Executive Summary

It is every normal parent's wish to have a happy child free of ailments and suffering. However, not all children are born free of diseases and suffering. Some are born with severe disabilities and others are born with congenital genetic problems that have less chances of cure or no cure at all. These unfortunate circumstances make parents of such children with severe medical conditions desperate and devastated to the extent that they try anything possible in attempting to improve quality of life of their sick children. No parent wants to see his or her child suffering. However, a more pressing situation is when parents decide to have a second child whose purpose is to save the life of the sick first child by donating stem cells from cord blood or bone marrow. This second child is sometimes referred to as the "Saviour sibling" and is born for the purpose of saving the life of the sick older child of the family. 'Saviour sibling is the media name for a child who is conceived, gestated, and delivered in order to provide umbilical cord blood, or, even more contentious, bone marrow desperately needed by the parents' older child' (Mills 2005:2).Because there is no matching donor for the ill older child, a donor is created in the form of a second sibling, whose match is genetically guaranteed by IVF, preimplantation genetic diagnosis (PGD), and tissue typing (Boyle and Savulescu 2001).

Given that children are already being created in other Countries such as the United States of America, France and Britain for the above-mentioned purpose, this research report will attempt to engage in the debate surrounding saviour siblings, the use of preimplantation genetic diagnosis (PGD) in creating these children, and the possibility of this technology being abused and misused for gender selection. Taking this into consideration, this research report will attempt to highlight what the South African laws and policies say about saviour siblings. Should parents with pressing issues as mentioned-above demand to have a "saviour child" of their own for the purpose of using him or her to save the life of another of their children in South Africa, on which grounds would it be rejected or accepted?

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CHAPTER 1 – AN OVERVIEW OF THE PAPER

1.1. Background

In Britain, Zain Hashmi was born with a hereditary blood disorder called beta thalassaemia (BT). Although his parents did not suffer from the disease, they were carriers of it. According to Sheldon and Wilkinson (2004), any child of the Hashmis conceived naturally had a one in four chance of having beta thalassaemia. Zain needed regular blood transfusions and he also needed a bone marrow transplant to survive. His parents did everything possible, even naturally conceiving another child with the hope of him being a matching donor, but they just ended with an extra child in their family. Zain's new brother Haris was born free of BT but he was not a match for his much needed stem cells and bone marrow (Sheldon and Wilkinson 2004). The parents also tried to launch a worldwide campaign to search for a donor, but that also failed (ibid). However, after applying to the Human Fertilisation and Embryology Authority (HFEA) to create a child free of beta thalassaemia (BT) with the help of IVF, preimplantation genetic diagnosis (PGD) and tissue typing to make sure that the embryo selected was the perfect match for Zain, they were given the permission under very strict conditions (ibid).

In another similar case in Britain, Charlie Whitaker was suffering from Diamond Blackfan anaemia (DBA), a rare form of anaemia in which few or no red blood cells are produced by the bone marrow. Its symptoms are not different from other forms of anaemia and daily injections and blood transfusions are needed. However, DBA is not hereditary but sporadic (ibid). Because DBA is not hereditary, Charlie's parents are not carriers of the disease (ibid). If they decide to naturally conceive another child with the hope of him or her being a perfect match for Charlie's bone marrow, chances are very rare that they will have another child with this disease. Therefore, according to the HFEA, Charlie's parents do not qualify to be given permission to use PGD and tissue typing, as they stand a very high chance of conceiving healthy embryos (ibid).

The HFEA has published certain criteria as its Code of Practice amended in 2009, which would aim to guide its future case by case decision-making (see Human Fertilization and Embryology Authority Code of Practice 8th Ed, 2009).
One of the requirements listed in the HFEA Code of Practice states that "the embryos conceived

in the course of this treatment should themselves be at potential risk from the condition by which the existing child is affected”. Thus, both parents must be carriers of the diseased gene that is causing the health problems of the existing child. However, the Whitakers’ embryos would be at a lesser risk of the disease suffered by Charlie, because both parents are not carriers of Diamond Blackfan anaemia (DBA), which is not hereditary but a sporadic condition.

According to the HFEA, the usage of preimplantation genetic diagnosis must be for the purpose of making it possible to select an embryo free of the genetic disease that is suffered by the existing ill child in the family. Thus the saviour child born with the help of IVF and PGD must be benefited (Spriggs 2005: 341), because such a child will be born free of the ailments suffered by his or her elder sibling. Therefore the HFEA do not grant a license for PGD and tissue typing if the procedure is not in the best interests of the new child as well as serving the interests of the ill existing child in the process. Thus, the embryo chosen with the use of PGD must benefit from the processes by being born free of the genetic disease suffered by the elder sibling. Therefore, in the case of the Hashmis, the use of PGD and tissue typing will make it possible for the saviour sibling to become a perfect match for Zain’s much needed stem cells and bone marrow. In addition and most importantly, in accordance with the HFEA requirements, the new child will also benefit because he or she will be born free of beta thalassaemia (BT) in the process.

After the Whitakers were denied a licence to use PGD and tissue typing by the HFEA in the UK, they travelled to America, and gave birth to their new son Jamie who was a perfect match for Charlie’s bone marrow transplant in 2003 (*MailOnline,* 06 May 2011). However, the HFEA has officially relaxed the rules of licensing PGD for creating a saviour sibling to allow for Whitaker-type cases in 2004 (Berry and Engel 2005).

Although this sounds like science fiction and so far as we know it has never been done in South Africa, the reality is that elsewhere in the world, children are being created for the purpose of being the perfect matching donors of stem cells and bone marrow for their sick siblings with the help of this modern medical technology. Therefore, the number of saviour siblings and the number of countries relaxing their health policies and law regarding the birth of saviour siblings is increasing.

1.2 Health Care in South Africa (Adapted from the South African home page).

South Africa has a two-tiered health system that consists of a large public sector and a smaller but fast growing private sector. The public health sector delivers services to about 80% of the population. The private sector, on the other hand, is run largely on commercial basis and caters to middle and high income earners who are mainly members of the medical schemes. However, from 2012, the Department of Health has implemented the National Health Insurance which aims at improving the health system. The NHI is intended to bring reform that will improve service provision and health care delivery. It will promote equality and efficiency to ensure that all South Africans have access to affordable, quality health care services regardless of their employment status and ability to make a direct monetary contribution to the NHI Fund.

In addition, an estimated 80% of South Africans consult with traditional healers alongside general medical practitioners. Based on patients' belief system, patients resort to both traditional medicine and western medicine.

1.3 Problem Statement

Modern medical technology is growing fast. Reproductive procedures such as IVF are already being used even here in South African. Elsewhere in the world, children are already being created for the purpose of being the perfect matching donors of stem cells and bone marrow for their sick siblings with the help of PGD and tissue typing. Consequently the number of saviour siblings and the number of countries relaxing their health policies and law regarding the birth of saviour siblings is increasing. However, the current legislation in South Africa is not as explicit as the United Kingdoms' legislation when it comes to issues of creating saviour siblings. Many other countries that allow the use of PGD and creation of saviour siblings modelled their regulations relating to saviour siblings and PGD around the HFEA's principles and can deal with these issues adequately and with clarity. The question then arises if the current South African law is adequate and sufficient enough in directing us should a parent of a sick, incurable child demands the use of PGD for the creation of a saviour sibling? Is it morally acceptable to do so?

1.4 Research Questions

What does South African law say about saviour siblings? Is the current legislation legally sound and sufficient in directing us should a parent demands to give birth to a saviour sibling? Is it ethically sound for a parent to demand to give birth to a child whose purpose is to be used to treat another of his or her sick children?

1.5 Aim

This research report aims at exploring whether the current South African law as compared to international legal framework and regulations is ready and adequate enough to direct us in issues involving saviour siblings should such issues arise.

1.6 Objectives

- To give an account of the ethical issues raised by the phenomenon of saviour siblings.
- To examine the existing law regarding the issue of saviour siblings both internationally and nationally.
- To identify the South African policy position regarding the issue of saviour siblings.
- To critique the philosophical/ethical underpinnings of existing statutes and international case law.

1.7. Methods

1.7.1 Study Design

This Research Report is a normative study that will utilise ethical and legal analysis.

1.7.2 Methodology

This Research Report will not involve study participants. It will be an ethico-legal paper attempting to analyse the problems surrounding “saviour siblings”. It will draw from the law and literature relevant to the topic. This report will use already available academic literature in the form of books, journals, and search engines to access both legal and ethical issues and debates around the saviour sibling.

1.8 CHAPTERS LAYOUT

Chapter 1 – Background to the study

In Chapter 1, a background to the study based on literature review is given followed by the problem statement, the research questions, aim of the study and the objectives. It is mentioned in this chapter that the paper is of normative nature and will mainly use the already existing academic literature.

Chapter 2 – Ethical issues raised by creating “saviour siblings”

In Chapter 2, the notion of “saviour siblings” and the importance and functions of PGD in the selection of these children are explained. The chapter further deals with ethical issues surrounding PGD and moral arguments raised by creating “saviour siblings”. In this chapter, an elaboration is given on how Utilitarianism and Deontology may approach the issue of PGD and “saviour siblings”.

Chapter 3 –What does the law say about PGD and creating “saviour siblings”?

Chapter 3 of this paper gives an explanation of various forms of legislation that different countries use to solve the issue of PGD and selection of “saviour siblings”. It also scrutinizes Chapter 8 of the National Health Act No 61 of 2003 of South Africa and its regulations to check if South Africa can handle cases and issues of PGD and “saviour siblings”. The Children Act No 38 of 2005 of South Africa is also explained in this chapter in order to understand how the best interest standard for children can be better applied. Several international case laws concerning children are also explained in this chapter in order to give an understanding of what is in the best interests of children.

Chapter 4 – A philosophical critique of the existing statute and policies regarding the use of PGD for selecting “saviour siblings”.

In this chapter, the existing HFEA regulations and principles are critically analysed using the moral theories of Utilitarianism and Deontology.

Chapter 5 – Conclusion of the study and Recommendations

In Chapter 5, an appraisal of both Utilitarianism and Deontological approach to the complex issue of “saviour siblings” is done. The two moral theories are compared and weighed against each other, and a conclusion is drawn from this appraisal on whether to use PGD for the selection of “saviour siblings” or not using it and let the sick siblings die. Recommendations in making policies and regulations concerning the issue of PGD and “saviour siblings” in South Africa are also given.

CHAPTER 2 -ETHICAL ISSUES RAISED BY CREATING "SAVIOUR SIBLINGS".

2.1 Introduction

Every normal parent wishes to have a happy child free of ailments and suffering. However, some parents carry recessive diseased genes that they pass onto their children. This gives rise to children who are born with severe disabilities and others born with congenital genetic problems that have minimal chances of cure or are completely incurable. These devastating and frustrating conditions may force some parents of children who are suffering from these congenital diseases to try anything possible in an attempt to improve quality of life of their ill children. However, modern medical technology offers some treatment hope in the form of stem cell transplants for many malignant and non-malignant diseases. Unfortunately, suitable stem cells and bone marrow are not readily available as it may not be easy to get a matching donor, even from close relatives (Robertson et al. 2002). In order to solve the problem of waiting for a suitable donor, modern medical science offers an answer by creating a child who is a perfect match with the help of IVF and pre-implantation genetic diagnosis (PGD). This matching donor is called a "saviour sibling", and its main purpose is to donate stem cells and bone marrow to the ill elder child (Mills 2005: 2). However, a moral dilemma and ethical issues arise when parents use a child as a source of body tissues to treat another of their own children in the family.

In order to clarify and give a simple understanding of the issues of "saviour siblings", in this Chapter, the paper will first explain what a "saviour sibling is and will also explain its relation to PGD. Furthermore, the paper will highlight the ethical problems that may be raised by both the notions of "saviour sibling and PGD. The paper will also explain how the two main moral theories of Consequentialism and Deontology work.

2.2 What is a "saviour sibling"?

"Saviour sibling" is the media name for a child who is conceived, gestated, and delivered for the main purpose of providing the umbilical cord blood and to some extent, bone marrow that is desperately needed by an already existing ill child in the family (Mills 2005: 2). Thus, without the stem cells obtained from the blood or bone marrow, the ill elder sibling will die as he or she suffers from an incurable genetic disease such as beta thalassaemia, Fanconi anaemia, etc (Overall 2012: 81). Hematopoietic stem cell transplants have become the treatment of choice for many malignant and non-malignant diseases (Robertson et al. 2006: 151). However, suitable donors for stem cells and bone marrow are not easily and readily available. Unfortunately this difficulty results in many patients including children born with these hereditary diseases suffer for many years or sometimes die because of lack of access to blood cells for transplant that match from close relatives (ibid). Due to lack of suitable stem cells donors in-vitro fertilization (IVF), pre-implantation genetic diagnosis (PGD), and tissue typing are usually carried out in the process of creating a saviour sibling, and also to make sure that the created child is a close genetic match for the ill older child (Boyles and Savulescu 2001).

2.3 What is the importance of PGD in the creation of "saviour siblings"?

Pre-implantation genetic diagnosis (PGD) makes it possible for the creation of a child who is free of the genetic diseases suffered by his or her elder sibling (Steinbock 2004: 175). It can also provide information on whether the child would be a good matching cord blood donor in advance (ibid). Thus, PGD provides a woman with a chance of not having to worry about abortion during her pregnancy because her foetus is already known to be free of a genetic disease that is troubling her elder child. This information is made available to her before the embryo is implanted into her uterus to make her pregnant. In addition, PGD also provides the chance for the created foetus to develop into a healthy child who would be a close match for donating cord blood and other tissues to the sick elderly child (ibid). Thus, PGD is the modern medical technique whereby diagnosis of genetic diseases is done through testing cellular DNA for chromosomal abnormalities (ibid). Its disadvantage is that it cannot detect other conditions such as spina bifida, anencephaly, encephalocele and many other diseases (Botkin 1998). In addition, PGD always requires IVF which subjects a woman to drugs which cause super-ovulation, multiple fertilization and many embryos (ibid). However, of the many embryos formed, those found to be having genetic defects are discarded or frozen indefinitely and only those embryos found to be free of serious genetic diseases or those perfect with no defects are then chosen to be implanted into the woman's uterus for gestation (ibid).

2.4 Ethical Issues Concerning PGD

PGD forms the basis of the creation of saviour siblings. However, it involves discarding of embryos. This action often raises issues of rights of human embryos by those people who believe that a human embryo is an early human being. According to Steinbock (2004: 178), “the purpose of PGD is not to simply inform couples about the genetic nature of the embryos, but to prevent the birth of a child with disability”. Although it may be perceived good to live in a society of healthy people with no incurable genetic ailments or disabilities, to deliberately and actively block the birth of children with disability may raise ethical, discrimination and rights issues especially to the already existing disabled people. In addition, if not properly controlled, PGD may be misused to create designer babies or can be used for non medical gender selection.

Some people believe that we should accept the children we are given as a gift instead of selecting or creating children with specific characters that satisfy our own wishes no matter how noble or caring the motivation may be (Berry and Angel 2005). In this perspective, it is wrong for human beings to create or treat other human beings as a commodity. However, saviour siblings are not born through a normal or natural process of procreation. These children are created in the laboratories with the help of PGD and IVF by scientists and doctors. Thus, medical laboratories act as manufacturing plants whereas doctors and scientists can be seen as manufacturers or creators of these children (Kass 1997: 17-26). Thus, procreation has been turned into literally something handmade (ibid). It is now like woodcraft or sculpturing (ibid). When performing PGD, doctors and scientists pick and choose embryos. Thus, embryos with potential problems are not given a chance to develop into human beings as they are usually discarded or destroyed. This raises ethical questions of treating people as a commodity where only the best products are bought for human consumption. Thus, creation of saviour siblings can be seen as the process whereby parents shop for perfect children free of ailments from the manufacturers. Kass (1997) argues that children created in this way, where IVF is involved, are made and formed in the same manner as objects such as cars or bread of which the best and most perfect is bought and the malformed does not go out to consumers.

2.4.1 Advantages and Disadvantages of PGD

Advantages	**Disadvantages**
1. Can detect risk factors for many genetic diseases such as haemophilia, fragile x syndrome, cystic fibrosis, sickle cell anaemia and chromosomal abnormalities (Robertson 2002: 34-40).	1. Not 100% accurate in detecting genetic diseases. It cannot detect other conditions such as spina bifida, anencephaly, hypoplastic left heart syndrome and many others (Botkin 1998). Regardless of its success rate, many couples lack access to this technique because it is very expensive as it also involves IVF (Robertson 2002)
2. Can ensure that only disease free and perfectly matched embryos are transferred to the woman's uterus (Robertson 2002)	2 Demolition of embryos during biopsy and discarding of surplus embryos not chosen to be transferred for pregnancy. From the perspective of loss of prenatal life, PGD is worse than abortion, because it requires the creation of numerous embryos for each live birth produced (Botkin (1998).
3. Increase the chance of conceiving a healthy child free of genetic diseases carried by the parents in their genes and in addition, can make sure that a child born with the help of the procedure can be a perfect match for donating stem cells and other body tissues to another sick child in the family (Steinbock (2004: 178).	3 Some view the procedure as an element of discrimination against people with genetic illnesses and disabilities, because it emphasises on rejecting and not allowing embryos that have a serious genetic diseases to develop into human beings (Robertson 2002). Can be misused for negative eugenic purposes and for screening and exclusion for preferential reasons such as non medical sex selection and other physical traits (ibid). Widespread use of PGD and genetic technology to choose or exclude can alter genomes of offspring (ibid).

2.4.2 The Moral Status or Personhood of an Embryo

Most people believe that human life has special value. Hence there is no serious ethical theory that allows the killing of people without strong moral justification. There are serious debates centred on whether human embryos and foetus are humans or not, and whether destroying human embryos or aborting foetuses is actually killing people or persons. Among those who contributed in the debate is John Finnis. He is of the view that embryos and foetuses are human because they are conceived of human parents (Finnis 2006: 17-24). According to him, embryos can develop into human babies, children and adults if all goes well, although initially they consist of no more than a few cells (ibid). Finnis main argument is that personhood begins at conception and therefore any procedure or act that aims at intentionally destroying an embryo is impermissible (ibid). He argues that embryos should not be destroyed because they already have the biological capacity found in their genetic structure for supporting specifically human functions and operations such as self-consciousness, rationality and choice (ibid). According to him, embryos have the same status as persons; therefore, destroying or killing a few cells human organism has the same moral significance as killing a person (ibid).

However, Finnis view is completely rejected by many others, among them Michael Tooley. Tooley argues that the potential to become a person is not sufficient to give an embryo a right to life (Tooley 2006: 25-39). According to him, an embryo is not a person because it does not possess a concept of self and it has no capability of desiring to continue existing as a subject of experiences as it does not have any mental state (ibid).

2.4.3 Alternatives to “saviour siblings”

Conceiving a child in order to serve as a stem cell donor raises difficult medical, ethical, and legal issues (Robertson, Kahn and Wagner 2002: 34-40). The main ethical issue raised is whether it is ethically acceptable to conceive a child to be an organ or tissue donor for an existing child (ibid). However, there is always a need for transplants in order to help those who are sick in the society. Stem cells transplants have become the treatment of choice for many malignant diseases such as leukaemia, thalassemia and Fanconi anaemia (ibid). Unfortunately it is often not easy to obtain suitable cells unless the cells are from the sibling donor (ibid).

However, coital conception followed by gestation without prenatal testing offers the least certainty. There is one in four chance that a child born in this manner can be a matching donor (Sheldon and Wilkinson 2004) No one can tell in advance whether the second child will be the one in four that is a matching donor and free of autosomal recessive diseases (ibid).

Another alternative may be the use of embryonic stem cells. This involves producing stem cells directly from embryos left over from *in vitro* fertilization, killing the embryos in the process (Sithole 2011). This process avoids the birth of a child in order to obtain stem cells (Robertson, Kahn and Wagner 2002). Thus, embryos are not transferred to the uterus, raising many ethical questions and issues similar to those raised by PGD. Another controversial way of obtaining stem cells is the use of foetal tissues. This process may raise issues similar to those of abortion. Stem cells found in umbilical cords have also proven to be useful in treating diseases such as leukaemia (Sithole 2011). Umbilical cord blood stem cell transplants are less prone to rejection than bone marrow transplants, because umbilical blood lacks well developed immune cells (ibid). This gives umbilical cord blood cells a less chance to attack the recipient body (ibid).

2.4.4 Factors that may influence umbilical cord blood donation

The umbilical cord blood raises the issues of ownership and consent. According to Chima (2011), ownership of umbilical cord blood is debatable. Since the umbilical cord is embryologically derived from the foetal allontois, it may be considered property of the child (Chima 2011). However, umbilical cord blood is usually collected with the consent of the mother. In South Africa, legal personhood begins at birth. A foetus which is born and live *ex utero*, even if only briefly, becomes a legal person and he or she acquire the rights and status of a person (ibid). Although a new born baby is recognised as a legal person by law, he or she does not have the capacity to provide informed consent (ibid).

According to Bhengu (2004) cultural norms that direct attitudes and social factors play a major role in the shortage of organs or tissues for transplantations in South Africa. Organ donor referrals among Africans in 1995 and the year 2000 respectively were 28% and 17% while it was 60% and 72% among whites in South Africa (ibid). This racial or cultural discrepancy in organ donation was found to be caused by lack of knowledge, religious fear, cultural beliefs, fear of surgical complications and lack of communication between lay families and health care personnel (ibid). There is a strong and interdependence between the living and the dead or ancestors among black South Africans that adds to the fear that if this bond is broken, the ancestors will show anger by visitation in the form of ill- health, misfortune or even death (ibid). Belief in witchcraft, ritual murders for human tissue and organs for use in witchcraft may accentuate the problem of organs or human tissues donation (Conco 1972: 299).

2.5 Ethical Theories that influence Debate in the Creation of "Saviour Siblings".

The use of a child to save the life of another child always attract different ethical views based mainly on the moral theories of Utilitarianism and Deontology. However, these theories are often in conflict with each other, making it difficult for people to make moral choices that can be accepted by all without being frowned upon by others. Just like in real life situations, very often people do not reach an agreement on issues happening around them, whether it is based on politics, morality, economy, etc, because they use different methods of reaching to their judgements. Most Utilitarians in particular may favour the use of saviour sibling as he or she saves the life of a dying brother or sister. Deontologists on the other hand, might take the issue of saviour siblings as manipulative and unethical because, according to them, a saviour sibling is not being treated as human, but as a commodity and also as a means to other people's ends. To get a better understanding on how people involved in a situation such as the one we are dealing with of "saviour siblings" are influenced to reach their ethical judgements, we first have to understand how the theories of Utilitarianism and Deontology work.

2.5.1 Utilitarianism

Utilitarianism is a consequence based moral theory (Brody 1983: 10). It judges an action write or wrong solely based on its consequences (ibid). Thus, the right action is judged to be the one that leads to the best consequences or the greatest happiness for the greatest number for those involved in a situation. Therefore, in a given situation, Utilitarianism determine all the available alternatives, weigh options by trying to foresee the consequences of performing each action in the list, and then evaluate the results in terms of which is best. Thus, the action that is most likely to yield best consequences is the one that will be chosen as the right action and that will also determine the right thing to do (ibid).

Utilitarianism does not deal with known facts beforehand, but with probabilities because consequences of an action cannot be seen or known before an action is performed. Thus, in order to assess whether an action is right or wrong, Consequentialism looks at the after effects or consequences of such an action (ibid).

Interestingly, Utilitarianism may justify an action that violates someone’s human rights, as long as the consequences of the action performed can be shown to be in line with the general good (ibid). Thus, according to Utilitarianism, the very same action that gives bad consequences to some may be morally acceptable and praiseworthy as long as it yields greater benefits to the majority of people and the greater society involved.

In addition, Utilitarianism does not take into account our special moral obligations to people with whom we have a special relation (Brody 1983: 19). It does not account for the fact that we have special obligations to certain people such as family and friends (ibid). It does not give us the choice of putting the interests of special people that we love such as our children before the interests of strangers. Utilitarianism weighs the interests of everyone involved in a situation equally.

According to Rachels (2007: 97), good actions are those that bring more happiness and oppose suffering or unhappiness for those involved in a situation. The principle of Utility requires us to always choose whatever action or social policy that would have the best consequences for everyone concerned (Rachels 2007: 90) Therefore, the right actions are those that produce the greatest possible balance of happiness over unhappiness, with each person’s happiness counted as equally important (Rachels 2007: 100).

Furthermore, Utilitarianism can also be rule based. According to Rule-Utilitarianism, the proper moral rules are those which when followed lead to better consequences than one would get from following any alternative moral rule (Brody 1983: 28). In addition, the rightness of a particular action lies in its conformity with the proper moral rule (ibid). Interestingly, Rule-Utilitarianism allows for exception in special circumstances if such exceptions will lead to better consequences than following a stiff rule that is absolute. Therefore, if following the rule against the use of “saviour sibling” for instance will in general not lead to the best results (because this may lead to the death of a sick elder sibling), then the rule against the use of “saviour sibling” should not be followed in every case in which it applies.

2.5.2 Deontology

Deontology is a rule-based or duty based moral theory. It puts more emphasis on respect, dignity and rights of an individual human being. According to this moral theory, an action is right if it conforms and is in line with a proper moral rule (Brody 1983: 24). Therefore, an action is wrong when it violates such a rule (ibid). Thus the moral rule that determines the rightness or wrongness of an action does not necessarily refer to the consequences of the action. Rules in this case have an intrinsic value to the action, and are absolute. According to this moral theory, rules that prohibit telling a lie for instance ought to be followed all the times, because the prohibition holds even if telling a lie in a certain case will result in beneficial consequences. Kant, a great deontologist strongly believed that moral rules are absolute (Rachels 2007: 120). According to him moral rules hold without exception. He argued that no matter how the consequences may be, some things cannot just be done. However, other deontologists may be willing to allow for some exceptions and may not treat the prohibitions in question as absolute in the most extreme cases (Brody 1983: 24).

Kant views moral obligations as independent to our particular desires. According to him, moral requirements are categorical. Rules that are categorical have the form “do that or don’t do that” and it ends there. They do not say do this or do not do that in a certain situation, but all the time regardless of our particular wants and desires (Rachels 2007: 121). Therefore, for an action to have moral worth, it must be done from the sense of duty regardless of its consequences (Paton 2005: 10-13). Thus, things must be done because it is right to do so, even if it is against one’s inclinations.

According to Kant, we must “act so that we treat humanity, whether in our own person or in that of another, always as an end and never as a means only” (Rachel 2007: 130). Therefore, humanity should always be treated as an end and never as a means to other peoples’ gains, and this should be practiced all the time. Kant further argues that any human being no matter how he or she was conceived has an intrinsic dignity that makes him or her of value and worthy (Rachels 2007: 130)). Therefore, it is wrong to treat human beings, including children as instruments or as a means to other people's ends. In addition, Kant argues that the handicapped should be treated with the same respect and be protected as they have intrinsic dignity and rights as everyone else (Rachels 2007: 130-132).

Kant also argues that we should "act only according to that maxim by which we should at the same time will that it should become a universal law" (Rachels 2007: 121). Thus, an action is morally acceptable if after following the rule of doing that action, one is willing for that rule to be followed by all people all the times (ibid). According to Anscombe, "the crucial point is that there are many ways to formulate the rule" (Rachels 2007: 124). Suppose the rule says it is permissible to use PGD in the creation of a saviour sibling when doing so would save someone's life. Therefore, we could will that the use of PGD for the creation of saviour siblings be made a universal law.

Deontologists also look at the character of the moral agent or the person performing an action when analysing whether an action is morally acceptable or not. According to Kant, "nothing can possibly be conceived in the world, or even out of it, which can be called good without qualification, except a good will (Paton 1948: 63). Thus, the gift of nature such as the intelligence and wit given to scientists and doctors is undoubtedly good and desirable in many respects; but may also become extremely bad and mischievous depending on the will which is to make use of such intelligence and wit (ibid). Thus, the gifts of nature like intelligence can be misused by people with bad characters and wrong motives. We often hear of cases of scientific misconduct and the misuse of scientific research findings with dual usage by intelligent researchers. Therefore, the good will constitutes the good character of any moral agent. It is the precondition of goodness in all moral acts. It is the measure of moral value. According to Kant, nothing is good morally without the involvement of the good will (ibid). The goodwill is good for its own sake, not instrumentally as a means to something else (Paton 1948: 64). In addition, the good will denotes the willingness of a moral agent to do the right thing from the right motive (ibid).

2.5.3 The Ethics of Care

The ethics of care is closely aligned to virtue ethics (Dhai and McQuoid-Mason 2011: 13). Its focus is not directed on the macro organisation of society but on a micro level resulting in influencing the macro level (ibid). Care is central to morality of the ethics of care (ibid). It emphasises on a sense of responsibility and obligation to others, and it encourages emotional involvement in making moral judgements (ibid). The Ethics of Care promotes family relations and unlike Utilitarianism and Deontology, it does not emphasise on impartiality (ibid).

2.6. CONCLUSION

In this chapter, this paper reflected the views of the two main ethical theories that are involved in issues of saviour siblings, which are Utilitarianism and Deontology. However, these theories are often in conflict with each other. In this chapter, we found that Deontology or Kantianism is a strict moral theory that uses intrinsic rules that are absolute, whereas Utilitarianism is a situational based theory which allows exceptions.

However, in this paper, we are dealing with a very sick child who is about to die, against a healthy child whose stem cells and most probably bone marrow is needed to save the life of the sick child. The challenge we have is that some moral rules that are supposed to guide us into a balanced solution are said to be absolute. This is problematic because moral rules that are absolute and cannot be broken or cannot be overridden by other important and weighty rules in a given problematic situation such as the one we are dealing with in this paper always cause moral dilemmas. In the healthcare profession, dilemmas like these caused by conflicting moral rules may result in difficulties in making important decisions about patient’s care, and at the end patients may suffer or die because access to some treatments and care will never be available.

CHAPTER 3 - WHAT DOES THE LAW SAY ABOUT PGD AND CREATING SAVIOUR SIBLINGS?

3.1 INTRODUCTION

The issue of saviour siblings is a deeply divisive issue. Moral agreement on it is unlikely. It highlights broader tensions over whether new medical technology should be encouraged, tolerated or restricted. Legislation tries to resolve this problem, although laws do not always satisfy the moral beliefs of all citizens. The Choice on Termination of Pregnancy Act No 92 of 1996 is an example of legislation that many feel do not represent their true feelings and position about abortion. However, it is considered a good piece of legislation because it offers clear guidance and a workable solution in issues that involve abortion. Even if some legislation is not popular, it has to be respected. To avoid unnecessary debates and to have a working plan, laws and policy that deal with issues of saviour siblings are needed. When it comes to regulating the use of pre-implantation genetic diagnosis (PGD) for the sake of selecting a saviour sibling, different countries take different steps. South Africa’s position in allowing or not allowing the usage of PGD for embryo selection is not clear (Strode and Soni 2012).

3.2 PGD Legislation

Regulation of PGD in different countries varies from non-regulation, statutory ban, statutory mandatory licensing to regulation by professional organisations.

(a) Non- Regulation

The United States is an example of a country where the use of PGD is not regulated. There is no law or regulatory process enacted to limit its use. Decision on the usage of PGD is left to the clinics that offer the service. Consumers are left without interference by the Government to make their own personal choices about the use of PGD. Although some providers believe that certain uses of PGD such as sex selection for non-medical purpose are unethical and may refuse to do PGD under certain circumstances, others advertise these services and believe that parents should have freedom to decide what they want (Hudson 2006). PGD clinics have the power and authority to make their own decisions on moral and ethical issues concerning PGD. Each clinic has its own separate policies and services. One clinic can allow the use of PGD to select the gender of the baby, while another clinic prefers only to use PGD to screen severe genetic disorders.

(b) Statutory Ban

In countries such as Germany, Switzerland, Ireland, Western Australia and Austria, PGD is banned. The ban on PGD could be for a number of ethical, moral and social reasons. Where it is believed that an embryo has the right to life, as in Germany, PGD is unacceptable because it can often result will most likely results in the destruction of embryos. This can be equated to deliberate destruction of life. Thus, in Germany, the Embryo Protection Act of 1990 defines an embryo as a fertilized human egg capable of developing into a full human being (Isasi and Knoppers 2006) In addition, destruction of embryos that carry disease-linked genes is perceived as a slippery slope to a homicidal form of eugenics practised in the Nazi era. However, the ban on PGD usually gives rise to medical tourism. Couples often avoid the restrictive laws of their own countries on PGD by travelling to other places such as the United States where there are no regulations on PGD, and treatment is permitted including sex selection for non-medical reasons.

(c) Statutory Mandatory Licensing

In countries such as the UK and France, PGD is regulated through statutory mandatory licensing whereby a section of the government regulates PGD by requiring each clinic that provides services to be licensed before performing the procedure. The UK has stringent guidelines concerning the use of PGD. Its usage is regulated by the Human Fertilization and Embryology Authority (Sheldon and Wilkinson 2004). This is a statutory body governed by the Human Fertilization and Embryology Act of 2008. In the UK, PGD is allowed to be performed for the purpose of detecting severe genetic conditions and tissue typing matching for saviour siblings. This is done under strict criteria. Gender selection is not allowed. Each clinic that offers PGD services applies for a new licence for every new genetic screening case they would like to test in an embryo (ibid). This form of regulation creates clear and legally enforceable rules.

(d) Regulation by Professional Organizations

Countries such as Japan regulate PGD through professional organizations such as the Japan Society of Human Genetics (JSHG) and the Japan Society of Obstetrics and Gynaecology (JSOG). The guidelines relating to PGD in Japan require that it can only be performed for a serious hereditary disorder (Isasi and Knoppers 2006). In case of sex selection, it is allowed only for serious sex-linked recessive hereditary disorders (ibid). Clinics that provide PGD services must get approval from the organization to perform the procedure (ibid).

3.2.1 Specific International Laws concerning PGD and Saviour Siblings

In the United Kingdom, the Human Fertilization and Embryology Act of 2008 control the use of PGD (Strode and Soni 2012). The Human Fertilization and Embryo Authority (HFEA) is a statutory body governed by this Act of parliament. The HFEA gives licenses to assisted reproductive clinics for the purpose of using PGD for severe genetic diseases and tissue typing for ensuring the match of saviour siblings. Licensing is obtained under very strict criteria and the clinic applies for a new license for every new genetic disease to be tested in an embryo (Sheldon and Wilkinson 2004). The HFEA has set up a Code of Practice that was amended in 2009 and the following criteria should be followed as a guide on a case by case basis:

(a) The condition of the affected child should be severe or life threatening, and of sufficient seriousness to justify the use of PGD.

(b) The embryos conceived in the course of this treatment should themselves be at risk from the condition by which the existing child is affected.

(c) All other possibilities of treatment and sources of tissue for the affected child should have been explored.

(d) The techniques should not be available where the intended recipient is a parent.

(e) The intention should be to take only cord blood for purposes of the treatment, and not other tissues or organs.

(f) Appropriate implications counselling should be a requirement for couples undergoing this type of treatment.

(g) Families should be encouraged to participate in follow-up studies and as with PGD; clinics should provide detailed information about treatment cycles and their outcomes.

(h) Embryos should not be genetically modified to provide a tissue match.

In *R (Quintavalle) v Human Fertilisation and Embryology Authority* [2002] EWCA Civ 667, both the UK Appeal Court and the Human Fertilization and Embryology Authority (HFEA) position was to the embryo as a potential child whose interests were of paramount importance. It was presumed the embryo deserved to be benefited by being chosen and implanted with the help of PGD. Thus, the HFEA position was that an embryo or the person that the embryo would become, should be exposed to the risks of PGD only if it is likely to derive enough benefit that outweigh the risk of PGD (Sheldon and Wilkinson 2004). This was the case between the Human Fertilization and Embryology Authority (HFEA) and Comment on Reproductive Ethics (CORE) brought before the UK Court of Appeal.

This case has set a precedent internationally as it was the first of its kind where the use of PGD to create a saviour sibling was granted by the court. This resulted in the Human Fertilization and Embryology Authority (HFEA) being given authority to allow Mr and Mrs Hashmi to create a saviour sibling with the help of PGD to save the life and health of their son Zain. In this Appeal Court, Mance L. J explained that Mrs Hashmi needed the necessary knowledge that her child would not be born with the same disease that her elder son Zain was suffering from for her to carry on with the pregnancy (Sheldon and Wilkinson 2004). The Appeal Court then held that PGD was necessary and was required to assist Mrs Hashmi with such knowledge as both her husband and she are carriers of the disease beta thalassaemia (ibid). Interestingly, in Countries such as France, parts of Australia and many others where the use of PGD to create saviour siblings is permitted and is regulated with specific laws and regulations, jurisdictions have created legal frameworks, many of which are modelled on the UK's HFEA and its guardian legislations (Strode and Soni 2012).

3.2.2 Specific South African Law concerning PGD and Saviour Siblings

There is no specific law or regulations such as in the UK that deals with issues of selecting embryos with the use of PGD for the purpose of creating saviour siblings in South Africa. However, Chapter 8 of the National Health Act No 61 of 2003 of South Africa provides for the removal of gametes from a living person by a competent person to be used only for the medical or dental purposes, as long as such products are not removed from a mentally ill or a person younger than 18 years of age. In addition, sections 2(a) and 2(b) of the regulations relating to human biological material use allow for the removal of biological material for genetic testing by a competent person such as a medical doctor or a dentist with an informed written consent.

In terms of Chapter 8 of the National Health Act No 61 of 2003 of South Africa, regulation 5(a) provides that human biological material may be removed from a living person for the purposes of DNA, RNA and chromosome-based genetic testing. In addition, regulation 6 only makes it a prohibition to use preimplantation and prenatal testing for the sake of selecting the sex of a child, unless it is done for a serious sex linked or sex limited genetic condition. In terms of regulation 5(a) and 6 of Chapter 8 of the National Health Act and its regulations, the use of human biological material for genetic testing, pre-implantation and prenatal testing is allowed as long as the test is not performed for non-medical sex selection. Although it is not explicit, Chapter 8 of the National Health Act and its regulations may give provisions for competent persons to manipulate DNA and RNA to perform PGD even for creating saviour siblings.

3.2.3 Consent by Children

In South Africa, people over the age of 18 years have full legal capacity to give consent for their own medical treatment and surgical procedure. However, in the case of a child under the age of 18 years, generally, consent of the parent or guardian is required (Dhai and McQuoid-Mason 2011: 77). But, in terms of the Children's Act 38 of 2005 of South Africa, children may consent to their own medical treatment if they are over the age of 12 years, and they are of sufficient maturity and have mental capacity to understand the benefits and risks, and social and other implications of the treatment. When it comes to surgical interventions, according to the Children's Act of South Africa (Act 38 of 2005), children may consent to the performance of a surgical operation on themselves if they are over 12 years and they are of sufficient maturity and have mental capacity to understand the benefits, risks, social and other implications of the surgical operation. In this case, section 129(3) emphasises the attendance and assistance by their parents or guardian during the surgical procedure. This means a healthcare practitioner cannot perform an operation on a child without the knowledge of the parent or guardian, unless it is in a case of emergency.

When it comes to consent to medical treatment on behalf of children who do not have legal capacity, the Children's Act (Act 38 of 2005) provides that the parent, guardian, caregiver of the child or some other person with legal capacity can give consent on behalf of the child (Dhai and McQuoid-Mason 2011: 79). In this situation, the child must be under 12 years or over 12 years but of no sufficient maturity or is unable to understand the benefits, risks and social implication of the treatment or operation. Although caregivers can give consent on behalf of a child for medical treatment, they are not allowed to do so for surgical operations in terms of the provisions of the Children's Act (Act 38 of 2005)(ibid).

3.3 Legal Obligation to Donate Body Tissues

With regard to a claim of moral obligation in these circumstances, it should be noted that everyone has a right to bodily autonomy, and can make decisions on what to do or not to do with his or her own body as long as his or her actions do not cause harm to others. The law cannot force a person to use his or her body to aid another person. Human beings are under no legal compulsion to give aid or to take action to save or rescue one another, with the exception perhaps of those such as doctors, police, fire-fighters, whose job description and professional code requires it. In *McFall v Shimp* (1978) 10 Pa D&C 3d 90, Robert McFall approached the Court in Pennsylvania to force his cousin Shimp to undergo a bone marrow procedure. McFall was suffering from a deadly bone marrow disease and Shimp was the only compatible donor available. Shimp refused to undergo the painful bone marrow procedure. The Court could not force Shimp to save the life of McFall against his will. Although Flaherty J was sympathetic and condemned Shimp's refusal as morally indefensible, he ruled that it was wrong and a violation of a person's right to bodily security to compel Shimp to submit to an intrusion of his body. The judge noted the long standing rule of common law that by-standers are not legally required to aid or rescue others. Although exception to this rule is there in cases that involve special relationships such as guests and hotel keepers, drivers and their passengers, parents and their children, even in these situations, people may not be compelled to take actions that are risky to themselves. Flaherty J further emphasized that an adult cannot be ordered to surrender a kidney, bone marrow or any other parts of his body for donation to his or her child, relative or to anyone else. The Court had to defend Shimp's right of refusal, even if this meant McFall died as a result.

3.4 Children's Rights Regarding Tissue Donation

In terms of Chapter 2, section 7 of the Children's Act No 38 of 2005 of South Africa, the best interests of the child come first in everything that involves such a child. Every decision that a parent, government or anyone dealing with a child takes has to be in the child's best interests. When a parent or government has to make a decision or do something that involves children, the legal and personal issues that will affect the child must always be considered. Only if something to be done concerning a child is in such a child's best interests, should such thing then be done. Furthermore, in terms of article 3 of the United Nations' Convention on the Right of a Child (1989), of which South Africa ratified in 2000, the best interests of a child must be the primary concern in making decision that may affect children. When adults make decisions, they should think about how their decisions will affect children. Only decisions that will result in the achievement of the best for a child concerned must be chosen.

The state, parents and all involved with children must respect the rights of all children. Section 28(2) of the Constitution of South Africa also states that the child's best interests are of paramount importance in every matter concerning them. In addition, section 10 of the Constitution of South Africa provides for the equal dignity of the child. Parents, state and all involved in issues involving children must make sure that all children are treated equally and are not discriminated against. In addition, the rights of all children should be respected, protected and promoted. In terms of chapter 2, section 10 of the Children's Act No 38 of 2005, children have the right to be involved in health decisions and are provided with the autonomy to decide on medical treatment if they are over 12 years and of sufficient mental maturity. In other words, although parents have to decide on behalf of their minor children and give consent, every child has the right to participate and to have a voice in any matter that concerns his or her care and well-being, and this right depends on his or her age and maturity level.

In Australia, in the case commonly known as *In the Marriage of GWW and CMW* (1997) 21 Fam LR 612, the parents of an almost 10 year old boy who was a bone marrow transplant match made an application in an Australian Court to be given permission to give consent to doctors on behalf of their son. Consent was needed from the boy for the removal of the bone marrow to be donated to his sick Aunt. After the Family Court heard the wishes expressed by the boy, and considered the nature of the relationship between the child and his Aunt, an authorization for the child to donate his bone marrow was granted. In allowing the child to act as a donor to his aunt, the Family Court made it clear that it was doing so because it was being guided by the best interests of the donor child as the paramount principle. Thus, where an application is made to the court and the requirements of the legislation cannot be satisfied or are not clear, the court must be guided by the best interest standard in matters that involves a child.

In this case, Hannon J stated that where there is a relationship between the donor and the potential recipient, which is of benefit to the donor, it is in the best interests of the child that the opportunity be given for continuation of that relationship which may outweigh the risk or discomfort of a surgical procedure. The nature of the relationship is taken into account in applying the best interest standard. The courts have often made it clear that the risks will only be justified when there is a close relationship between the donor child and the recipient. The relationship between the donor child and the recipient should be in such a way that the donor is more likely to benefit from an ongoing relationship. In addition, denying a transplant and the resultant death of the recipient should more likely cause suffering or emotional harm to the donor.

In *Curran v Bosze* (1990) 566 NE 2d 1319, an unmarried mother was living separately with her 3 ½ year old twins. The father was living somewhere else with another woman with whom he had another child who was sick. The sick 23 year old Jean Pierre Bosze needed a quick bone marrow transplant to survive. The father, Mr Bosze approached the Court in a bid to force the mother of the twins, Ms Curran, to consent on behalf of the twins for a blood test in order to determine whether the twins were compatible to serve as bone marrow donors for a bone marrow transplant to Jean Pierre. The American Court ruled that there was no existing close relationship between the donors and the recipient. Therefore, there was no physical benefit to the donor children. In addition, there was no psychological benefit to the donor children either, as it is grounded firmly in the fact that the donor and recipient must be known to each other as family for them to develop emotions that may lead to psychological benefit or harm. In this case the intended donor children had no ongoing relationship with the intended recipient as the children involved lived separately and never knew one another as family members. Therefore, it was not in the best interests of the twins to undergo a blood test or an intrusive bone marrow harvesting procedure in order to save Jean Pierre whom they do not know as a close member of their family.

However, the application of the best interest standard by the courts is sometimes open to criticism. The risks or benefits to the donor child can be based on speculation and may often be exaggerated. In *Re Inaya* (Special Medical Procedure) [2007] Fam CA 658, an application was brought before the Family Court of Australia for a 13 months old baby to have a bone marrow removed to benefit her 7 months old cousin. The Court granted permission for the procedure to be performed based on the potential psychological harm if the child did not donate the bone marrow to her little cousin. Cronin J ruled that baby Inaya may suffer psychological harm derived from guilt, self-blame and exposure to a traumatised and grief-stricken family and community. In addition the judge commented that if the procedure was not performed, baby Inaya may also suffer psychological harm from the loss of her little cousin. Although older children may suffer psychological harm due to loss of their loved ones, it seems farfetched to assign such kind of harm, guilt and self-blame to an infant whose cognitive appreciation has not yet developed.

3.5 Conclusion

In this Chapter, I have examined the laws regarding the use of PGD, the legal obligations to donate body tissues to others and the rights of the children when it comes to body tissue donation. I have found that the legal aspect of saviour siblings rest on these three main areas. In addition, I also found that with the increasing medical technologies and science, ethical and legal concerns continue to grow as well. The emergence of PGD has raised ethical concerns and speculations about genetic manipulation of offspring (Robertson et al. 2002). I have found that even in the UK or elsewhere where the use of PGD is clearly regulated through legal frameworks, guidelines and legislation, not all people involved morally justify its use as they often take one another to Court. Heated ethical debates arise when it comes to the use of PGD. Whether it is used for selecting and creating saviour siblings that will benefit the well being of the sick children or it is used for helping a woman to give birth to a healthy child free of genetic defects, PGD raises ethical and moral concerns. This further strengthens the general belief that not every moral obligation involves a legal duty, but every legal duty is founded on a moral obligation. This brings us to the conclusion that it is not just law that ought to give guidance to the use of PGD, but ethics must also play a role in helping policy makers to reach a balanced legal framework that attempts to guide those involved based on morality.

CHAPTER 4 - A PHILOSOPHICAL CRITIQUE OF THE EXISTING STATUTE AND POLICIES REGARDING THE USE OF PGD FOR SELECTING "SAVIOUR SIBLINGS".

4.1 Introduction

In this Chapter, I will examine the existing legal framework related to the use of PGD and creating "saviour siblings" both in the UK and South Africa and analyze it through the Kantian and Utilitarian ethical framework. Many people with Consequentialist views agree that PGD offers many benefits to those involved, including lowering the risk of a woman giving birth to a child with serious genetic defects. According to them, PGD gives assurance to parents who are carriers of genetic disorders that their children will not be affected by the disease. When PGD is performed, only the genetically normal embryos are selected and placed in the uterus for gestation (Steinbock 2004: 175). PGD lowers the rate of abortion in the process because the woman already knows before the embryo is implanted into her uterus that her foetus will be free of genetic abnormalities (ibid). PGD also benefits the saviour sibling because it makes sure that he or she is born free of the genetic disease suffered by the elder sibling. In addition, and as it is expected, PGD benefits the sick elder sibling by making sure the embryo chosen for gestation will develop into a healthy child who would be a match for donating umbilical cord blood, bone marrow and other body tissues to save the life of the sick elderly sibling (ibid).

According to Steinbock (2004), the HFEA, and others, the main purpose of PGD is to test embryos for genetic disorders. In the process the genetically flawed embryos are selected, discarded and destroyed. However, choosing, discarding, destroying and freezing the embryos for whatever reason are practices not accepted by people with deontologist views and other views such as Christianity. Selecting and destroying embryos or freezing them for later usage generally raise ethical issues. Ethical issues raised involve the moral status and rights of embryos. Some people believe that embryos have moral status, rights and interests that are equal to that of a person, whereas others do not believe in that. On the other hand, the law says life begins at birth. To give a better understanding of the arguments that people engage themselves into when it comes to matters of PGD, embryos and the saviour siblings, this paper will look into the following ethical debates:

4.2 A Kantian v/s Utilitarian Ethical Analysis of the Legal Framework of PGD and Saviour Siblings

In R. (*Quintavalle) v. HFEA (2002)* E.W.H.C. 2785 (Admin), the High Court in the UK agreed with the Comment on Reproductive Ethics (CORE) that PGD and tissue typing intention was to make sure that the characteristics of the child born to a particular woman were changed (Sheldon and Wilkinson 2004). According to the ethical theory of deontology (refer Chapter 2), to manipulate an embryo in order to change the characteristics of a child developing out of such an embryo, may be viewed as treating a human being as a commodity and as unethical. The purpose of PGD and tissue typing is to make sure that the saviour sibling would have body tissue that was a match to those of an elderly sick sibling (ibid). However, this purpose is not acceptable to most people; especially those with deontologist views as it may also be viewed as using a fellow human being as a means to others ends (refer Chapter 2). Thus, manipulations done with the help of PGD to the embryo that will develop into a saviour sibling are only done for the main purpose of making sure that the sick elder sibling is cured. Maurice Kay J, in favour of the deontological views raised by the CORE, ruled that PGD and tissue typing was not a necessity for the purpose of assisting a woman to carry a child to term during pregnancy (Sheldon and Wilkinson 2004). The sole intention in this situation was to ensure that a child would have tissue compatible with its older sibling (ibid).

However, this ruling was overturned by the UK's High Court of Appeal in favour of the Utilitarian view presented by the HFEA in R (*on the application of Quintavalle) v. Secretary for Health (2003)* U.K.H.L.13. The High Court of Appeal agreed with the HFEA that PGD and tissue typing would help a pregnant woman to carry a child to term. Mance L. J ruled that the woman's wish to carry a child to term depends on the knowledge that the birth of her child would be capable of saving the life and health of her already sick elder child (ibid). A woman can only know whether the child she will be carrying is capable of saving the life of her already existing sick child if PGD is used before implantation (Steinbock 2004 : 175).

4.2.1 The Argument that We Should Not Use People as Means only Against the Argument that We Should Save as Many as We Can

The UK's High Court of Appeal ruling set precedence in allowing the creation of saviour siblings with the help of PGD. For the first time, a woman was allowed by the Court to choose an embryo to be implanted into her for the sole purpose of giving birth to a child who will rescue others from death. The Court empowered the woman to put certain criteria and requirements as qualification for the embryos to be implanted into her. She has been given a right to pick and choose the kind of embryo to be her child. The child that she needs must be capable of saving her existing child from death. The main reason and intention for her to fall pregnant and carry a child to term is if and only if the embryo implanted in her is capable of curing her elder sick child and saving him or her from a disease. Otherwise, there is no need for the embryo to be implanted into her uterus for gestation if it cannot serve that purpose. However, for this to happen, the embryo must be manipulated first through the process of PGD.

The UK's High Court of Appeal and the HFEA gave permission and licensing for the embryo to be manipulated, not for its own sake, but for the sake of it developing into a child who would be a matching donor to donate bone marrow and other stem cells for transplant into the sick elderly sibling. This manipulation of the embryo ensures that it develops into a child that carries the hope of medicinal cure for others. In its 2009 guideline, (a) states that "the condition of the affected child should be severe or life threatening, and of sufficient seriousness to justify the use of PGD. Item (c) of the same guideline also emphasizes that "all other possibilities of treatment and sources of tissue for the affected child should have been explored" for the HFEA to permit performance of PGD. Items (a) and (b) of the HFEA guideline explicitly treat an embryo that went through PGD process as a rescuer of the sick sibling. In this manner, The HFEA encourages a situation where PGD and tissue typing are used to create and implant an embryo for the sole purpose of benefiting another human being. Kant would not agree with the HFEA guideline regarding the use of PGD in this manner.

(a) The Argument that Human Beings must Never be Used as a Means to an End

Although Immanuel Kant was an 18th Century philosopher, his theories still influence modern ethics. According to Kant, we must “act so that we treat humanity, whether in own person or that of another, always as an end and never as a means only” (Rachels 2007: 130). He called this the Categorical Imperative that should be followed all the time regardless of our particular wants and desires and regardless of the ends we wish to achieve (Rachels 2007: 121). According to Kant, moral rules hold without exceptions. Even if following the rule would lead us to terrible consequences in some circumstances, we must follow such a rule because it is categorical. However, the main purpose of permitting the use of PGD by the HFEA in the situation of saviour siblings is to benefit the sick elderly sibling. According to the HFEA, this should be achieved without causing much harm to the “saviour sibling” and by only using the regenerative tissues to help the sick sibling. Assuming that Kant believed that embryos were human beings or potential human beings or seeds to humanity, he would regard PGD and the use of “saviour siblings” as unethical because embryos are used as a means to other peoples’ ends in these cases. PGD is used to manipulate embryos genetically, for the main purpose of making sure that the saviour siblings born out of such manipulated embryos are a match to donate body tissues to the sick elder children. According to Overall (2012: 92), the important moral question about any saviour sibling is whether he or she would have been brought into existence at all if there was not a need for his or her cord blood or bone marrow. The saviour sibling was not wanted by his or her parents for his own sake, but for the most important purpose of saving his or her brother’s or sister’s life (Overall 2012: 92). The parents value the saviour sibling not for himself, but for the benefits that he may bring to them and the sick elder sibling (ibid). In Kantian perspective, the saviour sibling has been immorally made as a source of benefits to others and as a means to serve the ends of others (ibid).

(b) The Benefit Argument.

Some people, especially those with Consequentialist views may not agree with Kant. They regard the use of PGD for the creation of saviour siblings as important and valuable because it saves human life. First, consequentialists are not disputing the fact that it is wrong to have a child for the purpose of being used as a means to other people’s ends. However, they violate this principle anyway and try to justify the violations by pointing that people have been doing that all the time. Benatar and many others counter-argue in mitigation that children are always born to serve as means to some sort of an end (Benatar 2006: 129-130). They are born for instrumental purpose such as, completing a family, being a playmate for an existing child, saving a marriage, providing an heir, etc (Sheldon and Wilkinson 2004: 534). According to Sheldon and Wilkinson, "having a child as a means is not in itself objectionable", as long as this does not lead us to discarding or ill-treating the child once it has served its purpose (ibid). Provided that parents love their child, there is little problem with that child benefiting others because in reality children are born for a purpose (Boyles and Savulescu 2001: 1241). Perhaps then there is no better reason to have a child than to save another one (Benatar 2006: 130-131). Without saviour siblings, some children whose lives and well-being could have been saved will die (ibid).

Consequentialism deals with probabilities (refer Chapter2). Consequences of an action cannot be seen or known before an action is performed. This begs the usage of PGD in order to increase the probabilities of an ill free saviour sibling that is in addition a perfect matching donor for his or her ill elder sibling. The HFEA and many other consequentialists feel that PGD must be used for any saviour sibling case, so that the chances of curing the ill child are increased. If the ill child is not cured by the saviour sibling stem cells, the parents may find themselves in a situation where they have an extra child whom they would not have given birth to if it was not of the condition of their sick elder child. If this extra child does not serve the purpose of saving the life of the elder sick child, no one can guarantee that the parents will not feel disappointed and frustrated and their disappointment may not affect their attitudes towards the saviour sibling (Overall 2012: 84). However, the HFEA and many other utilitarians recommend the use of PGD as an exception mainly to avoid and decrease the chances of a non-matching donor and to avoid the related disappointment and frustration that may follow if the whole process does not work as expected. According to the HFEA, PGD maximises benefits both to the saviour sibling and the sick elder child. The HFEA and many other utilitarians claim that PGD makes sure that the saviour sibling is born free of genetical diseases, and on the other hand it makes sure that the saviour sibling becomes a matching donor to save the life of his or her elder sick sibling Even in Kantian perspectives, some deontologists may agree that the use of PGD for creating “saviour siblings” is a good thing because universalizing healing of incurable diseases is in line with an act of doing good which one can be willing that all people should follow all the times (refer to Chapter 2). The HFEA seem to believe that if we can benefit someone without harming anyone else, we ought to do so. According to them, using the “saviour siblings” umbilical cord blood or their regenerative tissues would benefit the sick children without necessarily harming the “saviour siblings”. Therefore, according to the HFEA, Steinbock and many others, we ought to use PGD to make sure that the “saviour siblings tissues are the perfect match to save the sick children.

4.2.2 The Argument that Human beings must not be treated as a Commodity v/s An Illness Free Existence

(a) Manipulation and Selection of Embryos

Kant believed that human beings have an intrinsic value, which is dignity. He would not agree with the HFEA, Mance M.J, Steinbock and many other people on the use of PGD as he would not deliberately want a situation where human beings with disabling conditions were not given a chance of existence. According to Kant, human beings are born with inherent dignity which makes everyone of us equal (Rachels 2007: 130-132). Respect for human dignity requires that even the handicapped should always be treated with the same respect as everyone else, and their rights ought not to be violated. However, the main function of PGD is to inform those involved to discard an embryo before it is implanted. This is a form of discrimination because it involves picking and choosing those embryos considered perfect for implantation to develop into full human beings, and discarding or destroying without giving access or a chance of life to those embryos deemed imperfect to develop into human beings. The practice of discarding unused embryos is of ethical concern to those who believe that an embryo has moral status. According to them, destroying and discarding the affected embryos is to deny personhood of an embryo with genetic defects. Some people go to the extent of equating the practice of destroying embryos to destroying human life. In Germany, embryos are not supposed to be destroyed for this same reason. The Embryo Protection Act of 1990 of Germany defines an embryo as a fertilized human egg capable of developing into a full human being (Isasi and Knoppers 2006).

Kant would also not agree on the use of PGD to destroy embryos. According to him, “the only thing that is good without qualification or restriction is a good will” (refer to Chapter 2). The goodwill is good in itself, good independently of its relation to other things, good in all circumstances and it is an absolute or unconditioned good (Paton 1948: 63-65). The goodness of a good will is not derived from the goodness of the results which it produces (ibid). According to Kant, although PGD can be good because it can eradicate serious genetic diseases in new born babies and it can also save the life and well being of a seriously sick human being by providing a matching stem cells donor, unfortunately PGD is not good in all circumstances and may be thoroughly bad when it is used by a bad will. It can be used for non-medical sex selection, choosing certain desired human traits and discrimination against the disabled. In other words, Kant would see PGD as conditioned good that is good under certain conditions and not good absolutely or in itself.

The purpose of PGD or the motive behind it is to manipulate embryos for the sole purpose of creating a perfect tissue donor to donate stem cells to someone else. Kant would perceive this as morally worthless. In addition, the destruction of embryos clouds the goodness that PGD offers to the sick sibling. The end result is good because someone’s life is saved, but at the expense of many embryos destroyed by doctors and scientists during the process. In Kantian perspective, the ends do not justify the means.

(b) Genetic disease – free Children

According to Steinbock (2004), embryos are not people with disability because they are not people at all. Thus, destroying embryos found to have genetic or chromosomal disorders is not getting rid of disabled people (Steinbock 2004: 181). Spriggs and others suggest that the use of PGD is good because it increases the chance that the saviour sibling will not have the disease that is killing the older siblings (Spriggs 2005: 341, Steinbock 2004: 175). According to them, PGD minimizes the chance of children born with genetic abnormalities, thereby increasing the number of children born free of sickness and sufferings caused by the genetic diseases. In addition, PGD makes it possible for the new born child who is free of the genetic diseases suffered by his or her elder sibling to be a perfect match for stem cell transplant. If the transplant becomes a success, it may make many people, especially the parents and the sick child happy. Thus, PGD increases utility by saving the life and well-being of the sick elderly sibling thereby bringing happiness and opposing suffering for those involved in the process. If it is desirable that people live without health problems or diminished human capacities, it is hard to see what is wrong with a technique that selects healthy and normal embryos for implantation (Steinbock 2004: 182).

According to the HFEA and the Human Fertilization and Embryology Act of 1990 (amended in 2008), the usage of preimplantation genetic diagnosis must be for the purpose of making it possible to select an embryo free of the genetic disease that is suffered by the existing ill child in the family. In its guideline, item (b) states that "the embryos conceived in the course of using PGD should themselves be at risk from the condition by which the existing child is affected". The procedure must be in the best interests of the new child as well as serving the interests of the ill existing child. For the HFEA to grant licence for PGD use, the saviour child born with the use of PGD must be benefited and be born free of the ailments that are suffered by his or her elder sibling (Spriggs 2005: 341). The HFEA, Steinbock (2004) and others, see PGD as the only procedure that can make sure that the child born out of this process becomes a matching tissue donor to save the life of his or her sick sibling. Many people would agree that saving the life of someone who is dying even if it involves the use of PGD is a very good thing to do, and it is morally commended. According to the HFEA, PGD has to be treated as an exceptional case in the issue of saviour siblings as there is no other alternative to increase the chances of survival for the sick elder child.

4.2.3 Informed Consent.

(a) Autonomy

According to Kant, human beings occupy a special place in creation (Rachels 2007: 130 – 131). They are rational agents capable of making their own decisions, setting their own goals and guiding their conduct based on reason (ibid). Kant argues that human beings are autonomous and their autonomy should be respected. According to him, respect for autonomy flows from the recognition that all persons have an intrinsic worth, which is dignity and are capable of determining their own moral destiny (ibid). To violate a person's autonomy is to treat such a person merely as a means (ibid). According to Mill, respect for autonomy entails that society should permit individuals to develop according to their own convictions, as long as they do not interfere with a like expression of freedom by others (Beauchamp and Childress 2001: 64). Mill suggests that society should only interfere if there are false or ill-considered views (ibid). When dealing with issues of saviour siblings, informed consent becomes the most crucial aspect. Informed consent is governed by the ethical principle of respect for autonomy in the doctor-patient relationship (Dhai and McQuoid-Mason 2011: 70). However, other ethical principles and elements such as beneficence and non-maleficence determine whether consent should be given or not (ibid).

Section 12(2) of the Constitution of South Africa, 1966, states that everyone has the right to bodily and psychological integrity, which includes the right to security and control over their body. Accordingly, all patients in South Africa have the right to free choice, informed consent and they also have the right to refuse medical intervention (Dhai and McQuoid- Mason 2011: 76). We must respect individuals' views and rights so long as their thoughts and actions do not seriously harm other persons (Beauchamp and Childress 2001: 64). Thus, autonomy is not absolute. Respect for autonomy has only prima facie standing and can sometimes be overridden by competing moral considerations (Beauchamp and Childress 2001: 65) Most importantly, although the patient's ability to make free choices should be respected, the healthcare professional ought not to offer treatment when patient requests an illegal or non-therapeutic or other procedures that are against public policy (Dhai and McQuoid-Mason 2011: 76). Section 36 of the Constitution of South Africa (1996), allows for the limitation of rights provided that the limitation is reasonable and justifiable in an open and democratic society. Thus, although we should respect other people's autonomy, their self determination and choices can sometimes be justifiably overridden, resulting in the violation of the principle of respect for autonomy for a reason or necessity. An example can be that of patients with drug-resistant tuberculosis who are admitted and quarantined against their will. Here in South Africa, their rights are limited by invoking section 36 of the Constitution (ibid). Ethically, the principle of beneficence and the principle of non-maleficence are weightier than the principle of autonomy in this case. The general public has to be protected against the more risky situation of leaving a patient with a contagious disease walk around freely.

However, we should not just force anyone to undergo a medical treatment or donate his or her body tissue against his will, even if the procedure involves a child. This is emphasized in the court case of *McFall v Shimp* (1978) 10 Pa D&C 3d 90 brought before Flaherty J in Pennsylvania. The court ruled that it is unacceptable to force a person to donate body parts to another person even in a situation of medical necessity. (Refer to Chapter 3).

This court ruling is in line with the principle of autonomy and respect for persons. Kant would agree with the court ruling and would also support that a society which respects the rights and dignity of the individual cannot sink its teeth into the jugular vein or neck of one of its members and sucks from it against his or her will in order to sustain another member. Society should not force anyone to undergo medical procedures for the benefits of others. Although this is not absolute, the courts will not order a person to undergo a surgical procedure if doing so will violate his or her constitutional rights.

(b) Conflict of Interests

In terms of section 10 of the Constitution of South Africa 1996, everyone has inherent dignity and the right to have their dignity respected and protected. Section 10 of the Constitution of South Africa of 1996 is in line with Kantian views. It is a violation of the child's dignity for a parent to treat his or her child as a slave, spare part provider and rescuer of another of his or her children, unless they have valid reasons that justifiably can satisfy majority of people in a democratic society in terms of section 36 of the Constitution of South Africa. It is also a violation of the ethical code of conduct for a doctor to treat one of his or her child patient, who cannot give consent on his or her own, as a reservoir for spare parts to be used on another of his or her patients. Section 28(2) of the Constitution of South Africa, 1996 and Chapter 2, section 7 of the Children's Act no 38 of 2005 state that the best interests of a child are of paramount importance in every matter concerning such a child.

(i) The Healthcare Practitioner

The healthcare provider code of ethics states that he or she must do as much as possible to save the life of an ill patient. According to the Health Professionals Council of South Africa (HPCSA) and other ethical codes of conduct, the healthcare practitioner's primary commitment must always be the welfare and best interests of his or her patient. The patient well being is paramount and the patient's interests come first. In the case of saviour siblings, doctors usually are the one who suggest and start the entire process by bringing up the concept of a saviour sibling as a beacon of hope to the desperate parents who would agree and do anything to save their ill child. However, the doctor in this case is solely looking out for his or her patient's best interests. The doctor's responsibility lies first and foremost with the ill child. But, once the saviour sibling is born, the same doctor will also be the saviour sibling's physician as well. The question then arises whether the doctor is ethically right when he or she orders potentially painful and harmful procedures such as bone marrow transplants to be performed on the saviour sibling for the sake of healing his other patient. A medical procedure, especially done on a child, is usually undertaken to provide a health benefit to the child who undergoes it. In terms of Chapter 2, section 7 of the Children's Act No 38 of 2005 of South Africa, the best interests of the child come first in everything that involves such a child. It is difficult to think of any situation in which an individual who is unable to give consent nevertheless undergoes medical procedures to benefit another person (Spriggs 2005, 341).The end does not in this situation justify the means (ibid).

(ii) Parental Consent on behalf of the Child

Given the fact that legal personality begins at birth and children are also members of the society, the rights and dignity of a child are being violated when parents give informed consent on their behalf for doctors to remove stem cells and bone marrow for the purpose of being used to treat others. The validity of consent obtained by the doctors may be questionable in the sense that there is emotional coercion on the side of the parents. The parents' ability to provide a valid consent may be under the influence of emotions that the family members generally experience when there is someone seriously ill in the family. Moreover, according to Chima (2011), the usage of umbilical cord blood from the saviour sibling could arguably be considered as manipulation of human tissue without the owner's consent. In terms of section 65 of the National Health Act No. 61 of 2003, a donor may, before transplantation of the relevant organ into the recipient, revoke the donation. However, although a saviour sibling is a legal person who is protected by this law, parents or doctors can never be in a position to know whether an infant saviour sibling want to donate his or her tissues to the older sick sibling, or no longer want to or never wanted to do so.

The parents are not acting in the best interests of the saviour sibling but only considering the interests of their sick elder child. In Kantian perspective, parents ought to give consent on behalf of their child for a treatment that benefits the very same child, not for a treatment that rescues the life and wellbeing of others. Article 3 of the United Nation's Convention on the Right of a Child (1989) states that, only decisions that will result in the achievement of the best for a child concerned must be chosen. Each individual's interests are equally important, there are no privileged persons (Rachels 2007: 13). The welfare of a saviour sibling is just as important as that of a sick elder sibling (ibid). The problem with the saviour siblings issue is that parents are in a situation of conflict of interest. Their two children's interests do not coincide. Parents are obviously acting on the basis of the sick elderly child interests. They cannot be unbiased surrogate decision makers for the new baby. Parents should treat children equally. Section 10 of the Constitution of South Africa provides for equal dignity of the child. All children including saviour siblings should be treated equally without discrimination and favour. However, the parents of a saviour sibling are not being impartial when they give permission to doctors to extract body parts from one of their child to be used to rescue another of their children.

(c) The best interests standard

With reference to *Curran v Bosze* (1990) 566 NE 2d 1319 case, the American Court ruled that it was not in the best interests of a child to undergo blood tests or an intrusive bone marrow harvesting procedure in order to save a sibling whom the child concerned does not know. The Court explained that when it comes to body tissue donation involving a child and applying the best interest standard, the nature of the relationship between the donor child and the recipient is taken into account. The relationship between the donor child and the recipient must be of benefit to the donor. The benefits must outweigh the risks or discomfort of a surgical procedure. The courts have often made it clear that the risks will only be justified when there is a close relationship between the donor child and the recipient. The relationship between the donor and the recipient should be in such a way that the donor is more likely to benefit from an ongoing relationship. The death of the recipient should more likely cause suffering or emotional harm to the donor.

4.3 Conclusion

In this Chapter, I have critically analysed the legal framework regarding the use of PGD in creating saviour siblings. In order to reach a better moral and legal understanding of the issue of saviour siblings, a philosophical critique of PGD and the use of saviour sibling were done using the application of the Kantian, Utilitarian ethical theories and the law. I have clarified the issue of tissue donation involving children and critically analysed the legal and moral obligation to donate with the help of the best interest standard.

CHAPTER 5 - CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

One of the most difficult problems is that in which two moral rules come into conflict. In such cases, each of the rules seems plausible and yet there is no way to follow the demands of both. The issue of saviour siblings provides a very good example of this conflict. The fact that PGD and the creation of “saviour siblings” may be of greater benefit to the sick children, parents and the society as a whole is very good news. However, this very good thing may interfere with the right of the “saviour sibling” to self determination. The dilemma is that in the process of rescuing the life of a very sick elder sibling, we might be violating the rights and dignity of a saviour sibling. The question is when dealing with issues of a very sick child and a “saviour sibling”, which course should we follow? Do we treat the sick child and save him or her from death even if it means using a “saviour sibling” as a means to the recovery, or we let the sick child die for the sake of respecting the moral rule against the use of persons as a means to the ends of others?

In the previous chapter, the central ethical and legal issues raised were analysed by using both the Utilitarian and Deontological ethical theories. Ethical and legal issues of importance surrounding the issue of conceiving a saviour sibling concerned the child’s rights and welfare. It was debated whether the interests of the child should be compromised for the sake of the existing child and whether that is not treating a human being as a mere means to another person’s ends. Utilitarians do not claim to have a simple answer to this question. However, from the consequentialist perspective, the existence of a conflict in rules is a signal that we are dealing with one of those exceptional circumstances in which we cannot simply follow even the soundest of rules (Brody 1983: 18). In these circumstances, Utilitarianism advises us to examine the consequences of each of the options open to us and to choose the action with the best consequences.

5.2 Appraisal and Summary of the study

According to Beauchamp and Childress (2001: 345), no rule is absolute, and no rule is unrevisable. They further point out that according to the principle of utility, even rules against promise keeping, truth telling, etc, may be overturned or substantially revised (Beauchamp and Childress 2001: 345). According to utilitarianism, we should support permitting killing, for example in a war situation, if and only if those rules would produce the most favourable consequences (ibid). When it comes to promise keeping, although promises should be kept so that trust is maintained, it should also be set aside in cases in which breaking the promise would produce overall good (ibid).

(a) The Strength of Utilitarianism in support of PGD and Saviour Siblings

The above approach by Beauchamp and Childress may be applied to the issue of PGD and saviour siblings. In the case of a saviour sibling, we have conflicting prima facie duties. We have an obligation not to treat the saviour sibling only as a means to the survival of the very sick elder sibling. We have to respect the rights and dignity of the saviour sibling. On the other hand we have an obligation to save a sick elder sibling from suffering and possible death. The saviour sibling cord blood is the most possible mode of treatment needed to cure the sick sibling. Taking the blood from the umbilical cord of the saviour sibling will not hurt this child whereas the cord blood may save the life of the elder sibling. The obligation to save a life is much stronger than discarding the umbilical cord of the saviour sibling away without being used. In this situation, treating and saving the life of the sick child is in line with the principle of beneficence. This action also promotes the values of the principle of non-maleficence as the umbilical cord blood is used without causing much harm to the saviour sibling. Most Utilitarians will agree that we should support permitting the use of PGD if and only if using such medical technique would produce the most favourable consequences. Likewise, there should be rules allowing the use of saviour siblings if and only if those rules would maximize good consequences. From the Utilitarian point of view, making an exception to accepted rules is consistent with ordinary moral belief and common sense (Beauchamp and Childress 2001: 345).

The problem here is we are dealing with a very sick child who might even die. According to Beauchamp and Childress (2001: 343), studies have shown a higher rate of break up in families caring for chronically seriously ill children than other families.

(b) Can Deontology support the Use of PGD and Saviour Siblings?

Although universalization of PGD seems to be a very good thing as it may lead to an illness free population, Deontology or Kantianism does not seem to give a solution on how we should help the sick child in the family. In actual fact, a strict Kantian may argue that we must not be led by our emotions, sympathy, conscience or intuition in reaching the decision for treating this child. Deontologically, we must act out of duty. According to Kant, morality depends on reason and not on how we feel, so we must resist decisions that are driven by consequences or our feelings no matter how good the results may be. Deontology/Kantianism does not consider our concerns for the dying sick elder sibling or our affection and compassion as the basis for doing anything possible, including using another child, to rescue the life and welfare of the sick child. If we do that, Kant would argue that we are using a person merely as a means to others' ends or as a commodity and he would judge our action as unethical.

Deontology/Kantianism has a problem with conflicting obligations. According to this moral theory, rules are categorical. Deontology seems to suggest that we have an obligation not to use PGD because when we use it we genetically modify the saviour sibling so that he or she is in turn used to save the life of the elder sick sibling. However, on the other hand we have an obligation to save the life of the sick child. As parents, we have both a legal and moral obligation to aid and rescue our children, unless if the situation is risky and may cause further harm to us (refer back to Chapter 3). According to Kant, morality requires that we treat human beings always as an end and never as a means only (Rachels 2007: 132). Rachels explains that this means that we have a strict duty of beneficence towards other persons and among other things we must strive to promote their welfare and endeavour to further their ends (ibid). If this is true, it means that we must also include the sick older sibling in our efforts to promote and furthering the welfare of others. But, if we cannot use PGD and saviour siblings as deontology suggests, it would be impossible for us to save the sick older child, and in that manner we will be neglecting our duty of beneficence towards other persons as suggested above (ibid).

(c) The Weakness of Deontology and Utilitarianism when it comes to Treating the Sick Sibling

Theories of obligation such as Deontology are ill-suited to describe life among family and friends and cannot help a caring parent such as the one with a very sick child in his or her family, or any other normal, caring parent. Kant takes the notion of obligation as morally fundamental, and provides an account of what we ought to do. According to Kant, we must love and care for our children as a duty and not because of our feelings and the emotional bonds we have between our children and ourselves. However, in real life situation, a loving parent acts from motives other than duty. Parents who act from a sense of duty are bad parents. If parents care for their children only because they feel it is their duty, the relationship between the parent and the child will be a disaster. In the long run the children will sense the strict and stiff relationship and realize that they are unloved.

In Chapter 4, this paper found that the issue of a parent giving consent for a medical procedure to be done on one of his or her child for the sake of saving the life of another of his or her children was the most difficult one. This is because both Utilitarianism and Deontology promote the ideas of equality and impartiality. These notions seem to oppose the values of love, friendship and family. One of the founders of Utilitarianism, John Stuart Mill, goes to the extent of saying that a moral agent must be “as strictly impartial as a disinterested and benevolent spectator” (Rachels 2007: 107). However, a loving parent cannot be like a spectator. Faced with the problem of a dying sick child, any normal, loving parent will try anything possible to save the life of his or her child. We cannot be expected to treat our families as members of the great crowd of humanity with no special bonds to us.

5.3 Conclusion of the Study

In the UK, the Human Fertilization and Embryology Authority (HFEA) decides whether or not to allow the creation of a "saviour sibling" with the help of PGD based on clearly developed guidelines governed by the Human Fertilization and Embryology Act of 2008. Many other Countries such as France and Australia have adopted a model similar to that of the UK when it comes to issues of PGD and the creation of "saviour siblings".

5.3.1 Can the current South African Legal Framework lead us in Court in case a Parent of a Sick Child wants to use PGD for the creation of a Saviour Sibling?

South Africa does not have clear-cut regulations surrounding the concept of "saviour siblings". There is no mention of PGD in Chapter 8 of the National Health Act of 2003 and its current regulations. Without specifying PGD, regulation 5(a) of Chapter 8 of the National Health Act No 61 of 2003 of South Africa gives provision for a competent person to remove human biological material from a living person for the purpose of DNA, RNA and chromosome-based genetic testing. However, regulation 6 of Chapter 8 of the National Health Act 61 of 2003 prohibits the use of preimplantation and prenatal testing for the sake of selecting the sex of a child, unless it is done for a serious sex-linked or sex-limited genetic condition.

Chapter 8 of the National Health Act and its regulations do not have specific regulations or principles stating clearly as to when PGD may be used. It only deals with an important but narrow aspect of PGD and sex selection without establishing principles on other circumstances in which PGD would be appropriate. Unlike the HFEA and its legislation which clearly established principles and guidelines on when PGD should be used, the South African legislation relating to the regulation of pre-implantation genetic diagnosis and the creation of saviour siblings is confusing and not clear. It leaves a vacuum. Therefore, it is not legally sound to lead us in court in case there is a need for a "saviour sibling" by a parent with such demands.

5.3.2 Should we Approach Clinical Medicine in an Absolutist Manner?

In Chapter 4, the ethical theories of Utilitarianism and Deontology were critically analyzed. Given the conflicting situation of raising a very sick child whose life could only be saved by a "saviour sibling", this paper supports Beauchamp and Childress approach which states that, rules even within a Kantian framework need not be regarded as absolute (Beauchamp and Childress 2001: 345). It should be acceptable if someone violates the moral rules and principles for a valid reason that anyone of us would accept should they find themselves in a similar situation (Rachels 2007: 128). Even in Clinical Medicine where autonomy and self-determination is recognised as paramount, concepts such as consent and confidentiality are not absolute. Under certain special circumstances of necessity, a doctor can justifiably depart from a procedure consented to and extend his treatment to other areas if he or she detects another serious condition while the patient is already under general anaesthetic (Dhai and McQuoid-Mason 2011: 74). Furthermore, private and confidential information told to the doctor by the patient can also be breached under certain circumstances such as risk to others, court order, etc or if the benefit of breaching confidentiality outweigh the harm of threatening the trust in the practitioner-patient relationship (Dhai and McQuoid-Mason 2011: 88).

According to Rachels (2007: 8), it is not always wrong to violate the rights and dignity of a human being. In rare situations it may be right to do so if violating someone's rights will save the lives of others who can then go on and lead full lives (Rachels 2007: 8). Brody further argues that, even the most ardent adherents to rules agree that there are special cases in which the right thing to do is to disregard the rules. According to him, even the rule against torture may justifiably be broken by the police who caught a terrorist who does not want to disclose where the bomb is planted, in their attempt to get information to save as many lives as possible (Brody 1983: 17). Brody argues that Consequentialism seems to offer us a way out of this sort of dilemma by regarding plausible moral rules as a rule of thumb rather than as inviolate commandments (ibid). Although following rules will usually lead to the best circumstances, when circumstances are unusual and an examination of the consequences lead to the conclusion that the best will come from breaking the moral rule, then we must treat the case as an exception and break the rule (ibid).

The case of a “saviour sibling” need to be recognized as a special case in which there is good reason to believe that the consequences of following the traditional absolute moral rule are worse than the consequences of making an exception. If “saviour siblings” are the only alternative and the only life savers available to rescue very sick and possible dying children, then we have to allow the use of such children for medicinal purpose, as long as they are loved like any other children and not become ill treated thereafter. To follow an absolute rule that suggests not doing anything is simply not willing to help or to be involved in this conflicting situation.

5.3.3 The Risk- Benefit Principle

The medical procedure to get the much needed umbilical cord blood from the “saviour sibling” to save the life of his or her sick sibling is relatively not painful. Moreover, only regenerative tissues from the “saviour siblings” are used. Given the fact that prohibiting PGD for the selection of “saviour siblings” may result in the deaths of the existing ill children, this paper concludes that we must approach this conflicting issue as an exceptional case. We must weigh the harm caused to the “saviour siblings” against the benefits that these children can bring to the sick siblings, parents, society and the medical community as a whole. We should choose what is best for both children. If the best consequences regarding these children can be brought by using PGD to select a “saviour sibling”, then that should be our choice of action. Therefore, this paper find it ethically sound for a disparate parent in an exceptional situation to do anything possible, including giving birth to a “saviour sibling” with the help of reproductive technology such as PGD, for the purpose of using the new born sibling to rescue the life of a sick elderly sibling in the family. Although the South African legal framework is not explicit and leaves us to work in a vacuum when it comes to this issue, every normal parent is supposed to love his or her children with compassion and treat them as special as it is virtuous and in accordance with the ethics of care. Therefore South African laws should consider to explicitly legalizing the use of PGD for selecting “saviour siblings” based on the necessity and the need of each case.

5.4 Recommendations

A legal framework to regulate the use of PGD which is clear and modelled on the UK's Human Fertilisation and Embryology Authority and its guardian legislation is required to avoid confusion should the issue of saviour siblings arise here in South Africa. The issue of PGD for selecting "saviour siblings" is a hotly debated and complex one. Obviously it cannot just be solved through religious, moral or ethical absolution. Whatever solution we attempt to reach surrounding the issue of "saviour siblings", we must not undermine the ends of medicine, which is to heal the sick and alleviate unnecessary sufferings. Therefore, each case must be approached and judged on its own merit, depending on the cause of the sickness, the availability of the alternatives and how sick the elder sibling is.

In a democratic society such as the one we have in South Africa, we must have legislation and legal frameworks that offer us choices and provide our rights based on the Constitution. Parents of sick children must be able to exercise their choice of treatment suitable for their children. Like in the cases of abortion and the way the Choice on Termination of Pregnancy Act of 1996 is structured in this Country, those who do not like the idea must not interfere no matter what their position about "saviour siblings" are. As South Africans, we have a prima facie obligation to promote medicine, medical technology and medical researches so that we treat the sick and alleviate the sufferings.

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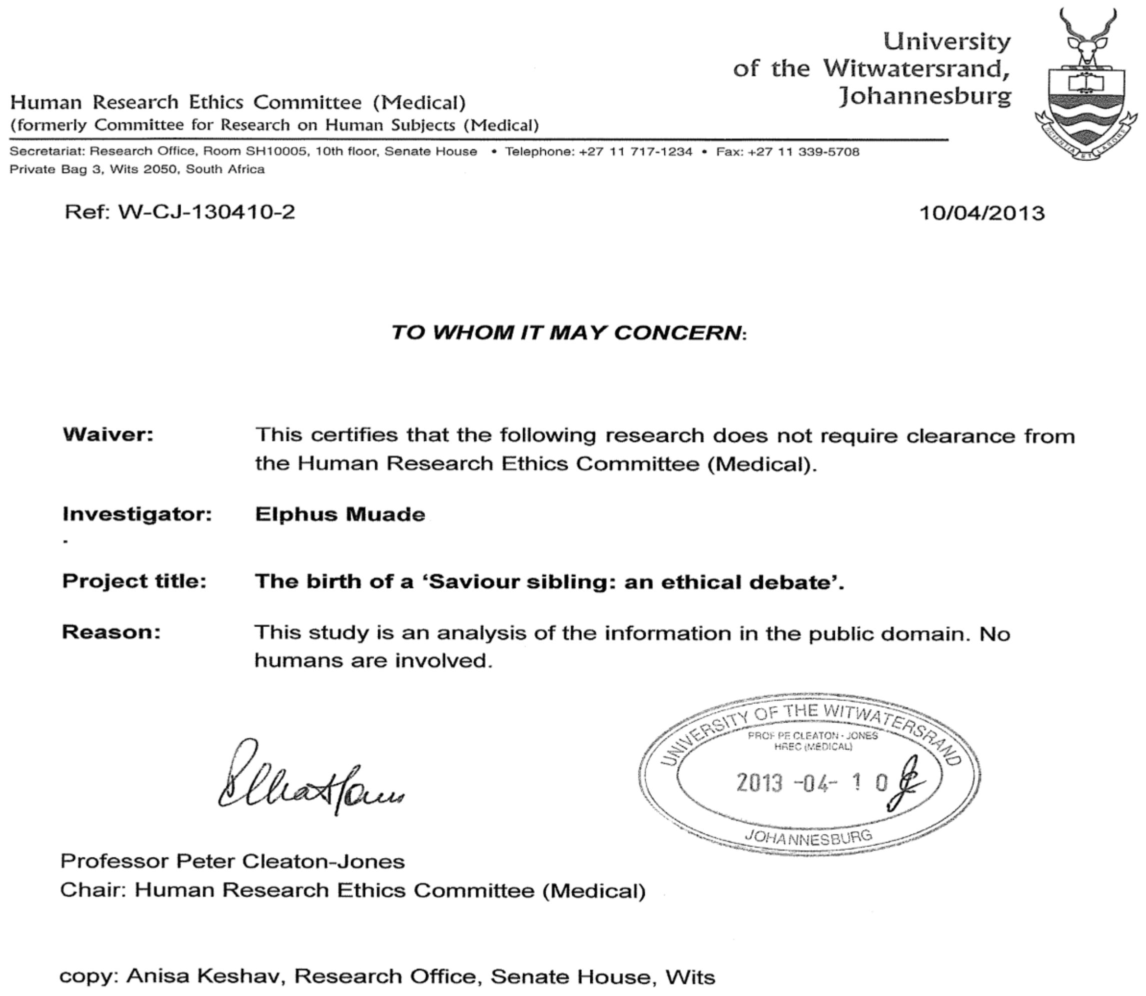
APPENDIX A – ETHICS WAIVER



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Ref: W-CJ-130410-2

10/04/2013

TO WHOM IT MAY CONCERN:

Waiver: This certifies that the following research does not require clearance from the Human Research Ethics Committee (Medical).

Investigator: **Elphus Muade**

Project title: **The birth of a 'Saviour sibling: an ethical debate'.**

Reason: This study is an analysis of the information in the public domain. No humans are involved.

PROF PE CLEATON - JONES
HREC (MEDICAL)
2013 -04- 1 0

Professor Peter Cleaton-Jones
Chair: Human Research Ethics Committee (Medical)

copy: Anisa Keshav, Research Office, Senate House, Wits