, 110). This is in fact what Sara believes; the procedure might not put Anna at great risk, but it must not be forgotten that there are a whole series of principles one must observe. A human being cannot just be used and abused, even if the main reason is the life of another person. Of course many of our fears of dealing with genetics are fears based on a substantial lack of facts or understanding of genetics and since this is one of the present-day worries, there is also the need for regulation, which I believe is an extremely complex process. But this does not mean that the problems of genetics and genetic changes should be ignored.

The changes are so fast and so many that it must be very difficult to envisage all the scenarios and define regulations for such broad subjects. Even so, we can refer to the attempt of the member states of the United Nations Educational, Scientific and Cultural Organization (UNESCO) which decided to develop a global statement on bioethics, presented to UNESCO's General Assembly for approval in 2005. The final Universal Declaration on Bioethics and Human Rights (UDBHR) was criticized by many, since it associates bioethics and human rights, but Michael Yesley, former coordinator of the US Program on the Ethical, Legal and Social Implications of the Human Genome Project claims that "referring to bioethics without human rights is not bioethics".

"The UDBHR presents 15 principles, including respect for human dignity, human rights and fundamental freedoms, and the priority of individual interests

and welfare over the interests of science and society.” From those principles I wish to stress the following aspects:

Article 3: Human dignity and human rights – 1. Human dignity, human rights and fundamental freedoms are to be fully respected.

(...)

Article 5: Autonomy and individual responsibility - The autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected. For persons who are not capable of exercising autonomy, special measures are to be taken to protect their rights and interests.

Article 6: Consent – 1. Any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information. (Wollinsky; 2006: 355, 356)

When analysing these principles, we come to a crossroads: as a parent, it is not difficult to understand this mother who would do anything to keep her sick daughter and heal her suffering but at the same time it's hard to accept the way she uses the other daughter, showing that she is important when the other one needs her “body”. Sara's reactions make Anna feel even worse, but in fact they are another proof that she decides everything by herself without even thinking about the feelings or ideas of the other members of the family. Even some of her reactions towards Brian, when he tries to make her reflect on her decisions and their consequences, also show that she just listens to her heart. The reader cannot but understand them, especially a mother or a father because, as Samuel D. Hensley wrote in the article mentioned above: “Our culture has generally considered parents to be the best judges of the welfare of their offspring”. But he also remarks that “even this has limits. Children are weak and vulnerable; they require protection from abuse and negligence. The ability for parents to choose which offspring die and which live and what traits they will manifest is an awesome responsibility” (Hensley). And it is here that Sara is unable to distinguish the frontier between what is reasonable and what is right. As she acknowledges, she

wants to keep both daughters and each time Kate's condition gets worse, she just turns to Anna as a saviour; the way Anna feels, the way she suffers, the lack of attention aren't important. Anna has never had the opportunity to make her own choices because, as she explains to Julia: "The way parents ask questions that they already have answered in their heads. *You weren't the reason that the whole second grade stayed in for recess, were you? Or, You want some broccoli, right?*"(112). She knows that, as a child, she just has to obey without questioning, but when it implies your own body, your own life, your own suffering, aren't you supposed to have your own opinion?

All this causes anguish in young Anna who doubts if she is loved, as she often mentions, and at the same time provokes a feeling of guilt. She knows that she is making her parents suffer but at the same time she wants to be able to take her own decisions. This is the normal process of growing up. She knows that Kate needs her but is it fair to submit yourself to such suffering in order to help someone you love, especially when that person has already suffered so much? Julia understands Anna perfectly: she also has a sister and she has no doubt she would do anything to help her if something similar happened to them. But she stresses that it would have to be her own decision, her own choice.

The dilemma that Anna is facing happens to be even deeper than one could imagine. When in court Anna's lawyer wants her to testify, she feels trapped: how can she tell everyone, especially her mother, the real reason why they are there? Is this really her own decision? Will her parents understand? She is only thirteen but her character reveals mature decisions, mature ideas; she reassures Campbell she will not testify because, as we later learn, it will imply making confessions in court not only about herself, about her family decisions, about the (ab)use of her body but also about Kate, and she knows that the revelations about the latter will be a perfect shock for her family. Only when Anna realizes that it is in court that she will have the opportunity to express her feelings, to make herself heard, is she brave enough to rise up and ask the judge for permission to speak. And what she reveals about the difficult decisions such a young child has to make to protect the ones she loves is in fact a shock: her decision to take her parents to court is another sign of the true love she has for the members of her family, especially for

the one who, as she mentioned, is the true reason of her own existence: Kate. Anna is, in fact, making an attempt to accomplish her sister's wish. Kate has been suffering for so long that she feels she cannot stand it anymore so she begs Anna to refuse to donate the kidney that might help her. That is the way out she finds for her suffering and for the suffering she knows that she is causing in her family. Anna confesses her problems about taking such a decision but at the same time it is difficult for her to see Kate suffering. She is also the only one to know that Kate has already tried to put an end to her life. These amazing revelations also lead us to other controversial issues related to human life and human rights which have been in the news, such as euthanasia.

There are other major aspects which must be addressed with regard to Anna's testimony. In court, Anna's lawyer asks Dr. Bergen, "the head of the medical ethics committee at Providence Hospital" (301), many questions. Dr. Berger explains to the court what an ethics committee is, "an educational and consultative committee whose role is to analyse ethical dilemmas and to advise and educate health care providers, patients and families" (Pozgar and Santucci; 2004: 389), emphasising the six principles of Western Bioethics that they try to follow.

These same principles are explained in *Principles of Biomedical Ethics*, where it can be read that "the principle of nonmaleficence asserts an obligation not to inflict harm on others" (Beauchamp and Childress; 2001: 113). The principle of beneficence implies that people are treated autonomously and that no harm is caused to them but it also implies that "we contribute to their welfare" (ibid.: 165); justice, meaning equal opportunities in health care (and words such as fair and equitable are mentioned as synonyms for justice); veracity, referring to "comprehensive, accurate and objective transmission of information as well as to the way the professional fosters the patient's or subject's understanding" (Picoult; 2005: 284).

After reflecting on these principles and the case under discussion, it is difficult to understand where we should draw the line between what is done and what is supposed to be done. Hasn't Anna's life also been one of suffering, not

only physically but, what is probably harder, psychologically? It is not just that she lives side-by-side with an almost terminal patient. Other situations also contribute to her distress: being almost ignored by her own mother, not having a personal life, not being able to express an opinion about the use of her body and especially having to pretend she had taken such a hard decision as to deny her sister a kidney.

Dr. Berger then emphasises that: “Generally we’re called to convene when there’s a discrepancy about patient care. For example, if a physician feels it’s in the patient’s best interest to go on with extraordinary measures, and the family doesn’t – or vice-versa” (301). Even more important: “We review the situation and make recommendations.” “Not decisions?” “No” (302). And he goes on to answer Campbell’s questions, to the point of stating that legally parents can decide everything till the child is eighteen but with some exceptions; according to Dr. Bergen, “once a child reaches adolescence, although they can’t give formal consent, they have to agree to any hospital procedure (...)” (302).

Anna is a perfect example of these exceptions. She is an adolescent and, according to the recommendations, she should agree to any hospital procedure but she is only thirteen, so her parents are entitled to decide for her. She is old enough to express her feelings, her emotions. So why shouldn’t she? Probably because her thoughts might contradict those of her parents or, rather, her mother’s desire, and Sara probably did not want to take that risk. She loves Anna, there is no doubt about that, and if she listened to her daughter, she knows how guilty she would feel, so for her it is better just to guess, not to listen. This position seems to go against what George D. Pozgar and Nina M. Santucci remark in *Legal aspects of health care administration*: “All patients have a right to be informed as to a diagnosis, prognosis, proposed intervention, risks of the intervention (...). After receiving this information, all individuals are legally empowered to either consent or to refuse the intervention”(389). This legal aspect is also mentioned by the judge when he has the first meeting with Anna and explains to her that “... no hospital in this country will take an organ from an unwilling donor” (87). What happens in Anna’s case is that she has never been informed or asked about her feelings or her wishes and the best proof is that after so many times in hospital

she should be regarded as any other patient, but in fact she isn't. She is even supposed to give consent to the intervention, as Dr Berger explains in court: "It goes without saying that no hospital in the country is going to take a kidney out of a child who doesn't want to donate it." (...) "Has Anna's case landed on your desk, Doctor?" "No." (...) "Can you tell us why?" "Because she isn't a patient" (303, 304).

In *My Sister's Keeper* is there the case of one patient to be considered by the ethics committee or are there two? Isn't Anna also a patient? Hasn't she been to hospital numerous times and in painful situations? The lawyer presents a whole range of documents from the hospital proving she has been there, so how can she not be considered a patient? The role of the ethics committee is questioned by the court, since it seems that the institutions exist, you have laws and regulations but in fact they do not work correctly. On the other hand, we must agree with what Dr Berger explains: "The problem is that this kind of medical situation hasn't existed before. There is no precedent. We're trying to feel our way as best we can" (304).

Indeed, situations such as the one Picoult develops in her novel pose a series of new questions and it is easy to understand the dilemmas since they deal with very important aspects: health care, human relations and the perspective of losing a beloved one.

Picoult develops her story around a family and the difficult decisions involving its members, not only using her own experience as a mother<sup>17</sup> but also studying cases from real life, speaking with patients and their families and then launching a series of questions we can undoubtedly say are extremely difficult to answer, especially because they have to do with people's feelings, people's lives, people's futures. When one reads about controversial situations such as genetic engineering, organ donation or euthanasia, it is easy to criticize or to judge but at the same time people must think about what they would do if they were in others' shoes. Genetic planning is becoming a subject of our everyday life, but scientific advances such as "making" a new person as the saviour of another one is surely a subject that I believe most of us are not yet ready to understand. As Neil J. Cooper

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<sup>17</sup> As she mentions in several interviews, her son Jake had to be submitted to "ten surgeries in three years" due to "bilateral cholesteatomas in his ears – benign tumors that will eventually burrow into your brain and kill you, if you don't manage to catch them" in "A conversation with Jodi Picoult" in *My Sister's Keeper*, A Readers' Club Guide.

and Simon Jonathan Hampton point out, “in the ordinary course of events, most parents (...) attempt to manipulate the physical and psychological characteristics of children and they do so as part of the process of good parenting” (498), probably implying that each parent wants the newborn to be healthy. However, in the same article they immediately alert the reader to the dangers of such procedures: they emphasise that this sort of decision can give rise to despotic parents since they expect their designer baby to be and act as they planned or they imagined; it is also a way of not allowing children to live their own lives and of putting their own selves at risk. That is what happens to Anna, who was genetically planned not to have blue or brown eyes, not to be tall and slim but to be the perfect match for her sister. The details of her conception are explained by the couple who happened to be invited for a TV interview while Sara was pregnant. Sara admits that her pregnancy is a desperate attempt to have a donor for Kate who was three years old at the time. The new baby was conceived and implanted through IVF, which, according to GRS (Georgia Reproductive Specialists) is “a procedure designed to enhance the likelihood of conception in couples for whom other fertility therapies have been unsuccessful or are not possible. It is a complex process and involves multiple steps resulting in the insemination and fertilization of oocytes (eggs) in (...) laboratory. The embryos created in this process are then placed into the uterus for potential implantation.” This is a technique which has been used successfully for more than twenty-five years and has allowed infertile couples to have a family, but with the fast pace in technological developments that society faces nowadays, it is possible to use these techniques for other purposes, as we can see from Picoult’s work.

In this regard, Habermas in his work *The Future of Human Nature* points out that “the question is how parents’ rights to make eugenic decisions will affect their genetically programmed children, and whether the consequences of these decisions infringe upon the objectively protected well-being of the future child” (...); “the parents’ decisions might indirectly have an adverse effect on the sense of her (child) autonomy” (Habermas; 2003: 77, 78).

Neil Cooper and Simon Jonathan Hampton also discuss this topic, addressing the concern “that a designed person will come to have a crisis of self-

identity” (499) and also “the claim that children have a right to an ‘open future’” (ibid.). They go beyond that and share their concerns about the future of humankind, citing Fukuyama’s remark that “(...) there is a concomitant concern that we are in danger of altering human nature and, in the process, of destroying ourselves as humans” (ibid.), but they come to the conclusion that every child needs guidance and that the future of designer babies won’t differ much from other children’s future.

As science and technology develop, new techniques also arise, which can be a great help in medical terms; as we can read in “Extending preimplantation genetic diagnosis: the ethical debate”:

PGD (Preimplantation Genetic Diagnosis) has also been used to enable a family with a child with Fanconi anaemia to have another child who would serve as a source of haematopoietic stem cells obtained from that child’s umbilical cord blood. Without a stem cell transplant, the first child is likely to die. (...) Parents willing to have another child to produce stem cells for an existing child will find PGD attractive because it enables them to transfer to the uterus only embryos free of the disease and HLA-matched to the existing child. (Robertson; 2003: 468)

People using this new system should be well informed, since there are embryos that will not have the chance of surviving. According to Agneta M. Sutton<sup>18</sup>

PGD involves the deliberate creation and destruction of human life. (...) the combination of IVF and PGD involves the creation of several embryos and the selection of embryos shown not to have a particular genetic disorder; embryos who do have the disorder are destroyed. (...) They should be told that tissue typing may require the creation of many embryos - healthy and unhealthy - before a single one is found that can be used as a donor for an afflicted sibling.

When using such techniques, parents should bear in mind that they will have a series of discarded embryos and that they are having another child, with its own characteristics, feelings, personality and not a sort of machine that should be

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<sup>18</sup> Agneta M. Sutton, PhD Fellow of The Center for Bioethics and Human Dignity.

turned on or off whenever necessary. Still, in the above cited article “Extending preimplantation genetic diagnosis: the ethical debate”, John A. Robertson emphasizes that “although helping an existing child is a motivating factor in having an additional child, such a reason alone is not likely to make the parents ignore the needs of the new child.” He observes that: “With stem cells available from umbilical cord blood no further intrusions on the new child will occur.” He goes even further, pointing out that “its birth might save the life of an existing, loved child, which would only increase its specialness. If the stem cell transplant fails, the parents will have a surviving child to love” (468). This “recommendation” goes against the Fitzgeralds’ idea of a ‘savior sibling’: it has to accomplish its task, no matter the consequences.

As in almost every field, the advances and the new techniques now available also have their drawbacks, since couples may start to see and use the new technologies in abusive ways, such as defining certain traits for their children or such as defining the baby’s gender. Foreseeing that the access to such techniques as the above mentioned PGD might give rise to less clear or even unacceptable use of those techniques, the HFEA – Human Fertilisation and Embryology Authority – came up with a list of conditions to be observed when using them, a list quoted by Deech and Smajdor in their book *From IVF to Immortality*:

- Firstly, the condition suffered by the existing child must be severe, life-threatening, or of sufficient seriousness to justify the use of PGD.
- It was also felt to be important that the embryos involved should be at risk of the genetic condition which was suffered by the sibling (...).
- Other treatment options should have been fully pursued before turning to the ‘saviour sibling’ possibility.
- None of the PGD/HLA techniques should be available where the intended beneficiary is a parent rather than a sibling.
- Only cord blood should be taken – no other organs or tissues. (70, 71))

In the novel under analysis, that same procedure was used with a specific aim, Anna being considered “a miracle” (100) since the family knew that this genetically engineered baby was the opportunity for Kate. But the problem is that it did not solve the situation for good, bringing a whole set of new problems when Kate’s body failed again. One of the most important rules was violated several times, in the case the last of those listed above.

The plot of *My Sister’s Keeper* is fictional speculation, and yet, in the context of present-day developments, it seems ever more realistic. Let us take the example presented by Agneta M Sutton, who observes in the above mentioned article that “In December of last year, (2001) the authority allowed Raj and Shahana Hashmi to create a baby by *In Vitro Fertilization (IVF)* and then undergo pre-implantation genetic diagnosis (PGD) and tissue typing to serve as a donor for their son suffering from thalassaemia. (...) the Hashmi couple were granted permission to undergo PGD precisely because they were at risk of passing on thalassaemia, a serious genetic condition”. Under other circumstances it would not probably be possible to do this. That is why fiction has an important role, as it allows authors to use their imagination and create (fictional) scenarios that might serve as a preparation for what is coming.

Deech and Smajdor also point out that “PGD does not cure genetic disease, it merely enables diseased embryos to be identified and discarded, leaving only unaffected embryos for implantation” (73). They invoke two examples of the use of PGD, with two cases from real life, in the United Kingdom, in which the HFEA (Human Fertilisation and Embryology Authority) came across two different decisions: in the first case, a couple wanted to have another child but it was likely to be born with the same congenital disease their other child had. In the other one, parents wanted to conceive a ‘savior sibling’ for their son who suffered from a rare kind of anaemia. The HFEA gave its consent to the use of PGA in the first case but not in the second, based on the fact that this one was not at risk since fewer “than 1000 individuals are known to suffer from the condition worldwide” (ibid.: 71) and they considered the sibling would not be affected more than any other child. The two cases discussed demonstrate the difficulty in dealing with such issues, when it is known that the second couple achieved their wish in

the United States: the sibling was a perfect match and helped to treat the sick child.

In an interview Picoult reveals where her ideas for this story came from: she picked up a real situation but she started asking other questions:

I heard about a couple in America that successfully conceived a sibling that was a bone marrow match for his older sister, a girl suffering from a rare form of leukemia. His cord blood cells were given to the sister, who is still (several years later) in remission. But I started to wonder... what if she ever, sadly, goes out of remission? Will the boy feel responsible? Will he wonder if the only reason he was born was because his sister was sick? When I started to look more deeply at the family dynamics and how stem cell research might cause an impact, I came up with the story of the Fitzgeralds. I personally am pro stem-cell research - there's too much good it can do to simply dismiss it. However, clearly, it's a slippery slope... and sometimes researchers and political candidates get so bogged down in the ethics behind it and the details of the science that they forget completely we're talking about humans with feelings and emotions and hopes and fears... <sup>19</sup>

In this extract Picoult emphasises her preoccupations about technological advances and their consequences and she also confesses to feeling constantly worried about what might happen to people's feelings and emotions, and accordingly to being led to question current wisdom insistently.

Feelings and emotions are not easy to handle and as human beings we have different ways of facing situations and reacting to circumstances; Picoult seems to be an expert in confronting her readers with controversial questions. Recall *Perfect Match*, published in 2002, which deals with the molestation of children by priests, and more recently *Change of Heart* (2007), about a criminal who is going to be executed and proposes to donate his heart to the sister of his victim who needs a heart transplant, or even more recently the controversy around her book *Handle with Care* (2009), in which the mother of a sick baby intends to sue her gynecologist for not having warned her about the baby's physical problem, so that she can have money to treat her baby; the question is that she will have to

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<sup>19</sup> "A conversation with Jodi Picoult" in *My Sister's Keeper*, A Readers' Club Guide.

lie in court about what she would have done, had she known, during pregnancy, of the rare bone disease the fetus already had.

As pointed out above, *My Sister's Keeper* poses several questions and confronts the reader with the discussion of many complex situations, as well as, more importantly, other questions and the "What-ifs" Picoult often mentions. In this novel the central question is that at the age of thirteen Anna does not yet know who she is and she often doubts her own existence; mentally she analyses that situation several times but she is unable to put into words why she took the decision of demanding legal control of the decisions over her own body.

Being narrated by the different characters, the book allows the reader to follow the events, but even more importantly, it allows us to be "inside" their minds, listening to what they say and to what they are thinking about, trying to guess what is behind their thoughts or what they intend to do. We "listen" to their monologues, we "see" their thoughts, becoming acquainted with their dilemmas and the difficult choices each has to make. Despite this, there is a series of things that turn out differently from what one might expect. That's how life is, unexpected.

After analyzing *The Future of Human Nature* I strongly believe that Jodi Picoult had several of Habermas' considerations and worries in mind when writing *My Sister's Keeper*. I have already remarked (Chapter 1, Part 3) how she prepares herself for the writing of each one of her novels and we must not forget her words when she mentions the fact that one of the reasons why she writes about controversial issues is exactly because she feels that this is a way of trying not to make things happen. But if they do happen, how do people react? If we have the chance of keeping a loved one, won't we do everything we can? The main question in this novel is that whatever one character tries to do to help another, implies a third person, in the case, Anna, a pre-programmed "baby". Does that character have the right to make the others do everything she wants and accomplish her wish, even if it is for the sake of others? Family bonds are usually very strong but moral values and respect also have to be observed. There is that old Portuguese saying that "a liberdade de cada um termina onde começa a dos outros", which does not appear to be respected by that desperate mother.

I see *My Sister's Keeper* as the example of what Habermas fears is about to happen to humankind: Anna was conceived to be her sister's saviour and she is perfectly aware of what her parents, mainly her mother, expect from her; and I say mainly her mother because in my opinion it is obvious that Brian has some difficulty in accepting all the decisions that Sara makes about Anna, especially the donation of a kidney. Anna has always accepted and obeyed her mother; she knew what she was expected to do, and even if she felt that she had the right to refuse to be hospitalised whenever Kate needed, or that she had the right to have her own freedom, her own friends and be with them, she rarely complained; as Habermas points out, such "pre-programmed children will have difficulty in being themselves and in relating to others" (Habermas; 2003: 73). That is the way Anna feels: on the one hand she wants to take her own decisions, she wants to be herself; on the other hand, she cannot help feeling that should something wrong happen to Kate, she will feel completely lost, as she confesses more than once. Among the passages from the novel that reveal her fears are the following: "I didn't come to see Kate because it would make me feel better. I came because without her, it's hard to remember who I am." (Picoult; 2005: 138), "I have a feeling that if I really try to figure out who I am without Kate in the equation, I'm not going to like who I see" (ibid.: 179).

Even more representative of her feelings is her comment to Campbell after the judge had pronounced the verdict that, despite being only thirteen, Anna would be "medically emancipated from your parents" (409). She asks Campbell "what do you think I should do?" and as she does not get an answer, she remarks that "I don't even know who I really am" (411).

Still, as Anna gets older, she realizes that it will be more and more difficult to be her own self: she knows that she was conceived in a specific way for a specific purpose, which makes her feel like an object with no personal will. When taking the decision to sue her parents she is not just trying to say that she is a human being with her own problems and her own personality; she is trying to make her parents realise she is someone able to take her own decisions, not only about herself but also to help others; in this case, she was trying to help her sister,

not in the way her mother wanted, but in the way her own sister begged her to. The dilemma she is living seems to get harder and harder to handle.

Anna is not free to pursue her own wishes and her own destiny; she matches perfectly what Habermas also criticizes in his book, “the grown” and “the made”. Picoult uses real material to show the problems that may arise if society is not able to distinguish between what is right or advisable and what is a vanity. The dilemma described in this novel could happen in real life, but the author goes beyond it and creates an even more complex situation, as Kate, the sick sister does not overcome her disease, as was expected. That leads to a complex situation, since Anna becomes a sort of “spare part”: she has been “made” with a certain purpose, and she knows that she will not be able to be her own self. She is a ‘designer baby’ used not as an end, but as a means for her parents to try to accomplish their dream of saving the other daughter. It is true that children are usually conceived as a means, except for those who come “by accident”; what seems hard to understand is that parents who conceive a ‘saviour sibling’ forget that they will use the newborn without caring much about the suffering they might cause. The case of the Fitzgeralds causes us to reflect upon the suffering they imposed on both daughters. That does not mean they did not love them; they were the true example of a family struggling to keep together, and the novel is a way of making people aware of the complexity of issues such as family bonds, genetic manipulation and human relationships.

## Final Remarks

Human rights are not for adults only. Children, too, are protected by human rights. But several special issues arise regarding children's rights. First, the term 'child' encompasses all human beings from birth until the age of 18. (...) some of the traditional human rights are of such a nature that they cannot be exercised or have significance until the child has reached a certain age (Smith; 1993: 447).

This is the way Lucy Smith starts her article "Children, Parents and the European Human Rights Convention", remarking that while the interests of parents and children are common, there seems to be no problem as the decisions are usually common; what might cause disagreement and conflicts are the decisions the others make for the child, especially when he/she is old enough to express ideas and fight for what he/she thinks is right. There is a conflict between the self-determination of the child and the parental authority. And that conflict can give rise to uncomfortable situations, as in the case of the novel I have been presenting.

*My Sister's Keeper* is a fictional story, as mentioned before, based on facts from real life, and with a whole series of thought-provoking situations, which remain in many readers' minds long after we have finished the reading. The prospect of creating clones for the sake of living people or of creating pre-programmed children with defined characteristics to serve as savior siblings, through genetic engineering, poses a whole range of ethical concerns and obliges us to rethink our role in today's society. I do not think we should be scared about the future, because as people usually say, if we think too much about bad things and feel afraid of the world, we will not live. To a certain extent, I share Cronenberg's opinion when he states that:

I've never been pessimistic about technology (...) I'm saying that we are doing some extreme things, but they are things that we are compelled to do. It is part of the essence of being human to create technology, that's one of the main creative

arts. We're never satisfied with the world as it is, we've messed with it from the beginning (Beard; 2006: 423).

On the other hand, we also know that the world (meaning society) is undergoing so many and such huge transformations that it is impossible to predict what will happen to us as humans.

It is undeniable that we are already influenced by every sort of technological advance; we are hardly able to live without our cell-phone, something unthinkable a few years ago; we wear contact lenses; if we have problems with our bones, we might undergo surgery and receive a spare part; we hear about people who undergo certain organ transplants, but we believe that most of us are not prepared to have a "spare me" to serve our needs if we get sick and our life is at risk. And this does not necessarily have to do with what that "spare me" can provide. What we believe is harder to understand is the way we will live, the kind of relationship we will establish with that "me", who in fact is a he or a she, with their own characteristics. Even though he/she is exactly like me, everyone has a different personality and each one of us establishes different kinds of relationships with the others.

In this field one must not also forget that each one of us has rights that ought to be respected, which in a certain way might collide with the interests of others, as dealt with by Picoult in *My Sister's Keeper*. In the novel, the parents, mainly Sara, strongly want to keep their sick daughter but at the same time we can argue that they are a source of pain, not only for Kate but also for Anna, whom they (consciously) oblige to do what they want, against her will and causing some pain to her. It is true that the law says that parents are supposed to make decisions for their kids until the age of eighteen, but this is such a tough subject that we believe the ones involved should have the opportunity to express themselves.

If one of our relatives, as is the case of Kate and Anna, were in need, I believe we would follow Sara's steps, probably not that far, as we would also need to establish a limit to the suffering of the other person, in this case Anna.

The twist in the plot, almost at the end, is an incredible way of showing the reader how things change unexpectedly and at the same time a way of increasing people's awareness of the delicate web that daily life is. At the same time it can be argued that, despite using Kate's illness and all the trouble it brought to the members of the family as a main topic for her writing, what Picoult in fact managed to do was to explore all the emotions and the ways family members really related to each other. It also shows that Sara made a great effort to save her daughter, but in her desperate wish to do that, she was not able to listen to her own family; she failed, she never asked about others' opinions or desires. She did not have the slightest idea about the way Kate felt and the way she suffered not only physically but also psychologically, because she knew the suffering she caused to others, in the case her "healthy spare" sister. That is not the way a family should live.

I consider the novel also as a way of making people look around them and reflect upon the changes occurring in our society, not only in technological terms but also in the way those changes interfere in the way we make decisions and relate to each other. Much has been discussed with respect to new technologies and their impact on society and I guess there is no right answer to the challenge whether it is advisable to follow those technologies as far as human reproductive cloning is concerned. In *From IVF to Immortality*, we can read that developed countries have different views on whether there should be regulation concerning embryo research; the authors emphasise that idea by observing that "an analysis of the various national structures of regulation has been made by DG Jones and CR Towns, who describe four types of regulation of stem cell research" (Deech and Smajdor; 2007: 211). That can be seen as evidence that such subjects are extremely complex and that there is no answer to be seen as definite. What is undeniable is that the human being is never satisfied with his/her knowledge and as the world goes round every day, so does humankind and its desire for controlling science and technology.



## *My Sister's Keeper* – the movie

Based on the novel with the same name, the American screenwriter Jeremy Leven adapted *My Sister's Keeper* to the film directed by Nick Cassavetes, released in 2009. There has been much discussion around the ending of the film and, even though there seemed to have been a sort of agreement with the author, it was not respected. Picoult reveals in an interview in her official site that she was a bit disappointed with it but as a whole she was very impressed with the work that Cassavetes presented to the audiences.

As for me, I must say that it was not easy to decide when to watch the film. I did some reading about it, even before it was produced and was already expecting a different ending. But it was not only that; one of the reasons that made me reluctant was the plot itself because I knew that it would be hard not to feel too weak and cry, something I believe happened with lots of other people. We know that the novel and consequently the film are fiction but it is not difficult for many of us, readers or viewers, to imagine such a scenario near us or with one of our relatives. I saw the film at school with a 10th grade class. Some students had already seen it and confessed they were very much impressed, others had some difficulty in seeing some scenes.

The novel and the film have the same plot but there are a few significant changes made by the director. Besides the change in the ending that I will discuss later, one of the characters, Julia, does not exist in the film and I believe her role is somehow important; she is the person appointed by the court to study the Fitzgeralds and escort Anna aiming to find out the kind of relationships and family life the family lead. Julia is also important to understand the bonds among sisters, in her case twins, and to clarify some aspects of the personality of Campbell and why he, Anna's lawyer, is a bachelor.

Another major difference is in Jesse's character; Anna's older brother is a rebellious boy who is an arsonist, robs cars, drinks a lot and seems to be always absent when the family needs him; in fact, he tries to help in his own way, going to

hospital with Anna to visit Kate, or giving some blood, without commenting on it with his parents. In the film he still looks lost but there is no sign that he is the delinquent person portrayed in the novel. It must be pointed out that he has a major role in the film when Anna is testifying in court: she doesn't want to confess to her mother why they are there and why she took the decision of suing her parents. Jesse is also in court and he cannot stand the idea of not using that opportunity to reveal the truth, the truth that he also knows (another hint that he is in fact worried not only about the sick sister but also about "spare" Anna). I believe it is worth reading the dialogue that takes place in that exact moment:

**Jesse** - Jesus Christ, Anna, just tell them.

**Anna** - You shut up.

**Jesse** - Tell them why we're here. Tell them what we're doing here in court...

**Anna** - [cuts in] You promised me that you wouldn't do this.

**Jesse** - God, you people are so stupid!

**Anna** - [shouts] you promised!

**Jesse** - Kate wants to die!

**Anna** - Stop it!

**Jesse** - She's making Anna do all this 'cause she knows she's not gonna survive another operation.

**Sara** - [yells] That's a lie, Jesse.

[...]Mum, no, it's not. Kate's dying and everybody knows it! You just love her so much that you don't want to let her go!

**Campbell** - Your honor?

**Jesse** - [continues] But it's time Mum, Kate's ready.

**Sara** - That's not true. Kate would've told me!

**Campbell** - Your honor, I...

**Jesse** - Mum, she did tell you,

**Brian** - She did. She told you million times, you didn't want to hear it.

From that moment on, the course of events changes radically and Sara realizes that she has to give up and let Kate go. What follows is a sequence of a familiar drama, where the life of a beloved one comes to an end, what makes the

film, in my opinion, avoid much of the ethical arguments dealt with in the novel; for the director, the family drama appears to be more important than the ethical issues and the dilemmas that Picoult dealt with so well in her writing. Why not explore the issues connected with organ donation after the car accident that so strongly affected the family, for example?

I must confess I enjoyed the film but I cannot but agree with most of the viewers who definitely advise people to read the book, not to see the film. We know that a film adaptation does not mean that the plot has to be exactly as in the text it is based on, but for those who read the book first, I admit the film is a bit disappointing and it truly alters the main idea of the novel: Anna does not end up as her sister's keeper as the novel portrays her. Many of the ethical and moral dilemmas presented in Picoult's work will not reach the audiences unless people take the decision of reading the novel.



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