



**The rights and regulation of saviour siblings in South Africa: An ethical and
jurisdictional comparative**

A dissertation submitted in partial fulfilment of the requirements for the degree

Of

MASTERS IN LAW

By

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January 2020

DECLARATION

I, Nonduduzo Penelope Gumede, declare that

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ABSTRACT

The creation of saviour siblings is contentious; therefore, the dissertation determines whether it is ethically justifiable to create saviour siblings and analyses the associated conflicting interests. It is crucial to do this as the child's best interests are of international, regional and national importance.

Moreover, the dissertation explores the regulation of the creation of saviour siblings in other jurisdictions and compares it with that of South Africa. The purpose of this is to determine if there are any lessons that South Africa can learn, especially as the procedure of saviour siblings has potential harms.

Lastly, the purpose of the dissertation is to assist the lawmakers in the sphere of medical law and children's rights to look at the existing legislation to ensure that there are no gaps to avoid the violation of rights.

ACKNOWLEDGEMENTS

I would like to thank all those who carried me on this journey. Firstly, I would like to thank my family members who supported from the time I started my masters. In addition, I would also like to express my deepest gratitude to my supervisor Prof Strode, who was extremely patient with me as circumstances would delay the writing of this dissertation. I appreciate the guidance she has given me, especially as I found legal writing daunting and challenging. I would also like to thank Prof Singh, my co-supervisor, who gave me the foundation of the ethical arguments and guided me in the writing of this dissertation. Lastly, I would like to thank Dr Goodier, who assisted me during the process of academic writing.

I dedicate this dissertation to my late father, grandmother, uncle and sister.

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CHAPTER 1: INTRODUCTION

1.1 Introduction

Having children is the most valuable aspects of life,¹ high expectations and fantasies often accompany the thought of having a baby by the parents and family members, but this may abruptly end when the child is born with a disability.² The reason for this is that during pregnancy parents develop a mental picture of the infant, however, if a child is born with a disability, the parents have to grief the loss of the envisaged infant and have to adjust to the child whom they have given birth.³ According to the World Health Organisation (WHO), 'disabilities is an umbrella term for impairments, activity limitations, and participation restrictions. An impairment is a problem in the body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while participation is a problem experienced by an individual in involvement in life situations.'⁴ A genetic defect can be seen as a disability, as a child with such a defect cannot lead a life similar to other children in a comparable age group.

Parents who have a child with genetic abnormalities grapple with the enormity of the diagnosis and face many challenges including the costs of medical treatment or interventions, and financing the child's future life, who may require additional care and assistance.⁵

Many parents of children born with inherited genetic conditions will go through lengths to save their children.⁶ The reason for this is because it is their parental duty to ensure that they look out for their wellbeing, as stipulated in section 11 of the Children's Act, and to ensure that the child is healthy by providing the necessary medical care to the extent that they can.⁷

¹ TM Cousineau and AD Domar 'Psychological impact of infertility' (2007) 21 *Best Practice & Research Clinical Obstetrics & Gynaecology* 293-308.

² MW Bristor 'The Birth of a Handicapped Child- a Wholistic Model for Grieving' (1984) 33(1) *Family Relations* 25.

³ Ibid.

⁴ World Health Organisation Disability and health available at <https://www.who.int/topics/disabilities/en> accessed 17 July 2020.

⁵ J Lemacks *et al* 'Insights from parents about caring for a child with birth defects' (2013) 10(8) *International Journal of Environmental Research and Public Health* 3467.

⁶ E Du Plessis *et al* 'A legal analysis of "saviour siblings" and "benefactor children" in South Africa' (2014) 35(2) *Obiter* 225.

⁷ Children's Act 38 of 2005, section 11.

Fortunately, advancements in medical technology and processes can turn a potentially devastating situation by giving a patient hope allowing them to live a better and healthy life, through improving 'biological functions' of the body.⁸ One of these medical advances includes the use of preimplantation genetic diagnosis where individual embryos are selected for implantation to conceive a saviour sibling; however, this gives rise to legal and ethical issues.⁹

1.2 What is a saviour sibling?

A "saviour sibling" is a 'child conceived his or her parents, specifically to be an organ or tissue donor for their sick sibling.'¹⁰ This term saviour sibling first appeared in an article in 2002 by Spriggs and Savulescu where they reported about an Australian couple granted permission to conceive a child that would be a tissue match for their sick child suffering from Fanconi anaemia;¹¹ later popularised in the novel by Jodi Picoult, *My Sister's Keeper*.¹² The novel illustrated that using a saviour sibling as a donor can lead to several ethical and legal issues as the child cannot develop in their own right.¹³ The novel illustrated the need for the preservation of life and also protecting one's life against harm and physical intrusion.¹⁴

There are two types of saviour siblings, and the one is where umbilical cord blood is provided immediately after birth.¹⁵ The other is where a child is conceived and used to treat the sick sibling by donating bone marrow at regular intervals,¹⁶ which is the focus of the dissertation. The first documented saviour sibling was in 2003, where the Hashmi family used preimplantation genetic diagnosis to select against beta-

⁸ A Strode and S Soni. 'Preimplantation diagnosis to create 'saviour siblings': A critical discussion of the current and future legal frameworks in South Africa' (2012) 102(1) *SAMJ* 21.

⁹ Ibid.

¹⁰ *Op cit* note 6 230.

¹¹ M Spriggs and J Savulescu "Saviour siblings" (2002) 28 *Journal of Medical Ethics* 289.

¹² J Picoult, *My sister's keeper: A novel* 2004. *My Sister's Keeper* is a novel where a couple struggled with the sickness of their child that suffered from acute promyelocytic leukaemia and turned to biotechnology as a 'solution', In addition, the novel highlighted a situation where a child not created out of desire but for the purpose of saving the life of their sibling, as the child was also required to be a tissue and organ donor.

¹³ A Meriska *et al* 'Psychosocial development of Anna Fitzgerald in *My sister's keeper* novel by Jodi Picoult' (2018) 2(3) *Jurnal Ilmu Budaya* 277.

¹⁴ M Goodwin 'My Sisters keeper? Law, children and compelled donation' 29(29) 2007 *Western England Law Review* 361.

¹⁵ Fertility care available at <https://www.pennmedicine.org/for-patients-and-visitors/find-a-program-or-service/penn-fertility-care/embryo-screening/treatments-and-procedures> accessed 10 October 2017.

¹⁶ M Zietsman, 'Who really needs saving? The ethics of savior siblings and their autonomy' available at <http://blogs.kentplace.org/bioethicsproject/2017/05/25/really-needs-saving-ethics-savior-siblings-autonomy/> (accessed 26 November 2017).

thalassemia their child was suffering from and needed treatment from a sibling donor.¹⁷

1.3 The biomedical procedure for creating saviour siblings

In certain legal systems, parents of a child with a debilitating or life-threatening illness have the option of creating a saviour sibling to help treat the disease of the ill sibling managed through stem cell therapy or organ donation. Creating saviour siblings through preimplantation genetic diagnosis entails the following procedure:¹⁸

1.3.1 A woman undergoes *invitro* fertilisation treatment enabling doctors to collect and fertilise her eggs.¹⁹

1.3.2 After the fertilisation of the eggs, embryos start to grow. These embryos are cultivated in a laboratory for two to three days until the cells are split, and each embryo consists of about eight cells.²⁰

1.3.3 An embryologist then removes one or two cells, blastomeres, from the embryos.²¹

1.3.4 The blastomeres are tested and examined to determine whether embryos from the cells contain the gene that causes the genetic mutation in the family, which the sick child suffers from.²²

1.3.5 In screening the genes that cause the genetic condition, a laboratory technician uses the same cells from the embryos to determine the tissue type of the embryos, while conducting numerous tests. The results determine if the embryo is a human leukocyte antigen (HLA) tissue match to the ailing sibling.²³

¹⁷S Sheldon and S Wilkinson 'Hashmi and Whitaker: An Unjustifiable and Misguided Distinction' (2004) 12(2) *Medical Law Review* 138.

¹⁸*Op cit* note 6 231-232.

¹⁹*Ibid.*

²⁰*Ibid.*

²¹*Ibid.*

²²*Ibid.*

²³*Ibid.*

- 1.3.6 Embryos without a genetic condition or defect and have the same type of HLA tissue as the sick child then they are transferred to the womb of the woman.²⁴
- 1.3.7 A pregnancy test is conducted after two weeks of implantation to assess whether the embryos have developed and if the operation was successful.²⁵
- 1.3.8 After delivery, there is the extraction of umbilical cord blood stem cells from the saviour sibling.
- 1.3.9 Alternatively, an allogeneic stem cell transplantation can take place immediately or regularly; the procedure requires the extraction of blood-forming cells from the saviour sibling, there is the extraction of the blood from the veins which then flows into a machine that draws the stem cells.²⁶
- 1.3.10 In cases where the sick sibling has cancer, the sick sibling will receive chemotherapy killing the cancer-causing cells, and when there is the extraction of stem cells from the saviour sibling, they receive the stem cells through a catheter in the blood vessels in the chest.²⁷ The use of the procedure is not only limited to the treatment of cancer but also genetic defects such as Fanconi anaemia.²⁸
- 1.3.11 The procedure requires hospitalisation under anaesthetic used to allow the collection of stem cells from the hips.²⁹

²⁴Ibid.

²⁵Ibid.

²⁶Ibid.

²⁷Ibid.

²⁸C Steward and A Jarisch 'Haemopoietic stem cell transplantation for genetic disorders' (2005) 90(12) *Archives of Disease in Childhood* 1259.

²⁹ National Cancer Institute Dictionary of Cancer Terms available at <https://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=270732> accessed 28 November 2017.

2. Problem statement

The creation of saviour siblings has been a contentious issue that has given rise to ethical and legal debates.³⁰ It is also unclear whether South African law provides adequate regulation for the use of this technology.

3. Research Questions

In light of the research aims, the research questions are:

3.1 Is there legal protection for a child used to save an existing child in South African law and international law?

3.2 Is it ethically and legally justifiable to allow parents to create saviour siblings?

3.3 Are there lessons that South Africa can learn from the approaches adopted in other jurisdictions such as Australia and the United Kingdom?

4. Literature review on saviour siblings

4.1 Introduction

The creation of saviour siblings on face value appears like it can be accepted by society as it saves a life; however, the technology has always been controversial and is a concern in society,³¹ as it brings rise to legal and ethical issues.³² This section seeks to review literature illustrating the legal and ethical issues.

4.2 Access to preimplantation genetic diagnosis and regulation of saviour siblings in South Africa

Certain jurisdictions have adopted different regulatory frameworks dealing with the use of preimplantation genetic diagnosis, and some have professional regulation requiring mandatory licensing.³³ Australia has gone as far as to have federal laws with boards of ethics for its different states.³⁴

³⁰R Sparrow and D Cram 'Saviour embryos? Preimplantation genetic diagnosis as a therapeutic technology' (2010) 20(5) *Reproductive BioMedicine Online* 670.

³¹ *Op cit* note 6 226.

³² *Ibid* 228.

³³ AR Fahrenkrog 'A Comparison of International regulation of pre-implantation genetic diagnosis and a regulatory suggestion in the United States' (2006) 15 (2) *Transnational Law & Contemporary Problems* 761.

³⁴ *Ibid*.

However, the South African regulatory framework concerning preimplantation genetic diagnosis used to conceive saviour siblings has been under scrutiny. One such commentator, Van Niekerk has heavily criticised the regulatory framework in South Africa for not serving its purpose even though the promulgation of the National Health Act³⁵ was to give a better 'structured framework and uniform system' intended to improve the South African health system.³⁶

As far back as 2012, Soni and Strode noted the absence of laws regulating preimplantation genetic diagnosis and there was hope that the draft regulations when finalised and implemented would cure the problem giving clarifying whether the sick sibling's parents would be allowed to harvest stem cells to donate to the latter.³⁷ Although the latter is now allowed, the South African legal framework has received criticism for not having principled guidelines.³⁸ As recent as 2017, the South African legal framework for the conception of saviour siblings has received criticism for inadequate regulation and the lack of official guidelines for assisted reproduction technologies and recognised bodies in the field of assisted reproduction technologies, used for the creation of saviour siblings.³⁹

Lastly, Pepper and Nöthling-Slabbert also criticised the South African regulation for not having guidelines or standards endorsed by the Department of Health, therefore not giving clarity for the medical professionals working in this area of medicine.⁴⁰

4.3 Institutional problems

There have also been concerns that there are no specialist bodies established either by the National Health Act⁴¹ or its regulations. Notably, it inhibits decision-making as there is no guidance for the use of preimplantation genetic diagnosis used to conceive saviour siblings.⁴²

³⁵61 of 2003.

³⁶ C Van Niekerk 'Strange (and incompatible) bedfellows. The relationship between the National Act and regulations relating to artificial fertilisation of persons and its impact on individuals engaged in assisted reproduction' (2017) 10(1) *SAJBL* 32-34.

³⁷ *Op cit* note 8 22.

³⁸ A Strode 'Law reform dealing with blood, tissues, organ transplants and health research: A lagging legal framework that is strangling innovation' (2012) 102(9) *SAMJ* 741.

³⁹ MS Pepper and M Nöthling Slabbert 'Human Tissue legislation in South Africa: Focus on stem cell research and therapy' (2015) 8(2) *SAJBL* 9.

⁴⁰ *Ibid.*

⁴¹ *Ibid* note 35.

⁴² *Op cit* note 8 23.

Moreover, South Africa has received criticism for not making efforts in establishing committees that would set conditions of licencing treatment and research of preimplantation genetic diagnosis like other jurisdictions that have adopted this.⁴³ Other jurisdictions have specialist committees that grant permission for the use of the procedures.⁴⁴ With the lagging of the regulation in South Africa, it has noted that the impact of this is that no one can access new developments within assisted reproductive technologies.⁴⁵

The existing regulatory oversight has received criticism for placing too much emphasis on ministerial approval, who may be an inexperienced minister or delegated official lacking knowledge of assisted reproductive technology for them to make educated and informed decisions thus hindering effective decision-making affecting the advancement of assisted reproductive technologies in South Africa.⁴⁶ The regulation does not state the circumstances it requires approval to be obtained from the minister of health.

4.4 Protection of the child

In South African law, personhood begins at birth, and the foetus lives *ex utero*, and it is from that moment that they are considered a legal person.⁴⁷ As children have limited capacity to act, South African law, therefore classifies children as a vulnerable group in society which requires protection.⁴⁸ Section 28 of the Constitution accords children absolute rights and protection,⁴⁹ reinstating the common law position, viz, that the rights of the child are paramount.

Accordingly, a saviour sibling should receive protection in terms of South African law from the moment they are born. However, the legal framework not providing explicit protection for children created through assisted reproduction technologies, makes saviour siblings susceptible to abuse.⁵⁰

⁴³ Ibid.

⁴⁴ Ibid.

⁴⁵ Ibid.

⁴⁶ L Prinsen 'Flawed Law: a critical analysis of the faults and shortcomings of Chapter 8 of the National Health Act' (2013) 34(3) *Obiter* 522-532.

⁴⁷ S Chima and F Mamdoo 'Ethical and regulatory issues surrounding umbilical cord banking' (2011) 4(2) *SAJBL* 80.

⁴⁸ F Vanclay 'International principles for social impact assessment' (2003) 21(1) *Impact assessment and project appraisal* 5-12.

⁴⁹ Constitution, 1996.

⁵⁰ *Op cit* note 8 22.

Furthermore, authors have also observed inconsistencies between the National Health Act⁵¹ and the Children's Act⁵². Van Niekerk has criticised the latter, stating that it does not compliment the National Health Act as it only deals with the artificial insemination for children conceived through surrogacy. The Act⁵³ offers limited protection as it only deals with the safekeeping of the information, parental rights and responsibilities of children born through this form of assisted reproductive technology.⁵⁴ It does not go further to include saviour siblings also conceived using artificial insemination and related procedures like children born for surrogacy.

4.5 Autonomy

Autonomy is a fundamental principle in medicine, and medical practitioners are obliged to respect the principle to avoid possible litigation.⁵⁵ Self-determination is an underlying principle of autonomy⁵⁶ that requires a patient to be informed of the treatment and its purpose to enable them to make an informed decision.⁵⁷

One concern that arises when dealing with saviour siblings is the issue of autonomy. The reason for the concern is that consent is not obtained before the medical procedures of donating from the saviour sibling, and the latter is not in a position to express their views or preferences. Saviour siblings cannot exercise self-determination by refusing medical treatment or being part of the procedure as they are minors and deemed not understand the consequences of refusing medical treatment or consenting to the medical procedure.⁵⁸ With the lack of regulation for the technology in South African law, it is not clear whether parents can consent on behalf of their children, like the saviour sibling, to participate in the procedure.⁵⁹

Du Plessis notes that there is the protection of children's autonomy in the Bill of Rights, and children are entitled to this right which requires giving due regard to the right to

⁵¹ *Supra* note 35.

⁵² *Supra* note 7.

⁵³ *Ibid.*

⁵⁴ *Ibid.*

⁵⁵ B Taylor. 'Parental autonomy and consent to treatment' (1999) 29(3) *Journal of Advanced Nursing* 571.

⁵⁶ *Ibid.*

⁵⁷ *Ibid.*

⁵⁸ *Ibid.*

⁵⁹ *Op cit* note 6 224

self-determination.⁶⁰ The main concern is that the saviour sibling is required to partake in the donation procedures with no consent obtained from them. Accordingly, the Children's Act requires that children not be denied the right to autonomy as it allows them to participate in decision-making in matters affecting their lives if they are over twelve years old.⁶¹

However, the twelve-year age restriction has received criticism as children mature differently, and there have been suggestions for considering consent on a case by case basis.⁶² Moreover, parental control has received criticism, and there have been suggestions for the relaxation of parental control, to give children the independence to make decisions even before they reach the age they are allowed to give informed consent.⁶³ At the end of the spectrum, authors like Du Plessis argue that children should be allowed to exercise their autonomy to promote their wellbeing and this will ensure parents act in a manner that is in the best interests of the child.⁶⁴

Lastly, it is noteworthy that parents have right to make decisions on behalf of their children, and believed to be acting in their best interests;⁶⁵ however, parents are medically inexperienced and could make a mistake in assessing what is in the best interest of the child.⁶⁶

4.6 Ethical issues

Many authors have raised ethical issues; one being Chima who argues that the use of stem cells brings rise to several ethical problems, particularly when looking at the issue of consent.⁶⁷ Whetstine points that one of the concern is whether it is morally acceptable to conceive a child and use them for the benefit of another, with no consent obtained from that child despite the procedures being painful and invasive.⁶⁸

⁶⁰ E Du Plessis *The Constitutional Rights of 'Benefactor Children' and 'Saviour Siblings' to Bodily Integrity and Autonomy* (LLM dissertation Nelson Mandela Metropolitan University, 2011) 61-62.

⁶¹ *Supra* note 7.

⁶² *Op cit* note 48 5.

⁶³ *Ibid*.

⁶⁴ *Op cit* note 6 244.

⁶⁵ T Dare 'Parental rights and medical decisions' (2009) 19(10) *Pediatric Anesthesia* 947.

⁶⁶ *Ibid* 948.

⁶⁷ *Op cit* note 47 81.

⁶⁸ LM Whetstine 'Ethical challenges in assisted reproduction: The Place of Pre-implantation genetic diagnosis in a just society' (2015) 30(5) *Journal of Child Neurology* 549.

Moreover, there have been arguments that conceiving saviour siblings using preimplantation genetic diagnosis amounts to eugenics as parents choose to give birth to a perfectly healthy child, thus affecting population diversity.⁶⁹ However, some proponents of the medical intervention argue that it is positive eugenics as the purpose of preimplantation genetic diagnosis is to prevent disease.⁷⁰ There have been arguments that using this medical intervention will reduce the prevalence of children born with congenital disabilities.⁷¹

Lastly, there have been arguments that conceiving saviour siblings using preimplantation genetic diagnosis is the choosing of the less evil, thus discriminating against children born with disabilities.⁷² Pembrey argues that choosing to have a healthy child that does not have disabilities is not devaluing a child with a disability.⁷³

4.7 The position of the medical practitioner

A medical practitioner has to maintain the confidentiality of their patient; this is a duty to protect the dignity of the patient. However, in the case of saviour siblings, it is not clear whether the medical practitioner discloses the medical condition of the sick sibling to the saviour sibling.⁷⁴

Although a medical practitioner has to obtain the consent of the sick sibling to disclose their condition, the ill sibling is often not at the stage where they cannot give consent or to understand the nature of the consent. A medical practitioner is also not able to obtain consent from a saviour sibling. It is submitted that the medical practitioner is put in a compromising position by not exercising their professional duty.

4.8 Consent, instrumentalisation and the best interests of the child

Consent is also a fundamental principle in medical practice. Consent to medical treatment is only valid where given voluntarily, the individual informed of the medical

⁶⁹ L Cherkassy 'Twenty-seven years of controversy, the perils of pgd' (2018) 2(1) *Journal of Pediatrics and Neonatal* 4.

⁷⁰ Ibid.

⁷¹ M Pembrey 'Ethical issues in preimplantation genetic diagnosis' (1998) 6 *European Journal of Human Genetics* 6.

⁷² Ibid.

⁷³ *Op cit* note 69 9.

⁷⁴C Yap and L Liew 'Legal and Ethical issues pertaining to preimplantation genetic diagnosis' 2003 C-8-4 available at <https://www.bioethics-singapore.gov.sg/files/publications/others/legal-and-ethical-issues-pertaining-to-preimplantation-genetic-diagnosis.pdf> accessed 23 August 2020.

treatment, and the individual is competent to give consent.⁷⁵ However, this is not the case with saviour siblings.

One of the objections levelled against creating saviour siblings is the instrumentalization of the child, as the saviour sibling is used as an instrument to cure the other child.⁷⁶ Some argue that this contrary Kant's ethical principle that is against using a person as a means to an end.⁷⁷ There are arguments that a saviour sibling is likely to feel a void when then the donation procedures are unsuccessful, and when the sick sibling dies.⁷⁸

As saviour siblings are not in a position to give informed consent due to their lack of capacity, there is a reliance on the best interest standard.⁷⁹ There have been arguments that the procedure does not serve their best interests as it does not give them any medical benefit.⁸⁰ The parents face the challenge of balancing the sick sibling's interests and those of the saviour sibling.⁸¹ Some argue that parents are more concerned with the welfare of the ill sibling than that of the saviour sibling.⁸²

It is unfortunate for saviour siblings as Bendorf and Kerridge note the risks associated with the use of the technology and bone marrow transplants which include complications such as immunodeficiency syndrome, renal failure, infertility and respiratory problems.⁸³ The concern raised by Bendorf and Kerridge is that the use of the technology is tricky as the decision is motivated by love and the need to save the sick child,⁸⁴ it does not take away the converse effects on saviour sibling. The ethical concerns range from medical problems and psychological effects, which will be discussed further in Chapter 2.

⁷⁵ B Taylor 'Parental autonomy and consent to treatment' (1999) 29(3) *Journal of Advanced Nursing* 572.

⁷⁶ G Pennings *et al* 'Ethical considerations on preimplantation genetic diagnosis for HLA typing to match a future child as a donor of haematopoietic stem cells to a sibling' (2002) 17(3) *Human Reproduction* 536.

⁷⁷ *Ibid.*

⁷⁸ *Ibid.*

⁷⁹ *Ibid.*

⁸⁰ *Ibid.*

⁸¹ *Op cit* note 76 537.

⁸² *Op cit* note 76.

⁸³ A Bendorf and I Kerridge, Ethical issues in bone marrow transplantation in children. (2011) 47 (9) *Journal of Paediatrics and Child Health* 617.

⁸⁴ *Ibid* 619.

There have been arguments that a saviour sibling should not be exposed to risks of the procedures unless the child will derive a benefit from the medical procedures.⁸⁵ Opponents of creating saviour siblings argue that the saviour sibling's rights should be protected as well, even if this protection interferes with the rights of the parents.⁸⁶

4.7 Parental responsibility and conflicting interests

Parents are legally responsible for giving consent to medical treatment and interventions on behalf of their minor children.⁸⁷ In their role as parents, they have to act in the best interests of the children.⁸⁸ However, the right of the parents to give consent on behalf of the children is problematic where a child may have dissenting views regarding medical interventions.⁸⁹

The parents face a situation where they have to give consent for the sick child to receive bone marrow and provide consent to medical treatment and procedures on behalf of the saviour sibling to donate bone marrow.⁹⁰ Taylor has argued that the parents only act in the interests of a sick sibling as there is a need to preserve life.⁹¹

Taylor notes that, while the practice of medicine requires the prevention of harm,⁹² one sees saviour siblings exposed to harm. Taylor argues that using someone as a donor cannot be morally justified, primarily where they do not derive any benefit.⁹³ However, some authors have argued that parents gave the saviour sibling the benefit of life by conceiving them,⁹⁴ disregarding that there is the subjecting of the saviour sibling to harm.

Taylor argues that, when using children as a donor for a sibling, bone marrow donation is justifiable as it may create a bond and attachment between siblings.⁹⁵ However,

⁸⁵ T El-Touskhy *et al* 'The ethics of preimplantation genetic diagnosis' (2008) 10 *The Obstetrician and Gynaecologist* 53.

⁸⁶ BM Knoppers Preimplantation genetic diagnosis: an overview of social-ethical and legal considerations 2006 7(1) *Annual Review of Genomics and Human Genetics* 205.

⁸⁷ *Op cit* note 73 571.

⁸⁸ *Ibid*.

⁸⁹ *Op cit* note 73.

⁹⁰ *Ibid* 573.

⁹¹ *Ibid*.

⁹² *Ibid*.

⁹³ *Ibid*.

⁹⁴ *Ibid*.

⁹⁵ *Op cit* note 73 574.

opponents argue that the donor sibling may be too young to develop such a relationship.⁹⁶

Furthermore, proponents of using a child as a donor argue that this child will feel a sense of achievement in saving a sibling who might have died.⁹⁷ On the other side of the coin, Taylor argues that focusing on the child's gratitude for life fosters an unequal relationship as the sick child is forever indebted to the other and at the same time the saviour child does not obtain any medical benefit.⁹⁸ There is an argument that this inequality is not beneficial to the saviour sibling.⁹⁹

Proponents of using a child as a donor for the benefit of the other child also argue that donating bone marrow involves a day of discomfort and a small risk associated with the anaesthesia, and this does not outweigh the benefit of having a healthy sibling.¹⁰⁰ Some authors argue that it is in the general interest for the family to have a living and healthy sibling, although this may not be in the medical interests of the donor child.¹⁰¹

Taylor suggested that parents should do what is in each child's best interests, and not using the child simply to benefit the other but to share the benefit instead.¹⁰²

4.8 Recommendations

There has been literature that calls for law reform in South Africa with all the legal and ethical issues stemming from creating saviour siblings. Firstly, Du Plessis has recommended the establishment of a national board to review cases involving saviour siblings¹⁰³ and to provide licences to create saviour siblings like in the United Kingdom.¹⁰⁴

According to Du Plessis, it would be good for South Africa to follow this approach, as there would be detailed provisions regulating saviour siblings.¹⁰⁵ Van Niekerk echoed the recommendation of a regulatory board by Du Plessis and stated that having such

⁹⁶ Ibid.

⁹⁷ Ibid.

⁹⁸ Ibid.

⁹⁹ Ibid.

¹⁰⁰ Ibid.

¹⁰¹ Ibid.

¹⁰² Ibid.

¹⁰³ *Op cit* note 6 251.

¹⁰⁴ Ibid.

¹⁰⁵ Ibid.

a board would ensure that South Africa is abreast with the developments of the technology.¹⁰⁶

Furthermore, Du Plessis has recommended that third parties must be appointed to decide what is in the best interests of saviour siblings when saviour siblings are used as donors since the law does not prescribe how the test ought to be applied.¹⁰⁷ Plessis suggested that an ombudsman is appointed to focus on the issues of children used as saviour siblings.¹⁰⁸

On another level, Du Plessis has recommended that a register of saviour siblings be maintained to monitor the wellbeing, the techniques and the treatment of the saviour siblings.¹⁰⁹ Du Plessis has also suggested that a 'mature approach' be adopted for consenting to medical treatment because it is not clear whether twelve years is the right age for consent.¹¹⁰ Du Plessis has recommended that the interpretation of 'medical treatment' in section 129 of the Children's Act¹¹¹ to include surgical operations.¹¹²

Lastly, there has been a recommendation that there be a review of assisted reproduction legislation to ensure that it is in line with technological developments.¹¹³ Another recommendation is that the law should develop at the same pace as medical interventions, and children and adults made aware of their rights as required by Article 42 of the United Nations Convention on the Rights of the Child.¹¹⁴

5. Research aim

This dissertation aims to explore the legal and ethical issues associated with saviour siblings.

6. Research Objectives

The aim is achieved by accomplishing the following objectives:

¹⁰⁶ *Op cit* note 36 35.

¹⁰⁷ *Op cit* note 6 252.

¹⁰⁸ *Ibid.*

¹⁰⁹ *Ibid.*

¹¹⁰ *Ibid.*

¹¹¹ *Supra* note 7.

¹¹² *Ibid.*

¹¹³ *Op cit* note 39 35.

¹¹⁴ *Op cit* note 6 253.

6.1 Exploring whether it is ethically justifiable to allow parents to create and use saviour siblings as a donor for the ailing sibling. Analysing the ethical principles and principles of biomedical ethics achieves exploration.

6.2 Establishing whether there is legal protection for saviour siblings in South African and international law; by reviewing the South African regulatory framework as set out in the Constitution,¹¹⁵ the Children's Act,¹¹⁶ the National Health Act,¹¹⁷ its accompanying regulations, the international and regional legal instruments that protect children's rights.

6.3 Exploring the regulatory framework in Australia and the United Kingdom, their legislation, to establish the lessons that South Africa can adopt from the countries.

5. Research Methodology

The research questions are answered through a survey of literature on saviour siblings obtained through desktop research.

6. Limitation of the study

The dissertation will not look at the rights and interests of the unborn child and the sick sibling. The dissertation will establish whether South Africa, through legislation, provides adequate regulation to protect the rights and interests of the saviour burdened with tissue donations and aspirations for bone marrow.¹¹⁸

7. Chapter Overview

The dissertation research questions are answered through desktop research in the following chapter structure:

Chapter 2 discusses the professional governing bodies and determines whether they guide the use of preimplantation genetic diagnosis, used to create saviour siblings and whether they deal with any ethical considerations in this matter. Furthermore, the chapter looks at biomedical, ethical principles and conflicting interests surrounding the creation of saviour sibling.

¹¹⁵ *Supra* note 49.

¹¹⁶ *Supra* note 7.

¹¹⁷ *Supra* note 35.

¹¹⁸ JA Robertson *et al* 'Conception to obtain hematopoietic Stem Cells' (2002) 32(3) *Hastings Centre Report* 35.

Chapter 3 discusses international legal instruments and determines whether the norms provide saviour siblings with any protection. Moreover, the chapter looks at bioethics conventions to determine how the saviour siblings should be protected.

Chapter 4 discusses the South African legal framework examining the Constitution,¹¹⁹ Children's Act¹²⁰ and National Health Act,¹²¹ and whether it allows saviour siblings to be created.

Chapter 5 discusses the regulation of saviour siblings in Australia and the United Kingdom. The chapter highlights the various styles and notes similarities in regulating the creation of saviour siblings.

Chapter 6 concludes with a summary of the information discussed in the dissertation and makes recommendations for the future of South African medical law in regulating assistive reproductive technologies, such as preimplantation genetic diagnosis used to create saviour siblings.

8. Conclusion

In conclusion, as noted above, conceiving children is a valuable element in one's life; but when a child is born with a genetic condition, it becomes a concern. Medical advances have enabled the improvement of the child's life through the treatment of the debilitating medical condition, which includes the use of preimplantation genetic diagnosis of and *in vitro* fertilisation to select disease-free embryos for pregnancy to use the resultant child as a donor; referred to as a 'saviour sibling.'

The medical procedure has ethical and legal challenges that have led to states such as the United Kingdom and Australia to provide regulation. From the above discussion, it is clear that there is a problem with South African law in providing regulation for the procedure.

¹¹⁹*Supra* note 49.

¹²⁰*Supra* note 7.

¹²¹*Supra* 35.

Therefore, it is not clear in the South African context whether the conception of saviour siblings is legally justifiable given the criticism levelled against its regulatory framework, namely the National Health Act¹²² and the Children's Act.¹²³

¹²² *Supra* note 35.

¹²³ *Supra* note 7.

CHAPTER 2: THE ETHICAL DIMENSIONS OF CREATING SAVIOUR SIBLINGS

2.1 Introduction

Chapter 1 highlighted the gap in South Africa's legal framework in providing regulation for saviour siblings. Therefore, this chapter determines whether professional statutory bodies and professional associations in medicine and genetics give normative ethics guidance on the creation of saviour siblings using preimplantation genetic diagnosis and *in vitro* fertilisation. This chapter will highlight the ethical dimensions of creating saviour siblings and the conflicting interests of the parties involved and illustrate why there is a need for regulation in South Africa.

2.2 Professional medical associations and normative ethics guidelines for medical practitioners

Medical practitioners have to make difficult decisions in their scope of duty, and if they were to make decisions based on their values and opinions, they could be 'misguided' which may be detrimental to the patients.¹²⁴ Therefore, practitioners seek guidance from the Hippocratic Oath and biomedical ethics.¹²⁵

The Hippocratic Oath is the foundation of medical ethics which outlines the ethical requirements of medical practice.¹²⁶ The Oath stipulates that medical practitioners should act in the best interests of patients,¹²⁷ as medicine should benefit patients and enhance their wellbeing.¹²⁸ An application of the Hippocratic Oath, in the case of saviour siblings, is necessary to establish whether conducting the procedure is in the interest of the saviour sibling.

The Hippocratic Oath morally binds all medical practitioners defining the doctor-patient relationship.¹²⁹ The Oath requires medical practitioners to provide beneficial treatment to patients and to protect their wellbeing.¹³⁰

Other than having medical practitioners bound morally to the Hippocratic Oath, certain bodies regulate branches of medicine and guide clinical practice within specific sub-

¹²⁴ A Campbell *et al Medical ethics* 3ed (2011) 3.

¹²⁵ *Ibid.*

¹²⁶ *Ibid.*

¹²⁷ *Ibid* 8-9.

¹²⁸ *Ibid* 8.

¹²⁹ TA Mappes and D DeGrazia *Biomedical ethics* 5ed (2001) 6.

¹³⁰ *Ibid.*

disciplines. In the case of saviour siblings, the relevant bodies are the Southern African Society of Reproductive Medicine and Gynecological Endoscopy, the International Federation of Gynaecology and Obstetrics, the South African Society of Obstetricians and Gynaecologists, and the South African Medical Association.

Firstly, the Southern African Society of Reproductive Medicine and Gynecological Endoscopy (SASREG) affiliated to the European Society of Human Reproduction and Embryology, the International Federation of Fertility Societies, the American Society for Gastrointestinal Endoscopy, the American Association of Gynecologic Laparoscopists, the South African Society of Obstetricians and Gynaecologists and the International Federation of Gynaecology and Obstetrics, all of which guide controversial aspects of reproductive sciences and legislation.¹³¹ SASREG represents gynaecologists with a particular interest in gynaecological endoscopy, 'sub-specialists, embryologists and scientists' in reproductive medicine., The body protects the rights and interests of patients undergoing fertility treatment.¹³²

SASREG provides guidelines on embryo transfers and sets limits on transferring of embryos for women of particular age groups.¹³³ However, it provides no guidelines for preimplantation genetic diagnosis, used to create saviour siblings. The International Federation of Gynaecology and Obstetrics (FIGO), an affiliate of SASREG, aims to provide the highest attainable standard for women in physical, mental, reproductive, sexual health and wellbeing.¹³⁴ Despite FIGO's objectives in improving health and wellbeing for women and new-born babies,¹³⁵ studying ethical issues arising from research and practice in obstetrics, gynaecology, and reproductive medicine, and recommending guidelines on ethical problems in the practice of obstetrics and gynaecology, FIGO does not guide procedures used to create saviour siblings.

In addition, the South African Society of Obstetricians and Gynaecologists which aims to improve women's health, and 'maintaining high ethical standards' in South Africa, only provides guidelines on the donation of genetic material for human reproduction.

¹³¹ Southern African Society for Reproductive Medicine and Gynaecological Endoscopy available at <https://sasreg.co.za/> accessed 13 December 2019.

¹³² Ibid.

¹³³ SASREG Embryo transfer guidelines available at <https://sasreg.co.za/downloads/Embryo-Transfer-Guidelines.pdf>. accessed 13 December 2019.

¹³⁴ GI Serour 'The role of FIGO in women's health and reducing reproductive morbidity and mortality' (2012)119 *International Journal of Gynecology and Obstetrics* s3.

¹³⁵ Ibid s4.

However, at the time of writing the dissertation, there were no issued guidelines on preimplantation genetic diagnosis.¹³⁶ Similarly, the South African Medical Association has issued no assisted reproductive technology clinical guidelines for creating saviour siblings and has only published clinical guidelines for the use of blood products in South Africa.¹³⁷

It is, therefore, clear that professional medical associations have not published guidance on the creation of saviour siblings despite having an obligation to promote the wellbeing of the patient. It will be crucial to determine if the bodies in the field of genetics do any better.

2.2.1 The South African Genetics Societies

The South African Genetics Society (SAGS) is a professional organisation for geneticists that oversees the discipline of genetics in South Africa and establishes standards of research, teaching and training.¹³⁸ However, SAGS has not issued guidelines on preimplantation genetic diagnosis to date.¹³⁹

The Southern African Society for Human Genetics also has not published any guidelines on preimplantation genetic diagnosis¹⁴⁰ despite the organisation purporting to advance human genetics in Southern Africa and ensuring that ethical and professionals are maintained.¹⁴¹

2.2.2 The HPCSA Guidelines for Good Practice in health care Professions: General Ethical Guidelines for reproductive health 2016

The Health Professions Council of South Africa (HPCSA) is a statutory body that governs twelve professional bodies registered in terms of the Health Profession's Act¹⁴² and protects the public and guides professionals by ensuring compliance to

¹³⁶ The South African Society of Obstetricians and Gynaecologists available at <https://www.sasog.co.za/Guidelines/Donation> accessed 13 December 2019.

¹³⁷ The South African Medical Association Clinical Guidelines available at https://www.samedical.org/clinical-guidelines-technologies/clinical_guidelines accessed 13 December 2019.

¹³⁸ South African Genetics Society available at <https://sagene.co.za/> accessed 13 December 2019

¹³⁹ Personal email from Prof S Naidoo 17 December 2019.

¹⁴⁰ Personal Email from Zane Lombard 17 December 2019.

¹⁴¹ Southern African Society for Human Genetics available at <https://sashg.org/about/> accessed 13 December 2019.

¹⁴² 56 of 1974.

ethical and professional standards.¹⁴³ The HPCSA publishes normative guidelines for its professional boards, such as the Medical Technology Board and the Medical Science Boards,¹⁴⁴ which comprises of professionals that would be responsible for the conception of saviour siblings. The HPCSA's 2016 *Guidelines on Reproductive Health* do not explicitly deal with preimplantation genetic diagnosis used to conceive saviour siblings, even though the technology falls within the ambit of reproductive health. Further, the guidelines place an obligation on health professionals to advocate for health improvement and to publicize and sensitize the public on health issues.¹⁴⁵ The guidelines only guide surrogacy, surrogate motherhood and blood collection procedures.¹⁴⁶

2.2.3 HPCSA Guidelines for Good Practice in health care Professions: Seeking Patients informed consent ethical considerations 2016

With regards to informed consent and saviour siblings, the HPCSA Guidelines for Good Practice in health care Professions: Seeking Patients informed consent ethical considerations only state that medical practitioners must respect patients' autonomy by obtaining consent before medical procedures.¹⁴⁷ Although the guidelines stress that consent of a patient is fundamental in legislation, such as the National Health Act and common law,¹⁴⁸ they do not explicitly deal with saviour siblings where consent is problematic.

Therefore, it is evident that the Health Profession's Council does not provide any guidance as it does not state whether it is permissible to conceive saviour siblings nor does it give any ethical guidance on the creation of saviour siblings, even though there is no consent obtained from the saviour sibling.

¹⁴³ Health Professions Council of South Africa available at <https://www.hpcsa.co.za> accessed 25 August 2020.

¹⁴⁴ Ibid.

¹⁴⁵ Health Professions Council of South Africa Guidelines for Good Practice in Health Care Professions General Ethical Guidelines for Reproductive health 2016 Booklet 8 6.

¹⁴⁶ Ibid 8,10,14.

¹⁴⁷ Health Professions Council of South Africa Guidelines for Good Practice in Health Care Professions: Seeking Patients informed consent ethical considerations 2016 Booklet 4 3.

¹⁴⁸ Ibid.

2.3 Ethics

The field of ethics considers moral issues and offers guidance on what is considered morally right, hence influencing what should be permitted or prohibited based on the public perception of justice and morality.¹⁴⁹

As noted in Chapter 1, the creation of a saviour sibling and using them as a donor is a contentious terrain.¹⁵⁰ Therefore, this part of the chapter evaluates the four principles of biomedical ethics and ethical theories of utilitarianism, consequentialism and deontology. This chapter seeks to determine whether it is ethically permissible to create a saviour sibling.

2.3.1 Biomedical ethics

Biomedical ethics is a branch of ethics that guides issues related to the practice of health care.¹⁵¹ The principles of biomedical ethics help guide and justify a particular action or policy on the part of health professionals, and provide an evaluative framework to give reasons for what ought to be done by health professionals. These principles ensure that the treatment of patients is with respect and their interests afforded moral weight. The biomedical principles premised on the criterion of objectivity, evaluate reasons for a particular action with only the best explanation taken into consideration.¹⁵²

Biomedical ethics also concerns itself with the doctor-patient relationship,¹⁵³ and its principles are widely used in the medical profession by health professionals faced with ethical issues.¹⁵⁴ In performing their duties and making an ethical analysis, medical practitioners ought to have due regard to the four principles of biomedical ethics espoused by Childress and Beauchamp, namely autonomy, nonmaleficence, beneficence and justice.¹⁵⁵ The principles will be discussed and applied to the case of saviour siblings.

¹⁴⁹ *Op cit* note 6 226.

¹⁵⁰ *Ibid.*

¹⁵¹ *Op cit* note 129 2.

¹⁵² W Glannon *Biomedical ethics* (2005) 6.

¹⁵³ *Op cit* note 129.

¹⁵⁴ N Hamidreza *et al* 'The doctor-patient relationship: toward a conceptual re-examination' (2016) 10 *Journal of Medical Ethics and History of Medicine* 6.

¹⁵⁵ *Op cit* note 124 10.

2.3.2 The principles of biomedical ethics

2.3.2.1. Autonomy

The notion of autonomy is an essential element in medical ethics, and it stems from Immanuel Kant's concept of personhood that defends human dignity of all humans¹⁵⁶ and argues for respect for persons as ends in themselves and autonomous beings with the capacity and right to self-determination.¹⁵⁷ According to Immanuel Kant, personhood commences at the beginning of life, at the time of conception.¹⁵⁸ The principle should not be construed as meaning that a person should not be used as a means but implying that a person should not be solely used as a means.¹⁵⁹

The principle of autonomy recognises that a patient has a right to accept or reject medical treatment.¹⁶⁰ This principle is also the underlying principle of deontology and John Stuart Mill's principle of liberty that recognises that persons are sovereign in their bodies.¹⁶¹ This principle is restricted when harm is caused to other people whilst exercising autonomy.¹⁶² The principle does not specify whether parental consent ought to be prohibited if the consent causes harm to another person, such as a saviour sibling.

The creation of a saviour sibling and using them solely as a donor is contrary to the principle of autonomy as a child is not able to grow and develop in their own right and compelled to be donors from the time of their birth. The reason for this is their inability to express dissent, as the parents provide surrogate consent leaving the saviour sibling unable to weigh the decisions with regards to who can access their body.¹⁶³

The principle of autonomy is important to a medical professional who is requested to perform the procedures of the donation from the saviour sibling to the ailing sibling. The medical practitioner has to ensure that the patients' autonomy is respected.

¹⁵⁶ S Rolf 'Human Embryos and human dignity: differing presuppositions in human embryo research in Germany and Great Britain' (2012) 53(5) *The Heythrop Journal* 744

¹⁵⁷ Ibid

¹⁵⁸ S Rolf. 'Humanity as an object of respect: Immanuel Kant anthropological approach and foundation for morality' (2012) 53(4) *The Heythrop Journal* 595.

¹⁵⁹ G Pennings 'Saviour siblings: using preimplantation genetic diagnosis for tissue typing' *International Congress Series* (2004) 1266 313.

¹⁶⁰ *Op cit* note 152 2.

¹⁶¹ Ibid 3.

¹⁶² Ibid.

¹⁶³ J Mills, *Understanding The position of the savior sibling: how can we save lives and protect savior siblings?* (Master of Arts Thesis Wake Forest University Graduate, 2013.) ix and xi.

However, the medical practitioner is compromised as the parent is giving assent detrimental to the wellbeing of the donor child.

2.3.2.1.1. Informed consent

On the same level of respecting the patients' right to self-determination, the notion of informed consent is a key facet of autonomy. As it is central to biomedical ethics, the principle requires ensuring that patients understand and give authorisation for the medical treatment or procedure they are to undergoing.¹⁶⁴

The issue of capacity is important for informed consent; this is determinable by the person's ability to express themselves, appreciate the information given to them and the consequences of the medical treatment and their decision on the life they desire to live.¹⁶⁵

Informed consent for medical interventions and treatment should be given voluntarily with no undue influence by the patient.¹⁶⁶ Where consent is given voluntarily, it is consistent with the right to self-determination and allows the patient to withdraw their consent if they are no longer comfortable with the process.¹⁶⁷

The creation of saviour siblings and using them as a donor for a sick sibling is not aligned with the objective of informed consent as the parents' consent to medical procedures on the child until the child is considered to have sufficient maturity.¹⁶⁸ Thus this threatens the saviour sibling's right to autonomy from the time that they are born as they must serve the needs of the sick sibling and cannot exercise their right to self-determination. The parents of saviour siblings have a conflict of interest in consenting to procedures on the saviour child, as they do so in the best interests of the sick sibling. Therefore, this morally disqualifies them as legitimate surrogate decision-makers of the saviour child.

Autonomy and informed consent also allow the child conceived as a saviour sibling to refuse to be a donor for the sick sibling.¹⁶⁹ The saviour sibling is subject to highly

¹⁶⁴ K Moodley. Medical ethics, law and human rights: A South African Perspective (2011) 43.

¹⁶⁵ Ibid 44.

¹⁶⁶ A Zúñiga-Fajuri 'Born to donate: proposals for "savior sibling" regulation in Latin America' (2018) 49(3) *Colombia Médica* 230.

¹⁶⁷ *Op cit* note 164 44-45.

¹⁶⁸ *Op cit* note 166 229.

¹⁶⁹ *Op cit* note 16.

invasive procedures,¹⁷⁰ not allowing the child to pursue self-determination and to consent to the body tissue withdrawn from them. Although the procedure may be necessary for the sick sibling, it is evident that it places the medical practitioner in a compromising position as they are obliged to ensure that a patient consents to procedures performed on them and that the medical procedure is in that patient's best interest. Neither of these factors is true in the case of the procedures performed on the saviour sibling.

2.3.2.2. Nonmaleficence

Central to biomedical ethics and in clinical practice is *nonmaleficence* as medical practitioners need to adhere to the principle to protect the patient, and it is one of the concerns when dealing with a saviour sibling.¹⁷¹ The principle of nonmaleficence is related to the term in medical ethics of *primum non-nocere*, which means "above all, do no harm." This principle used by medical professionals asserts an obligation on them not to intentionally cause harm to patients.¹⁷²

Harm is a violation of a person's interests¹⁷³ and is anything that affects the reputation, property or freedom of a person, physical and psychological wellbeing of that person.¹⁷⁴ This principle does not look at the arguments regarding the quality of life but requires weighing the benefits and burdens of treatments.¹⁷⁵ As noted above, the donation of tissue from the saviour sibling to the sick sibling is a harmful procedure, which violates the biomedical principles of ethics.

Harm includes several factors,¹⁷⁶ and it relates to an injury or damage to a person.¹⁷⁷ The creation of saviour siblings can cause psychological and physical harm to the saviour sibling.¹⁷⁸ The process of transplantation carries risks due to side effects of

¹⁷⁰ *Op cit* note 166 229.

¹⁷¹ G Rubies and F Steger 'Saving who? The ethical challenges of harvesting tissue from saviour siblings' 2019 (103) *European Journal of Haematology* 478.

¹⁷² T Beauchamp and JF Childress. *Principles of Biomedical Ethics* 4ed (1994) 189.

¹⁷³ *Ibid* 193.

¹⁷⁴ *Ibid*.

¹⁷⁵ *Op cit* note 172 189-190.

¹⁷⁶ MK Smith. *Saviour Siblings and the Regulation of Assisted Reproductive Technology: Harm , Ethics and Law* (2015) 108.

¹⁷⁷ *Ibid*.

¹⁷⁸ *Op cit* note 16.

the anaesthesia, which ranges from cardiorespiratory arrest, strokes, or chronic pain where the stem cells are withdrawn.¹⁷⁹

They are arguments that the procedure causes psychological harm to the saviour sibling as the medical procedures are ‘psychologically burdensome,¹⁸⁰ posing a threat to the wellbeing of the saviour child, despite using the intervention to save the life of their sibling.

The principle is used in the clinical practice and requires the medical practitioner to consider whether the harm inflicted on the saviour sibling exceeds the benefit of saving the sick child.¹⁸¹ Although the sick sibling’s deteriorating health may necessitate prioritization in treatment decision-making, it reduces the saviour sibling’s quality of life as they spend their childhood in the hospital which goes against the principle of nonmaleficence as there is an infliction of harm.¹⁸²

In applying the aforementioned to saviour siblings, using medical procedures on the saviour sibling as a donor for the sick sibling is intended to save the latter. However, there are potential risks of causing harm to the saviour sibling, which may cause adverse psychological effects to that child.

2.3.2.3. Beneficence

Beneficence is also central to biomedical ethics as it is one of the duties entrusted to a medical practitioner which requires the balancing of benefits, risks, and consequences of actions to a patient.¹⁸³ In medical practice, beneficence refers to an activity that is beneficial to a patient.¹⁸⁴ It affirms the duty to help others and the prevention of harm by weighing good against harm.¹⁸⁵ In the context of this dissertation, the patient to whom the principle of beneficence is applied is the saviour sibling, and the issue is whether the “harvesting” procedure is in the best interests of the saviour child.

¹⁷⁹ Ibid.

¹⁸⁰ I Riezzo *et al* ‘Donor selection for allogeneic hemopoetic stem cell transplantation: clinical and ethical considerations’ (2017) *Stem Cells International* 4.

¹⁸¹ *Op cit* note 16.

¹⁸² Ibid.

¹⁸³ *Op cit* note 172 260-261.

¹⁸⁴ Ibid 260.

¹⁸⁵ Ibid.

The creation of a saviour sibling to save the sick sibling does not yield a direct benefit for the former¹⁸⁶ as the transfusion process carries risks to the saviour child,¹⁸⁷ and is it thus not in the best interests of that child.

Therefore, the medical practitioner is placed in a compromising position, as the parents require them to save the sick sibling at the expense of the saviour sibling. In addition, the medical practitioner cannot ensure that treatment is beneficial for siblings with medical defects. There have been arguments that the saviour siblings might experience a positive psychological change as they may feel heroic in saving the sick sibling's life, thereby increasing their sense of pride, which might improve their quality of life.¹⁸⁸ However, this possible indirect benefit does not outweigh the harm they experience.

2.3.2.4 Justice

One of the essential principles of biomedical ethics is that of justice. At the core of the principle is fairness and equity in the treatment of people.¹⁸⁹ The procedure of creating a saviour sibling provides benefit by improving the health and wellbeing of the sick sibling; however, there are probable risks associated with the transfusion process.¹⁹⁰ The donation procedures do not seem to have any fairness on the part of the saviour sibling, as the procedures yield no health benefits for the saviour sibling.¹⁹¹

2.4 Summary

Given the preceding discussion, it is evident that the professional bodies do not guide medical practitioners on the ethical dimensions of performing procedures on saviour siblings, nor do they guide whether conceiving saviour siblings is acceptable or not. From the analysis of biomedical principles and the Hippocratic Oath, the creation of saviour siblings is ethically unacceptable as it violates the principles of biomedical ethics. Although saviour siblings are not in the position to give informed consent, it does not take away the fact that they are subjected to harm and to procedures that serve no benefit to them. The medical practitioner, guided by the biomedical principles,

¹⁸⁶ *Op cit* note 166 229.

¹⁸⁷ *Op cit* note 171 480.

¹⁸⁸ *Op cit* note 16.

¹⁸⁹ *Op cit* note 172 335.

¹⁹⁰ *Op cit* note 171 480.

¹⁹¹ *Ibid.*

should refuse to conduct such procedures based on the ethical norms espoused by the principles.

2.5 Major bioethical theories

2.5.1 Consequentialism

As a moral theory applied in the practice of medicine, consequentialism concerns itself with what is beneficial to a patient and supports treatments which will give the best result and not harm the patient.¹⁹² Consequentialism determines if the action is right or wrong by analysing the consequence of the action and actions are justifiable if they result in good.

Consequentialists are likely to argue that the best consequence is that the sick sibling obtains medical assistance through a donor to defeat their disease. A consequentialist would say that saving the ill child by having the saviour sibling as a donor is in the best interests of the family or the wellbeing of the family as the parents will not have the anxiety that their child will have a premature death.

The one form of consequentialism is the utilitarianism theory that holds that the rightness or wrongness of an act depends on the result of that act.¹⁹³ Utilitarianism holds that an action is right if it tends to yield the greatest net utility and that an action is good if it promotes the greatest happiness for the greatest number of people, and promotes welfare.¹⁹⁴ There are, however, various forms of utilitarianism but their unifying factor lies within the stance that the 'consequence' for the greatest number of people is the deciding principle when making judgments about rightness or wrongness, goodness or badness.

As utilitarianism is concerned with creating the greatest good for the greatest number, with a corresponding obligation to stop suffering and create happiness,¹⁹⁵ the principle creates a duty to ensure the assistance of the sick sibling to end the pain and suffering caused by the condition that they are suffering from, which will yield happiness for the family. The principle does not say that the minority should suffer at the expense of the majority. Building on the foundation laid by Bentham and refined by John Stuart Mill,

¹⁹² *Op cit* note 152 7.

¹⁹³ *Ibid*.

¹⁹⁴ J Mill *Utilitarianism, On Liberty, Essay on Bentham*(1962) 257.

¹⁹⁵ *Ibid* 8.

utilitarianism requires equal treatment of persons and holds that everyone as no one is entitled to better treatment than another person.¹⁹⁶

The saviour sibling donating bone marrow is an act of altruism and would bring happiness to the family when the sick child gets treatment; however, there is a commodification of the saviour child.¹⁹⁷ Most Christians have argued based on the utilitarian theory that it is wrong to have saviour siblings as the child that is conceived, utilised as a means to an end and not as an end in itself.¹⁹⁸ The aspect of the theory illustrates that creating saviour siblings is not morally acceptable.

The conceiving a saviour sibling to be a donor for the sick sibling is morally impermissible as there are aspects which raise the brow and require consideration as they purport not to support the use of the technology. A consequentialist or utilitarian approach to this issue is untenable as it is not in the best interests of the saviour child.

2.5.2 Deontology

The ethical theory deontology, derived from the Greek term *deon*, which means “duty.”¹⁹⁹ Deontology defines what is right and wrong based on the duty to respect and value the rights of patients and sets limitations on what a person may do while giving due recognition to the rights of persons.²⁰⁰ The theory requires individuals to act in line with certain principles despite the consequences derived from pure human reasoning free of emotions.²⁰¹ Hence, all actions are motivated by an obligation and well thought of before execution. In other words, actions are right if performed according to morality and or as an act of duty.

With Kant’s arguments borne in mind, it is worth noting that parents conceive children to fulfil specific purposes²⁰² ; however, the instrumentalization of a person who cannot consent has a connotation of exploitation.²⁰³ There is a need to respect persons and

¹⁹⁶ Ibid 9.

¹⁹⁷ C Berry and J Engel ‘Saviour siblings’ (2005) *Christian Medical Fellowship* 1.

¹⁹⁸ Ibid.

¹⁹⁹ *Op cit* note 195.

²⁰⁰ Ibid.

²⁰¹ Kantian Duty Based (Deontological) Ethics available at <https://sevenpillarsinstitute.org/kantian-duty-based-deontological-ethics/> accessed 13 March 2017.

²⁰² *Op cit* note 197 2 .

²⁰³ G Pennings ‘Saviour siblings: using preimplantation genetic diagnosis for tissue typing’ *International Congress Series* (2004) 1266 312.

not to reduce them as a means to an end.²⁰⁴ Although the theory does not speak about saviour sibling, in considering the circumstances in such cases, it is evident that conceiving and using the saviour sibling to be a donor goes against the theory of deontology. The theory of deontology does not prohibit the use of the technique, as it is silent on the issue.

There have been arguments that saviour siblings will not be used as a means to an end as people living in society serve the society in numerous ways and valued for their abilities and talents, and they will also be an end as they would be able to live their lives and each life is important and of intrinsic value.²⁰⁵ Deontology states that persons not be reduced and used as a means to an end.²⁰⁶ The principle should not be interpreted as meaning that a person should not be used as a means, but states that a person should not be used solely as a means.²⁰⁷ In light of a saviour sibling, a medical practitioner will find it challenging to argue that their actions of 'harvesting' the saviour child is a respectful and good action, and will be beneficial to that child. Therefore, the procedures performed on the saviour child are not justifiable on deontological grounds.

2.6 Other ethical concerns

There have been other ethical concerns raised with regards to saviour siblings. Firstly, there has been criticism that the creation of a saviour child will create a slippery slope and used for selecting nonmedical traits, adversely affecting biodiversity and uniqueness.²⁰⁸

Moreover, there are arguments that parents who have used this technique have given love and shown affection to the saviour sibling. However, it has also argued been that the parents are more interested in the child donating and the period spent in creating the saviour sibling.²⁰⁹

Some argue that there is no obligation to conceive saviour siblings; therefore, the latter must be grateful that they exist.²¹⁰ This argument falls short in the case of saviour

²⁰⁴ Ibid 312 -313

²⁰⁵ Ibid.

²⁰⁶ Ibid 312 -313.

²⁰⁷ Ibid 313.

²⁰⁸ El Touskhy *et al* 'Ethics:The ethics of pre-implantation diagnosis' (2008) 10(49) 51.

²⁰⁹ *Op cit* note 159.

²¹⁰ Ibid.

siblings as the parents conceive the child to be a donor, and one cannot be content for their existence if there is their exploitation.

An argument levelled against the creation of a saviour sibling is that parents should not create the child that they want but should accept the child that they fortuitously get.²¹¹ Those who argue for the acceptance of creation of a saviour sibling assert that having a child designed for a specific purpose should not be a problem as life is lived as a design, with people choosing the lifestyles they want to their family to lead. Includes selecting values, religious beliefs and the schools to which children attend.²¹²

There have been concerns that the medical technologies can pose several risks which can result in the child not fulfilling the purpose for which they were born.²¹³ There is also fear that when a child cannot provide the required tissue, the child could have a problem in having the parents accept them.²¹⁴

There is a concern that a saviour sibling might find it burdensome to have repeatedly donated their tissues to sick sibling all their life.²¹⁵ In addition, there are concerns that the creation of saviour siblings might give rise to slippery slopes where parents might want to use the procedure for sex selection.²¹⁶

Moreover, the issue of creating saviour siblings has received criticism in that it puts the doctors in an awkward situation as doctors are responsible for selecting the donor and providing care to the sick sibling, and the doctor is unduly influenced as they derive a financial gain in the situation.²¹⁷

Furthermore, there have been concerns raised by opponents of the procedure in that the procedure does not allow nature to take its course as they have associated the procedure with parents "playing God."²¹⁸

²¹¹ Ibid

²¹² Ibid.

²¹³ *Op cit* note 16.

²¹⁴ *Op cit* note 197 2.

²¹⁵ Ibid 1.

²¹⁶ Ibid.

²¹⁷ *Op cit* note 180 4.

²¹⁸ *Op cit* note 6 226.

Lastly, there are also concerns that parents would not love the saviour sibling in their own right.²¹⁹ The saviour sibling may view their existence as conditional as they may have attributes that may save the sick sibling, therefore feeling inferior and as a 'subordinate' to the ill sibling.²²⁰

2.7 Conclusion

As noted above, professional bodies that govern professionals involved in the field of assisted reproduction do not provide any guidance for the creation and use of saviour siblings. However, if one considers this issue from an ethics perspective, and the application of the biomedical and ethical principles, it demonstrates that it is unethical for a health practitioner to assist in the conceiving a child to be a saviour sibling, and unethical to perform harvesting procedures on a saviour sibling after their birth as the procedure is not therapeutic or beneficial for the saviour child. The surrogate consent provided by the parents is inappropriate as they are conflicted in their decision-making.²²¹ Accordingly, the rendering of professional services on the part of the health practitioner to create a saviour sibling and to 'harvest' that child for the benefit of their sick sibling, is unethical.

²¹⁹ M Lotz 'Procreative reasons-relevance: the moral significance of why we have children' (2009) 23(5) *Bioethics* 296

²²⁰ *Ibid.*

²²¹ *Op cit* note 166 230.

CHAPTER 3: THE PROTECTION OF SAVIOUR SIBLINGS IN INTERNATIONAL AND REGIONAL INSTRUMENTS

3.1 Introduction

Chapter 1 illustrated that South African law does not provide regulation for saviour siblings. This chapter will discuss the core treaties that protect children, namely the United Nations Convention on the Rights of the Child and the African Union Charter on the Rights and Welfare of the Child. In addition, the chapter will discuss the essential treaties in bioethics being the Universal Declaration on Bioethics and Human Rights and the Convention on Human Rights and Biomedicine of the European Union. The chapter will discuss these treaties in relation to saviour siblings, with a focus on whether any of these norms can guide the legislative approaches to saviour siblings at a domestic level.

3.2. The United Nations Convention on the Rights of the Child, 1989

The United Nations adopted the Convention on the Rights of the Child on 20 November 1989, and it came into effect on 2 September 1990.²²² Five years later South Africa ratified the Convention on 16 June 1995.²²³ The Convention is the first international human rights treaty to enshrine the civil and political rights as well as the economic, social and cultural rights of the child in one document.²²⁴ It is the only legally binding treaty that sets out the protected rights for children.²²⁵

The Convention considers children as the bearers of human rights²²⁶ and protects children below eighteen years of age unless the law of a country set the age at less than eighteen years.²²⁷ The Convention is premised on four principles, viz, the right to non-discrimination; the best interests of the child; the child's right to life; survival and development; and having respect to the views of the child.²²⁸ The principles are discussed below in light of saviour siblings.

²²² United Nations Convention on the Rights of the Child
<https://www.ohchr.org/en/professionalinterest/pages/crc.aspx> accessed 12 January 2020.

²²³ United Nations Convention on the Rights of Child 1989 1.

²²⁴A Parkes *Children and International human rights law* (2013) 1.

²²⁵ Ibid.

²²⁶Ibid 5.

²²⁷ Article 1 United Nations Convention on the Rights of the Child 1989.

²²⁸ *Op cit* note 224 6-7.

3.2.1 Best interests of the child

The Convention addresses the principle in Article 3, which stipulates that the best interests of children must be the 'primary concern' in decision-making all matters affecting the child in question.²²⁹ The principle requires adults to consider the best interest of the children and whether their decisions will affect the child, and this includes decisions for medical treatment.²³⁰ Some argue that the procedures saviour siblings are subject to are not in their best interests because the procedures are not beneficial to them and have inherent risks.²³¹

The principle further addressed in the General Comment No 14, interprets the words 'shall be a primary consideration' to mean that when states adopt policies, they do not have the discretion to decide whether the rights of the child should be taken into consideration.²³² The General Comments state that the rights of the child should not be considered with equal weight as other considerations,²³³ and where the best interests of the child conflict with other rights, the best interests ought to take priority.²³⁴

Although parents have to look out for the best interests of the sick sibling, the use of the saviour sibling as a donor is not in their best interests as they are subjected to risky procedures.²³⁵ It is a submission that the saviour child's best interests should take preference over the parent's surrogate consent.

3.2.2 Right to life, survival and development

Article 6 of the Convention provides children with the right to life, survival and development as it states that governments need to ensure that children's survival and development is protected.²³⁶ The section provides all children with a better quality of life by providing the best attainable health from the time they are born.²³⁷ The difficulty with this right is that it gives rise to competing interests as it affords both the saviour sibling and the sick child the right to life obtainable through the best attainable. However, subjecting the saviour sibling to procedures that are risky and may cause

²²⁹ Article 3 United Nations Convention on the Rights of the Child.

²³⁰ *Op cit* note 224 28.

²³¹ *Op cit* note 166 230-231.

²³² United Nations Convention on the Rights of the Child General Comment No. 14 10.

²³³ *Ibid*.

²³⁴ *Ibid*.

²³⁵ *Op cit* note 166 233.

²³⁶ *Op cit* 173 Article 6.

²³⁷ *Op cit* note 171 480.

bone, nerve and tissue injury.²³⁸ There are risks associated with the blood transfusions, although Rubies and Steger argue that the chances of complications arising are considerably low.²³⁹ The greater risk is that the development of the saviour sibling as an individual may be compromised when they learn that they were born for the benefit of another person; this may have a long term impact on their psychological wellbeing.²⁴⁰

3.2.3 Rights of children to child participation and to have their views heard

The Convention on the rights of the child allows children to take part in decision making, as seen Article 12. The article requires states to consider the opinions of children and involve them in decision making in matters affecting them; however, this depends on whether the child has sufficient maturity.²⁴¹ The General Comments No.14²⁴² requires states to consider the child's evolving capacity and recognises their ability to speak for themselves when deemed to have sufficient maturity.²⁴³

General Comment 20 affords adolescents the right to be heard as they are at a stage where they gain understanding and maturity.²⁴⁴ The right is essential when dealing with saviour siblings as they are unable to consent to the procedures from the time they are born.²⁴⁵

From the analysis of this article, saviour siblings can only decide against the procedure if they are adolescents, and are of sufficient maturity. It is submitted that when younger and immature children and subjected to such medical procedures, parents violate the children's rights.

3.2.4 Right to dignity

The right to dignity is interpreted to mean that humans are inviolable and cannot be sacrificed, like saviour siblings.²⁴⁶ With regards to saviour siblings, we are confronted with a situation where a child is born not because their parents wanted to conceive

²³⁸ Ibid.

²³⁹ Ibid

²⁴⁰ S Sheldon and S Wilkinson 'Should selecting saviour siblings be banned?' (2004) 30(6) *Journal of Medical Ethics* 533.

²⁴¹ *Op cit* note 116 230.

²⁴² *Op cit* note 183 1.

²⁴³ *Op cit* note 175 41.

²⁴⁴ United Nations Convention of the Rights of the Child General Comments No.20 on the implementation of the rights of the child during adolescence 7.

²⁴⁵ *Op cit* note 171 480.

²⁴⁶ *Op cit* note 166 232.

them,²⁴⁷ but to use them as instruments. The procedures saviour siblings undergo to carry several health risks, including complications caused by anaesthesia when performing biopsies in surgery; bone, nerve and tissue injury as a result of bone marrow extraction.²⁴⁸ Moreover, not only is the needle used to extract bone marrow from the pelvic bone painful,²⁴⁹ there are blood transfusion risks.²⁵⁰

Using a saviour sibling as a donor, a child comprises their dignity,²⁵¹ and is contrary to Article 19, as it requires the protection of children from all forms of violence.²⁵² Moreover, subjecting the child to such procedures affects the child physically and psychologically; it goes against Article 27, which provides that children have the right to an adequate standard of living to meet their physical and mental needs.²⁵³ It is a submission that a procedure that affects the saviour sibling psychologically does not meet their cognitive needs.

Furthermore, the procedures are contrary to General Comment No.14, as it requires children to be raised in an environment that promotes their human dignity to ensure they have an opportunity for holistic development.²⁵⁴ Although using the saviour sibling as a donor may be beneficial for the sick child, the procedure exposes the child to medical risks and harm. For this reason, this goes against the child's right to dignity and does not foster an environment for their holistic development.

3.3 The African Union Charter on the Rights and Welfare of the Child 1990

The African Union Charter on the Rights and Welfare of the Child is a regional charter, for the African continent.²⁵⁵ The African Union adopted the Charter on 11 July 1990, and it came into effect on 29 November 1999.²⁵⁶ It was ratified by South Africa on 7

²⁴⁷ *Op cit* note 30 671.

²⁴⁸ *Ibid* note 171 480.

²⁴⁹ I Sample. What risks do saviour siblings face? 10 March 2005

<https://www.theguardian.com/science/2005/mar/10/thisweekssciencequestions1> accessed 30 January 2020.

²⁵⁰ *Op cit* note 171 480.

²⁵¹ M Spriggs 'Is conceiving a child to benefit another in the best interests of the new child?' 2005 31(6) *Journal of Medical Ethics* 342.

²⁵² Article 19 United Nations Convention on the rights of the Child.

²⁵³ *Ibid* Article 27.

²⁵⁴ United Nations Convention of the Rights of the Child General Comments No.14 on the right of the child to have his or her best interests taken as a primary consideration 11.

²⁵⁵ D Olowu 'Protecting children's rights in Africa: A critique of the African Charter on the Rights and Welfare of the Child' (2002) 10 *The International Journal of Children's Rights* 130.

²⁵⁶ African Charter on the Rights and Welfare of the Child.

January 2000.²⁵⁷ The Charter establishes a child's rights framework in the same way as the Convention on the Rights of the Child.²⁵⁸ The Charter is based, like the Convention, on four principles for its interpretation. These include non-discrimination in Article 3, best interests of the child in Article 4, the right to life, survival and development in Article 5 and respect for the views of the child in Article 4(2).

Similarly to the United Convention on the Rights of the Child, the Charter applies to children below eighteen years of age.²⁵⁹ However, the African Charter on the Rights and Welfare of the Child does not limit when a person considered to be a child, as different countries have different legislation for when a person is considered a child.²⁶⁰ The implication of this is that even if they are older than eighteen, a person may be considered a child. According to the Charter, a saviour sibling may be a donor, even when they are over eighteen years of age.

3.3.1 The best interests of the child

Similarly, to the Convention of the Rights of the Child, Article 4(1) of the African Union Charter on the Rights and Welfare of the Child provides that the best interests of the child must be the primary consideration.²⁶¹ Although the wording is different, the principle is just as important as it is in the Convention. However, the African Union Charter on the Rights and Welfare of the Child uses a 'definitive' article and making it a firmer requirement,²⁶² giving children like saviour siblings better protection. The African Union Charter on the Rights and Welfare can cater for saviour siblings in the African continent but would require the consideration of the best interests of the child.

3.3.2 Right to life, survival and development

Similarly, to the Convention on the Rights of the Child, the Charter in Article 5 provides for the right to life. The right has two aspects; the first aspect is that "every child has an inherent right to life."²⁶³ Moreover, the second component places an obligation on states to ensure children are provided survival, protection, and development to the

²⁵⁷J Heaton and H Kruger *South African Family Law* 4ed (2015) 297.

²⁵⁸*Op cit* note 255 128.

²⁵⁹ Article 2 The African Union Charter on the Rights and Welfare of the Child.

²⁶⁰ O Ekundayo 'Does the African Charter on the Rights and Welfare of the Child (ACRWC) only Underlines and Repeats the Convention on the Rights of the Child (CRC)'s Provisions?: Examining the Similarities and the Differences between the ACRWC and the CRC' (2015) 5(7)(1) *International Journal of Humanities and Social Science* 149.

²⁶¹ *Op cit* note 260.

²⁶²*Op cit* note 261 149-150.

²⁶³*Ibid* Article 5(1).

'maximum extent possible.'²⁶⁴ The Article requires states to have adequate measures to protect children's rights and interests. The right to life and survival can be interpreted in a broad sense to include physical health, emotional, and mental development.²⁶⁵ Therefore, regarding saviour siblings, the Article places an obligation on states to implement legislation that will not only provide children with the right to life but also foster their development.

3.3.3 Rights of children to participate and to have their views heard

Similarly, to the United Nations Convention on the Rights of the Child, the African Charter provides children with the right to express their views, even though children have limited capacity to consent. Article 7 provides for the right and stipulates that "every child capable of communicating his or her own views shall be assured the right to express his or her opinions freely in all matters and to disseminate his opinions subject to such restrictions as are prescribed by laws."

This section also gives the saviour siblings the right to express themselves when they no longer want to be a donor; however, the stage of this depends on whether state law considers them to be adequately mature.

3.3.4 Right to dignity

Lastly, the African Union Charter on the Rights and Welfare of the Child values the dignity of children as it is the underlying principle of the Charter. One sees the importance of the principle in the preamble which outlines that states ought to have due regard for the child's needs to foster physical and mental development and recognise the child's right to human dignity.²⁶⁶

3.3.5 Summary of the discussion

The United Nations Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the child are silent on whether they apply to saviour siblings. They recognise that children are holders of rights from the time they are born, but do not deal with the rights of the unborn child.²⁶⁷ The Convention and the Charter only deal with broad rights of the child, which can be interpreted to apply and protecting

²⁶⁴ Ibid Article 5(2).

²⁶⁵ *Op cit* note 255 128.

²⁶⁶ Preamble of the African Union Charter on the Rights and Welfare of the Child.

²⁶⁷ *Op cit* note 255 131.

saviour siblings. They safeguard the welfare of the child²⁶⁸ and state that the best interests of the child are of prime importance in all matters concerning the child.²⁶⁹

3.4 Bioethics Conventions

The right to health is an integral part of international and regional law.²⁷⁰ The bioethics treaties²⁷¹ such as the Convention on Human Rights and Biomedicine, the United Nations Educational, Scientific and Cultural Organization's Universal Declaration on Bioethics and Human Rights and the Oviedo Convention deal with the right.

3.4.1 Universal Declaration on Bioethics and Human Rights

The Universal Declaration on Bioethics and Human Rights was adopted by the United Nations Educational, Scientific and Cultural Organization on 19 October 2005.²⁷² The aim of the Organization [sic] was to provide a framework to guide states when drafting legislation and policies in bioethics to protect human rights and preserve human dignity.²⁷³

The Declaration on Bioethics and Human Rights was issued to set out universal norms for bioethics and human rights,²⁷⁴ as it governs the application of medical interventions on humans internationally, regionally and nationally.²⁷⁵ Although the declaration's norms do not bind states or deal with saviour siblings, it has core principles that can apply to saviour siblings.

3.4.1.1 Human Dignity

In compliance with the United Nations Convention on the Rights of the Child and African Charter in the Rights and Welfare of the Child, Article 4 of the Declaration on Bioethics and Human Rights provides that benefits should be 'maximised', and harm 'minimised in applying medical practice and related technologies.'²⁷⁶ In applying Article

²⁶⁸ Ibid 135.

²⁶⁹ Ibid 129.

²⁷⁰ J Brännmark 'Respect for Persons in Bioethics: Towards a Human Rights-Based Account' (2017) 18 *Human Rights Review* 171.

²⁷¹ Ibid.

²⁷² A Gercas 'The Universal Declaration on Bioethics and Human Rights: Promoting international discussion on the morality of non-therapeutic research on children' (2006) 27(2) *Michigan Journal of International Law* 630.

²⁷³ Ibid 636.

²⁷⁴ Ibid 630.

²⁷⁵ Ibid.

²⁷⁶ Article 4 Universal Declaration on Bioethics and Human Right 2005.

4, it is evident the saviour sibling gains nothing from the procedures as they cause 'unnecessary pain' and harm them, therefore maximizing harm.

Moreover, Article 5 requires the autonomy of a person to be respected and for those who can not exercise their autonomy measures must be implemented to protect their rights and interests.²⁷⁷

Article 6 requires obtaining informed consent before conducting any therapeutic or diagnostic procedure and the individual provided with relevant information about the procedure. The article allows withdrawing consent at any stage;²⁷⁸ however, with saviour siblings, this is not the case as they are born to serve as a donor, and the parents make the decisions.

3.4.1.2 The Best Interests of the Child

The best interest of the child is equally important in the Universal Declaration on Bioethics and Human Rights as the other instruments. The Declaration states that where a person is unable to give consent, like minors, there should be the consideration of domestic law, and obtain authorisation in line accordance with the domestic law in the best interest of the individual.²⁷⁹

The Declaration protects saviour siblings in Article 8, which requires the consideration of the vulnerability of the persons involved in medical interventions and their integrity to be respected.²⁸⁰ In promoting the best interests of children, the declaration requires children to be involved in decision-making.²⁸¹ It is not the case with saviour siblings, as parents are worried about the health of the ill sibling.

3.4.2 The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine²⁸²

²⁷⁷ Ibid Article 5.

²⁷⁸ Ibid Article 6 .

²⁷⁹ *Op cit* note 274 630.

²⁸⁰ *Op cit* note 278 Article 8.

²⁸¹ Ibid note 274 638.

²⁸² The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine 4.IV. ETS No 164.

The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine was adopted by the Parliamentary Assembly of the European Council on 19 November 1996 and opened for ratification by states in Oviedo, Spain on 4 April 1997.²⁸³

The Oviedo Convention is the only international legally binding instrument which protects the human rights of human beings in biomedicine.²⁸⁴ The treaty is binding on member states of the European Union for biomedical issues²⁸⁵ and developed to ensure that biomedicine is not misused as it affects the human dignity of individuals.²⁸⁶ The fundamental principle of the Convention is human dignity; therefore, it aims to protect the identity of human beings,²⁸⁷ respect the integrity of persons together with other rights stipulated in the Convention.²⁸⁸

The Convention sets out essential principles applicable in the general practice of medicine and also deals with genetics and transplantation of organs and tissues. Although the Oviedo Convention only applies in Europe,²⁸⁹ it is the only biomedicine treaty relevant to the context of this dissertation.

3.4.2.1 Human dignity

The Convention also gives human dignity considerable weight, as Article 1 provides protection of human dignity for all in the application of medical procedures and interventions.²⁹⁰

Furthermore, Articles 5 to 9 require obtaining of informed consent a person before performing any biomedical intervention, and that they must understand the purpose, nature and risks of the treatment.²⁹¹

²⁸³ R Ardorno 'The Oviedo Convention: A European Legal Framework at the Intersection of Human Rights and Health Law' (2005) 2(4) *Journal of International Biotechnology Law* 133.

²⁸⁴ Oviedo Convention available at <https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164> accessed 28 November 2017.

²⁸⁵ *Op cit* note 285.

²⁸⁶ *Op cit* note 284 1.

²⁸⁷ *Ibid* 2.

²⁸⁸ *Ibid*.

²⁸⁹ T Goofin *et al* 'Why eight EU Member States signed, but not yet ratified the Convention for Human Rights and Biomedicine' 2008 86 *Health Policy* 229.

²⁹⁰ *Op cit* note 285 137.

²⁹¹ *Ibid* 138.

The articles require providing an individual is with all relevant information about the intervention, the purpose, and its implications.²⁹² The articles also require that informed consent to be given without coercion or undue influence.²⁹³ It is not the case with saviour siblings, as they are subjected to procedures when they are very young.

Although children cannot give consent to medical treatment, the Convention protects minors as Article 6(3) and provides that minors should be allowed to express their opinions; however, with the consideration of their age and maturity.²⁹⁴ Article 6(5) provides for the withdrawing consent, although this may be relevant for the saviour sibling,²⁹⁵ it will depend on their capacity to give consent.

Lastly, the Convention requires respecting people in the promotion of dignity, and this is evident in Article 10 that every individual has the right to private life, and expects everyone to respect information about their health. According to the provision, the saviour sibling would have the right to know the reason for subjecting them to the procedures.

3.4.2.2 The best interests of the child

Although the Oviedo Convention does not refer to the child, Article 2 states that the welfare of humans should prevail over society's and science's interests,²⁹⁶ it incorporates the best interests of the child. The Oviedo Convention has children's interests at heart, as Article 14 permits the use of preimplantation genetic diagnosis when they are susceptible to genetic diseases.²⁹⁷ However, it does not state what should happen if there is a violation of the saviour sibling's rights.

3.5 Conclusion

In conclusion, it is not clear whether international norms cover saviour siblings. It is, however, evident that, as seen in the United National Convention on the Rights of Children, the international standards recognize the rights of children and advocates for their protection.²⁹⁸

²⁹² *Op cit* note 285.

²⁹³ *Ibid* 2.

²⁹⁴ *Op cit* note 284 3.

²⁹⁵ *Op cit* note 284 Article 6(5) 2.

²⁹⁶ *Op cit* note 285 137.

²⁹⁷ *Ibid* note 284 4.

²⁹⁸ SO Oladiji *The Role of international, regional and domestic standards in monitoring children's rights*. (LLM Dissertation University of South Africa, 2012) 1.

Moreover, the African Union Charter on the Rights and Welfare of the Child has a 'striking' similarity with the United Nations Convention on the Rights of Children in the framing children of the rights,²⁹⁹ where both denote the essential principles such as human dignity, to regard the best interests of the child, the right to survival and development, and the right to participate in all decisions affecting them.

The treaties require the protection of children against practices that affect their psychological, physical, and mental development. Furthermore, the treaties illustrate that the wellbeing of children is vital for the child's development. Therefore, it is evident that the international treaties cannot justify subjecting a child to painful procedures on behalf of another, as in the case of saviour siblings. The norms alluded to in the Universal Declaration on Bioethics and Human Rights, and the Oviedo Convention requires the protection of children's dignity in all medical interventions.

Moreover, these bioethics conventions require that in medical procedures, there is the prevention of harm and that medical procedures should be beneficial and in the best interests of the child. Arguably, subjecting a child to procedures as a saviour-sibling is not consistent with the requirements of the bioethics conventions.

²⁹⁹ Ibid.

Chapter 4: SOUTH AFRICAN LEGISLATION IN RELATION ON THE CREATION OF SAVIOUR SIBLINGS

4.1. Introduction

In other jurisdictions, the creation of saviour siblings using preimplantation genetic diagnosis is regulated, as will be seen in Chapter 5. This chapter investigates whether South Africa provide adequate regulation for the creation of saviour siblings.

4.2. Constitution of the Republic of South Africa, 1996

The dignity of the child is a concern in cases involving saviour siblings, as seen in Chapter 3. The right to dignity, provided for in section 10, is a fundamental right within the Constitution³⁰⁰ and is considered critically important in South Africa as held in *S v Makwanyana*,³⁰¹ where the court held that right is the 'intricately' connected to other rights.³⁰²

Human dignity is a value underlying the Constitution,³⁰³ that protects everyone's right to human dignity as it states that "everyone has inherent dignity and the right to have their dignity respected and protected."³⁰⁴ The right to dignity entails recognising people's intrinsic value and treating people with equal respect.³⁰⁵

It incorporates respecting one's autonomy, and afforded to all persons, including children.³⁰⁶ The saviour siblings have the right to human dignity,³⁰⁷ even when they lack the legal capacity for consent. It is a submission that it is not respecting the saviour sibling's intrinsic worth if they are subjected to bone marrow and blood transfusion procedures that are associated with risks, and are of no benefit to the saviour sibling.³⁰⁸

³⁰⁰ S Soni. 'Prêt-à-Porter Procreation: Contemplating the Ban on Preimplantation Sex Selection' (2019) 22 *PER / PELJ* 15.

³⁰¹ 1995(3) SA 391(CC).

³⁰² I Currie and J De Waal *The Bill of Rights Handbook* 6ed (2016) 620.

³⁰³ R Steinman 'Law and Human dignity at odd over assisted suicide' (2015) 558 *De Rebus* 25.

³⁰⁴ W Ganya *et al* 'Autonomy of the child in the South African context: is a 12 year old of sufficient maturity to consent to medical treatment?' (2016) 17(66) *BMC Medical Ethics* 5.

³⁰⁵ *Ibid.*

³⁰⁶ *Op cit* note 304 5.

³⁰⁷ *S v M* (Centre for Child Law as Amicus curiae) 2008(3) SA 323(CC) para 18.

³⁰⁸ A Lai 'To be or not to be my sister's keeper: a revised legal framework safeguarding savior sibling's welfare' (2011) 32 *The Journal of legal medicine* 267.

Notably, in the case of saviour siblings, the parents' rights appear to supersede that of the saviour sibling as indicated in Chapter 2 and Chapter 3 as they exercise their parental responsibility to the detriment of the saviour siblings. However, this would not be the case in South Africa as section 12 provides for right the freedom and security of the person:

(2) Everyone has the right to bodily and psychological integrity, which includes the right— (a) to make decisions concerning reproduction; (b) to security in and control over their body; (c) not to be subjected to medical or scientific experiments without their informed consent.

From the section noted by Du Plessis, children are the bearers of rights and have the right to bodily and psychological integrity in terms of section 12.³⁰⁹ Section 12(b) assumes that persons are able and equipped to make decisions.³¹⁰ Whether or not all children can make decisions will be discussed in the section below on the Children's Act.

Although section 12 applies to children, it equally applies to the mothers, as it affords the autonomy to make reproductive choices.³¹¹ This right includes deciding whether or not to conceive children, and whether or not to conceive children for any reason.³¹² Section 12 gives women the autonomy to create a saviour sibling to save a child in ill health.

The last right relevant to this scenario is section 28(1)(c), which provides for the right to basic health care services for children.³¹³ Section 28(2) provides that "a child's best interests are of paramount importance in every matter concerning the child."³¹⁴ Accordingly, parents must ensure that they are acting in the best interests of the child in health-related matters.³¹⁵ However, it is not in the best interests of the saviour siblings when they undergo procedures harming their physical and psychological health.

³⁰⁹ E du Plessis *et al* 'The Constitutional rights of children to bodily integrity and autonomy' (2014) 35(1) *Obiter* 3

³¹⁰ *Ibid* 4.

³¹¹ *Op cit* note 6 226.

³¹² *Ibid*.

³¹³ *Supra* note 49, S28(1)(c).

³¹⁴ *Supra* note 49, S28(2).

³¹⁵ *Op cit* note 308 15.

The principle of best interests of the child has been dealt with in several cases, including *Fletcher v Fletcher*,³¹⁶ which established the principle where the Appellant Division held that the principle is not a factor in custody matters, it is a "paramount and overruling factor" in all matters concerning a child.³¹⁷

In addition, in *S v M (Centre for Child Law as Amicus curiae)*,³¹⁸ the court held the best interests of the child should protect and advance the rights of the child,³¹⁹ and that principle is a guideline in all matters affecting the child.³²⁰

In Minister of Welfare and Population Development v Fitzpatrick,³²¹ although decided before the latter case, the court held that principle is not merely a guiding principle, but must be understood to be a stand-alone right that needs protection at all times.³²²

For this reason, in the case of saviour siblings, the parties involved must be mindful that the best interests of the child principle is a paramount right, and must serve as a guide in all matters affecting the child. The parents of the saviour siblings will have to have this principle borne in mind.

4.3 Children's Act, 38 of 2005

In assessing the regulation of saviour siblings, it is essential to look at the Children's Act.³²³ The purpose of the Act is to supplement and give effect to children's rights as stipulated in the Bill of Rights of the Constitution,³²⁴ whilst promoting and protecting the wellbeing of the children.³²⁵ The best interests of the child standard, provided for in section 9,³²⁶ is one of the underlying principles of the Children's Act, which stipulates that:

in all matters concerning the care, protection and well-being of a child the standard that the child's best interest is of paramount importance must be applied.

³¹⁶ 1948 (1) SA 130(A).

³¹⁷Z Sisilana *The best interests of the child; a critical evaluation of how the South African court system is failing to use section 7 of the Children's Act accordingly in divorce proceedings* (LLM Dissertation, University of Cape Town, 2016) 17.

³¹⁸ 2008(3) SA 323 (CC).

³¹⁹ *Supra* note 322 para 15.

³²⁰ *Ibid* para 14.

³²¹ 2000 (3) SA 422 (CC).

³²² *Op cit* note 306 620.

³²³ *Supra* note 7.

³²⁴ *Supra* note 49.

³²⁵ *Op cit* note 313 7.

³²⁶ *Supra* note 7, section 9.

Section 6(2)(a) of the Act, requires that all actions or decision-making concerning a child must promote and respects a child's right and best interests standard in conjunction with the factors set in section 7.³²⁷ Section 7 lists the factors for consideration in determining what is in the best interests of the child. Nevertheless, this assessment is dependent on the facts of each case.³²⁸ Justice Sachs in *S v M* held that the factors are endless and therefore, not making the list exhaustive.³²⁹ Thus one is justified in considering whether the decision to make the child a donor and donation have a therapeutic effect on the saviour sibling. The ultimate objective of medicine is to conduct procedures on patients that are beneficial and to treat and cure the diseased.³³⁰ However, subjecting saviour siblings to such medical procedures that do not serve this purpose.

It has been established that the saviour siblings are subjected to medical procedures that are not in their individual best interests, as the procedures serve no therapeutic purpose for them and are risky.³³¹ Other than medical procedures having a therapeutic benefit, the patient's informed consent is required.³³² However, it is not the case in the case of saviour siblings, as the parents give surrogate consent from the time they are born.³³³

Furthermore, the Children's Act does not deal with saviour siblings or their consent to medical treatment, in section 129 of the Act.³³⁴ However, it does considers the use of assisted reproductive technologies for surrogacy and other purposes.

Despite the omission of not referring to saviour siblings where consent is an issue. Section 129(2) and 129(5) stipulate the requirements of consent to medical treatment for children; however, this applies to children over the age of twelve years, as provided below:

A child may consent to his or her own medical treatment or to the medical treatment of his or her child if- (a) the child is over the age of 12 years; and (b)the child is of sufficient maturity

³²⁷ *Supra* note 7, S6(2).

³²⁸ *Op cit* note 257 172.

³²⁹ *Supra* note 322 para 24.

³³⁰ *Op cit* note 166 231.

³³¹ *Ibid* note 204.

³³² *Op cit* note 166 230.

³³³ *Ibid*.

³³⁴ *Op cit* note 308 2.

and has the mental capacity to understand the benefits, risks, social and other implications of the treatment. The parent or guardian of a child may, subject to section 31, consent to a surgical operation on the child if the child is – (a) under the age of 12 years; or, (b) over that age but is of insufficient maturity or is unable to understand the benefits, risks and social implications of the operation.

Where a child is less than twelve years of age, according to Section 129(4) of the Children's Act, parents give consent on behalf of the child.³³⁵ Therefore, in the case of saviour siblings, it is a form of assault where they are not able to consent.³³⁶ This is because they can give consent only if they are above the age of twelve years, where they illustrate the appropriate maturity.³³⁷ However, the Act does not state how a medical practitioner ought to assess whether the child has sufficient maturity to make decisions for medical treatment.³³⁸

Although the parents make the decisions on behalf of the children, they are limited by the Act, as they can only make decisions that are in the best interests of the child, especially where the child is under the age of twelve and cannot give informed consent.³³⁹ Moreover, the Act recognises the evolving capacity of children, allowing them to voice their opinions on matters concerning them; therefore, parents need to take cognisance of this.³⁴⁰ Section 31³⁴¹ stipulates that before decisions are made, the 'views and wishes' of a child should be taken into account, especially if it will adversely affect their health.³⁴² The section is supported by section 10 of the Children's Act,³⁴³ which stipulates that:

every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration.

It is submitted that saviour siblings can voice their opinions if they do not wish to participate in the procedure, as the use of the words any 'matter' in section 10 has

³³⁵ *Supra* note 7 Section 129(4).

³³⁶ *Op cit* note 313 8.

³³⁷ *Ibid*.

³³⁸ *Op cit* note 308 3.

³³⁹ *Op cit* note 313 9

³⁴⁰ *Op cit* note 308.

³⁴¹ *Supra* note 7.

³⁴² *Op cit* note 313.

³⁴³ *Supra* note 7, section 10.

been interpreted by Du Plessis to include related to health matters.³⁴⁴ However, based on the discussion above, this will only be when the child is over the age of twelve.

The rights protected by the Act are established, and it is worth determining whether the Act covers the procedure used to create saviour siblings. The Act refers to medical and surgical treatment; however, it is not clear whether it encompasses the reproductive procedures used to extract bone marrow or tissues from saviour siblings.³⁴⁵ The Children's Act has received criticism for its deficiency as it fails to stipulate what can be considered medical treatment, or surgical treatment, respectively.³⁴⁶

Lastly, another deficiency observed in the Act is that it remains silent on the use of preimplantation genetic diagnosis.³⁴⁷ However, the silence cannot be interpreted, as the Children's Act prohibiting the use of the procedure.³⁴⁸ For this reason, the discussion below will establish whether South Africa provides regulation through the National Health Act.³⁴⁹

4.4 The National Health Act 61 of 2003

The purpose of the National Health Act is to provide a uniform and structured regulation for the South African health system.³⁵⁰ The relevant chapters of the Act are Chapter 2, which deals with the rights of patients and duties of health personnel, and Chapter 8, which is deals the use of blood, blood products, tissue, and gametes in humans.

Section 7 of Chapter requires that a person gives informed consent for medical treatment³⁵¹ and where a person cannot give consent in the case of a minor, the parents can provide consent on their behalf.³⁵² As noted, the procedures saviour siblings are subjected to are performed without their informed consent which is a violation of this section.

³⁴⁴ Ibid.

³⁴⁵ Ibid note 8 22.

³⁴⁶ *Op cit* note 308.

³⁴⁷ *Op cit* note 8 22.

³⁴⁸ Ibid.

³⁴⁹ *Supra* note 35.

³⁵⁰ A Dhai and S Mahomed 'Healthcare in crisis: A shameful disrespect of Constitution' (2018) 11 (1) *SAJBL* 8.

³⁵¹ *Supra* note 35 S7(1)(a).

³⁵² *Supra* note 35 Section 7(1)(a)

Notably, the Act protects the rights of the patient; therefore, it is worth establishing whether the Act protects savour siblings. The National Health Act³⁵³ does not have specific provisions that regulate saviour siblings; however, it is evident when the Act is read together with the regulations.³⁵⁴ The Act, as seen below, does not address the procedures used to conceive saviour siblings; however, it allows related procedures such as the withdrawal of blood, tissue and artificial insemination. Whether the procedures are prohibited or permitted is not indicated by the lack of reference to the procedures.

Section 54 provides that a minister may establish institutions to conduct procedures to acquire and use blood products and tissue.³⁵⁵ Further, section 55 stipulates that tissue, blood, blood products may be withdrawn from a person when they have given prior consent.³⁵⁶ Moreover, Section 56(1) provides that a person may use tissue or gametes removed or blood or a blood product withdrawn from a living person only for medical or dental purposes.³⁵⁷ Section 56(2)(a)(ii) provides that stem cells may be extracted for medical or dental purposes as noted in Section 56(1); however, the section does not prescribe which medical conditions warrant the drawing blood and tissue from a person for testing³⁵⁸ and whether this includes extracting bone marrow to save another like in the case of saviour siblings.

Furthermore, section 56(2)(b) provides that the Minister of Health may give authorisation for the removal of tissue, blood and blood product and set conditions for the removal.³⁵⁹ Moreover, Section 58³⁶⁰ provides that a person may not remove tissue from a person for purposes of transplantation unless it is at a hospital or authorized institution.³⁶¹ The section requires written authorisation from a medical practitioner in charge of clinical services or any other person in charge of the hospital or approved institution, in the absence of a medical practitioner.³⁶² Further, section 58(2) provides

³⁵³ *Supra* note 35.

³⁵⁴ *Op cit* note 6 238.

³⁵⁵ *Supra* note 35 s54.

³⁵⁶ *Supra* note 35 s55.

³⁵⁷ *Supra* note 35 s56(1).

³⁵⁸ *Op cit* note 6 239.

³⁵⁹ *Supra* note 35 s56(2)(b).

³⁶⁰ *Supra* note 35.

³⁶¹ *Supra* note 35 s58 (1)(a).

³⁶² *Supra* note 35 s58 (1)(b)(i) and (ii)

that a medical practitioner should not conduct transplantation unless authorisation is obtained.³⁶³

Furthermore, section 59(1) provides that only a registered medical practitioner may remove tissue from a person or use tissue for transplanting tissue to another person.³⁶⁴ It is clear that sections of the National Health provide for the withdrawal of blood and tissue; however, it is not clear whether it applies to the procedures that used for donation between a saviour sibling and the sick child. Therefore, the section below will analyse the regulations to determine whether they give precise regulation.

The National Research Ethics Council is limited to deal with health-research related issues as it mandated to determine guidelines for health research Committees and set norms and standards for researching human and animals, including norms and standards for conducting clinical trials.³⁶⁵

The mandate of the Research Ethics Committee is to report violations of professional and ethical rules by healthcare providers³⁶⁶ to the Health Professions Council of South Arica to institute disciplinary proceedings against individuals who breach norms, standards or guidelines set for conducting research.³⁶⁷ The role of the Council is limited to dealing with ethical and professional issues in health-related research. Arguably, the mandate of Council requires widening to deal with clinical aspects of medicine which includes the use of technologies such as *invitro* and preimplantation genetic diagnosis used for the conception of saviour siblings. If the Council can report violations of research guidelines and norms, it can report the violations of professional rules of clinical practice when there is the widening of their mandate.

Section 69 of the National Health Act establishes the National Health Research Committee, which is mandated to ensure that research agendas and research resources prioritise health problem.³⁶⁸ The National Health Research Committee is required to develop and advise the Minister of Health on the implementation and application of a national strategy for research.³⁶⁹ The committee should have

³⁶³ *Supra* note 35, s58.

³⁶⁴ *Supra* note 35 s59.

³⁶⁵ *Supra* note 35, s72(6)(c).

³⁶⁶ *Supra* note 35, s72(6)(e).

³⁶⁷ *Supra* note 35, 72(6)(f).

³⁶⁸ *Supra* note 35, s69(3)(b).

³⁶⁹ *Supra* note 35, s69(3)(c).

extended powers to deal with clinical procedures and issues, as suggested for the National Research Council. The mandate should entail providing guidelines for the use of medical technologies such as *in vitro* fertilisation and preimplantation genetic diagnosis, determine conditions for the use of such technologies, and the providing licences for the use of the technologies. The committee should advise the Minister of Health on the implementation and application of a national strategy for the use of the medical technologies in clinical practice as it does for medical research. Such change will give proper guidance for parents who want to conceive saviour siblings; it will prescribe guidelines for medical practitioners and will state whether the procedures are allowed or not.

4.4.1 Regulations relating to Artificial Fertilisation of Persons GN R175 in GG No.35099 of 2 March 2012

The Regulations allow artificial fertilisation in section 1 and defines artificial fertilisation as the "insertion of gametes into the internal reproductive organs of a female person for the purpose of human reproduction and includes artificial insemination and *in vitro* fertilisation," which is a similar procedure used when creating saviour siblings.³⁷⁰ Regulation 9 provides that a competent person can do artificial fertilisation or embryo transfer³⁷¹ at an authorised institution.³⁷² Moreover, Regulation 11 allows artificial fertilisation as it states that a gamete can be withdrawn from a woman's body for such testing, analysing or other processing of that gamete.³⁷³ The Regulation allows for the transfer of such gamete back to the woman's body.³⁷⁴

Regulation 13 provides that preimplantation and prenatal testing for selection-selection is prohibited unless there is a severe sex-linked or sex-limited genetic condition.³⁷⁵ The Regulations relating to Artificial Fertilisation of Persons looks at the use of preimplantation genetic diagnosis narrowly in this regard, as preimplantation genetic diagnosis has wider uses which include the conception of saviour siblings,

³⁷⁰ Regulations relating to Artificial Fertilisation of Persons GN R175 in *Government Gazette* 35099 of 2 March 2012, Regulation 1.

³⁷¹ *Supra* Regulation 9 (2).

³⁷² *Supra* Regulation 9 (1).

³⁷³ *Supra* Regulation 11.

³⁷⁴ *Supra* Regulation 11(b)(iii).

³⁷⁵ *Supra* note 374, Regulation 13

used to select against a genetic condition, and where parents want to conceive a child that has no genetic defect and is disease-free.

4.4.2 Regulations relating to the taking of Buccal Sample or Withdrawal of Blood from a Living Person for Testing GN R944 in GG No.34750 of 11 November 2011.

The Regulations relating to the Taking of Buccal Sample or Withdrawal of Blood from a Living Person for Testing,³⁷⁶ deal with the extraction of blood from a person. Regulation 2 allows for the withdrawing of blood from a person³⁷⁷ as contemplated in section 55 or 56 of the National Act.³⁷⁸ The Regulation does not state what blood it allows for withdrawal, the purpose the blood for the withdrawal, therefore, making it unclear as to whether the removal applies in cases of saviour siblings where there is a withdrawal of stem cells.

4.4.3 Regulations relating to the Use of Human Biological Material GN R177 in GG No. 35099 of 2 March 2012.

Regulation 5 of the Regulations provides for the withdrawal of human biological, which includes DNA, RNA and chromosome-based genetic testing.³⁷⁹ The Regulation does not state if the extraction for DNA and RNA is to prevent genetic diseases as in the case of saviour siblings. Regulation 2 stipulates that only a competent person may remove such biological material for genetic testing, genetic health research, or therapeutic purposes in an authorised institution,³⁸⁰ or prescribed institution.³⁸¹

Moreover, Regulation 3 requires written informed consent for the removal of biological material from the individual concerned.³⁸² The Regulation stipulates that where the child is under eighteen years of age but above twelve years of age, written informed consent is required, provided that the child is of sufficient maturity and has the cognitive ability to understand the benefits, risks, social and implications of the procedure.³⁸³ Further, the Regulation stipulates that where a child is younger than

³⁷⁶ Regulations relating to the Taking of Buccal Sample or Withdrawal of Blood from a Living Person for Testing GN. R944 *Government Gazette No. 34750* of 11 November 2011.

³⁷⁷ *Supra* Regulation 2.

³⁷⁸ *Supra* note 35.

³⁷⁹ Regulation 5(a) of Regulations relating to the Use of Human Biological Material GN R177 in GG 35099 of 2 March 2012.

³⁸⁰ *Supra* Regulation 2(b)

³⁸¹ *Supra* Regulation 2(b)(ii).

³⁸² *Supra* Regulation 3(a).

³⁸³ *Supra* Regulation 3(b)(i).

twelve years of age, the parents must give consent.³⁸⁴ The regulations examine the use of the biological material narrowly as approval from the registered health research ethics committee is for only research purposes.³⁸⁵ There is no reference to a clinical body or committee that looks into the uses of preimplantation genetic diagnosis or other clinical applications of biological material.

4.4.4 Regulations regarding the General Control of Human Bodies, Tissue, Blood, Blood Products and Gametes GN 392 in GG 40816 of 26 April 2017

The Regulations regarding the General Control of Human Bodies, Tissue, Blood, Blood Products and Gametes Regulation 3(1)(a) allow the withdrawing of tissue and blood for transplantation to another individual.³⁸⁶ Regulation 3(1)(b), allows for the withdrawal of blood for the administration to another person.³⁸⁷ The regulations require informed consent if a person is older than eighteen years, and ³⁸⁸ where the person is younger than eighteen, consent is only obtainable from parents.³⁸⁹ However, the regulations do not refer to saviour siblings where there is a withdrawal of blood from the latter for their sick sibling where they are younger than eighteen.

4.4.5 Discussion

South Africa offers fertility clinics in the private sector to deal with assisted reproductive technologies, however, to access the clinic one must contact the SASREG to obtain confirmation of the registration of the fertility clinic with the Southern African Society of Reproductive Medicine and Gynaecological Endoscopy.³⁹⁰

To access assisted reproductive technologies in South Africa, for creating saviour siblings, extracting tissue, blood and blood products, must be performed in a hospital or institution established by the Minister of Health in terms of section 54 of the National Health Act.³⁹¹ The removal of blood should be done by a medical practitioner or

³⁸⁴ *Supra* Regulation 3(b)(ii).

³⁸⁵ *Supra* Regulation 3((2).

³⁸⁶ Regulation 3(1)(a), Regulations regarding the General Control of Human Bodies, Tissue, Blood, Blood Products and Gametes GN 392 in GG 40816 of 26 April 2017.

³⁸⁷ *Supra*, Regulation 3(1)(b).

³⁸⁸ *Supra*, 2(1)(a).

³⁸⁹ *Supra* Regulation 2(1)(b).

³⁹⁰ Embryo Genetic Testing available at <https://www.aevitasfertilityclinic.co.za/embryo-genetic-testing/> accessed 30 January 2020.

³⁹¹ *Supra* note 35.

personnel who are trained and qualified.³⁹² The person who performs artificial fertilisation and insemination ought to be a medical practitioner registered in terms of the Health Professions Act³⁹³ as a gynaecologist, medical scientist, medical technologist, and clinical technologist trained in reproductive technology and laboratory procedures.³⁹⁴ The requirement is also the same in Regulations relating to the Use of Human Biological Material; however, a nurse registered under the Nursing Act can also withdraw the blood³⁹⁵ or a phlebotomist registered under the Health Professions Act.³⁹⁶

Furthermore, Regulation 2 Regulations relating to Blood and Blood Products³⁹⁷ requires institutions conducting blood transfusions, in terms of section 53 of the National Health Act, to have licences to do so. When drawing tissue, gametes and blood, the Regulations regarding the General Control of Human Bodies, Tissue, Blood, Blood Products and Gametes require the withdrawal to be performed at a blood transfusion institution authorised by the Minister of Health.³⁹⁸ In addition, the withdrawal should be done by a competent person who is a medical practitioner registered in terms of the Health Professions Act,³⁹⁹ or a nurse registered in terms of the Nursing Act.⁴⁰⁰

In analysing the National Health Act, the South African legal framework is silent on whether it allows the creation of saviour siblings using preimplantation genetic diagnosis.⁴⁰¹ The Act is not clear whether it makes provision for saviour siblings as it states that blood, stem cells, and tissue can be drawn for medical and dental purposes, not defining the medical conditions. Despite the lack of clarity, the Act goes on to state that any authorised hospital can conduct the procedures, and does not prescribe any requirements for the medical personnel.

The regulations do not provide much value, as the Regulations relating to artificial fertilisation of persons allows for the creation of persons through using *in vitro*

³⁹² *Supra* 380 Regulation 2 ,3 and 4.

³⁹³ 56 of 1974.

³⁹⁴ *Supra* 312 Regulation 1(a) and (b).

³⁹⁵ Act 33 of 2005.

³⁹⁶ *Supra* note 142.

³⁹⁷ Regulations relating to Blood and Blood Products GN R179 in GG No.35099 of 2 March 2012.

³⁹⁸ *Supra* 383 Regulation 1.

³⁹⁹ *Supra* note 142.

⁴⁰⁰ *Supra* note 399.

⁴⁰¹ *Ibid* note 8 22.

fertilisation, excluding preimplantation genetic diagnosis used to conceive a saviour sibling. Regulation 5 of Regulations relating to the Use of Human Biological Material permits the withdrawal of human biological material, which includes DNA, RNA and chromosome-based genetic testing.⁴⁰² However, it does not date whether they apply to conceiving saviour siblings or extracting bone marrow from saviour siblings.

Moreover, Regulations regarding the General Control of Human Bodies, Tissue, Blood, Blood Products, and Gametes requires informed consent to be obtained if the person is over eighteen years of age; where a person is young than eighteen, a parent can consent on their behalf. The requirement is apparent in the Regulations relating to the Use of Human Biological Material.

Therefore, South Africa's legal framework for the conception and use of saviour siblings through the regulations fails to provide guidelines for decision making and does not state whether creating saviour siblings using preimplantation genetic diagnosis is permitted.⁴⁰³ The regulations only look at the use of preimplantation genetic diagnosis narrowly, by prohibiting the use the technology for sex-selection.⁴⁰⁴ The regulations do not prescribe conditions for drawing blood for children born using *in vitro* fertilisation and preimplantation genetic diagnosis. It does not provide regulations or guidelines⁴⁰⁵ for preimplantation genetic diagnosis to justify the creation of saviour siblings.⁴⁰⁶

4.5 Conclusion

In conclusion, the Constitution⁴⁰⁷ provides children protection affording them rights. These rights endorsed in the Children's Act⁴⁰⁸ and National Health Act⁴⁰⁹ which protect children's rights in the medical context. However, the South African legal framework through the National Health⁴¹⁰ and Children's Act⁴¹¹ is silent on whether saviour siblings can be created using preimplantation genetic diagnosis and later used as

⁴⁰² *Supra* 383 Regulation 5(a).

⁴⁰³ *Op cit* note 8 23.

⁴⁰⁴ *Ibid.*

⁴⁰⁵ *Ibid.*

⁴⁰⁶ *Ibid.*

⁴⁰⁷ *Supra* note 49.

⁴⁰⁸ *Supra* note 7.

⁴⁰⁹ *Supra* note 35.

⁴¹⁰ *Ibid.*

⁴¹¹ *Supra* note 7.

donors.⁴¹² The regulations also do not make express mention of creating saviour and looks at the use of preimplantation genetic diagnosis narrowly by prohibiting sex selection and does not look at saviour siblings. The National Health Act⁴¹³ attempts to provide guidelines preimplantation genetic diagnosis similarly to the United Kingdom and Australia. However, it fails to accommodate the creation and the use of saviour siblings.

Further from the analysis of the Children's Act,⁴¹⁴ one can argue that saviour siblings cannot consent to medical interventions and treatment and voice their opinions until the age of twelve.⁴¹⁵ Children younger than twelve years have their right to bodily integrity infringed as they undergo painful medical procedures.⁴¹⁶ However, the Children's Act⁴¹⁷ and the Constitution confirm that children's best interests are paramount.⁴¹⁸ Arguably the Act⁴¹⁹ in allowing parents full reproductive autonomy and enabling them to exercise parental responsibility violates the saviour sibling's right to bodily integrity as they undergo procedures that are invasive, harmful and traumatic without their consent. The rights of the parents seem to override those of the saviour siblings,⁴²⁰ despite saviour siblings having the right to dignity.

The current regulatory system in South Africa creates a problem by not implementing regulatory measures for conceiving saviour siblings and using them as a donor,⁴²¹ as the lack of regulation can lead to saviour siblings becoming susceptible to the infringements of their rights.⁴²² Therefore, adequate regulation is required to assist in balancing conflicting interests when parents decide to conceive saviour siblings when the latter subjected to donations and to address the legal conundrums arising from the use of the technology.⁴²³

⁴¹² *Op cit* note 8 22.

⁴¹³ *Supra* note 35.

⁴¹⁴ *Supra* note 7.

⁴¹⁵ *Op cit* note 6 243.

⁴¹⁶ *Op cit* note 6 244.

⁴¹⁷ *Supra* note 7.

⁴¹⁸ *Ibid.*

⁴¹⁹ *Ibid.*

⁴²⁰ *Op cit* note 6 245.

⁴²¹ *Op cit* note 6 244.

⁴²² *Op cit* note 6 240.

⁴²³ *Op cit* note 8 22.

Chapter 5: THE REGULATION OF SAVIOUR SIBLINGS IN AUSTRALIA AND THE UNITED KINGDOM

5.1 Introduction

As noted in Chapter One, this chapter analyses the regulation of saviour siblings in Australia and the United Kingdom. These countries have been pioneers in regulating the creation of saviour siblings by limiting the use of assisted reproductive technologies through general legislation, professional regulation, and soft regulation through guidelines. The purpose of this comparative analysis of these jurisdictions is to determine how to regulate saviour siblings for parliamentary proposal.

5.2 Australia

Australia is a federal state with no uniform legislative framework for assisted reproductive technologies.⁴²⁴ The regulation of the creation of saviour siblings and the use of assisted reproductive technology varies among states.⁴²⁵ The federal National Health and Medical Research Council Act 1992 established The National Health and Medical Research Council to address social and ethical concerns arising from assisted reproductive technologies, primarily where the regions don't individually regulate the technologies.⁴²⁶ The National Health and Medical Research Council does this by providing guidelines for reproductive technologies intended to improve national standards and maintain good practice.⁴²⁷

5.2.1 Professional regulation

The Fertility Society of Australia is a federal professional body which comprises of scientists and health professionals in Australia.⁴²⁸ It administers assisted reproductive technology in Australia and provides accreditation through its Reproductive Technology Accreditation Committee established in 1987.⁴²⁹ Certification depends on

⁴²⁴ M Taylor-Sands *Creating Saviour Siblings: Reconsidering the Role of the Welfare of the Child Principle in Regulating Pre-Implantation Tissue Typing in Australia* (Phd Thesis Melbourne Law School University of Melbourne, 2010) 17.

⁴²⁵ *Op cit* note 166 230.

⁴²⁶ M Smith. *Regulating IVF and Pre-implantation tissue-typing for the creation of "saviour siblings": a harm analysis.* (Phd Thesis Queensland University of Technology ,2010) 36.

⁴²⁷ DJ Coker. *Obtaining Salvation – Regulation of Access to Preimplantation Genetic Diagnosis for the Selection of Saviour Siblings in Australia.* (Honours thesis The Australian National University, 2008) 18-19.

⁴²⁸ K Petersen and M Johnson 'SmARTest regulation? Comparing the regulatory structures for ART in the UK and Australia.' (2007) 15(2) *Reproductive BioMedicine Online* 239.

⁴²⁹ *Op cit* note 42819.

compliance with the Reproductive Technology Accreditation Committee's Code of Practice (RTAC) and the recommendations of the National Health and Research Council Guidelines.⁴³⁰ The clinics have to comply with professional standards and requirements of the Reproductive Technology Accreditation Committee on scientific and clinical aspects of assisted reproduction.⁴³¹ The Code is to be read together with state legislation on assisted reproductive technologies.⁴³²

5.2.2. Clinical Practice

The National Health and Research Council Guidelines provide ethical guidelines in clinical practice in Australia. The National Health and Research Council Guidelines have a statutory basis since their establishment by the Australian Health Ethics Committee in terms of the National Health and Medical Research Council Act 1992, now amended to the Medical Research Council Amendment 2006.⁴³³ The guidelines are not legally enforceable, but as they provide soft regulation, they are binding on states. The guidelines are as follows:⁴³⁴

1. Assisted reproductive technologies, and related procedures conducted in a manner that respects individuals involved.⁴³⁵
2. In all decisions, the needs and wellbeing of the individual, including those born through assisted reproductive technologies, should be the primary consideration.⁴³⁶
3. Assisted reproductive technologies activities to be conducted in a way that minimises harm and benefits all persons involved in assisted reproductive technologies, including children born through the techniques.⁴³⁷
4. Decision-making in the clinical practice of assisted reproductive technology must recognise and consider the biological and social relationships in assisted reproductive technologies.⁴³⁸

⁴³⁰ Ibid .

⁴³¹ Ibid note 429 239.

⁴³² Fertility Society of Australia Code of Practice for Assisted Reproductive Technology Units (2014) 6.

⁴³³ Act 50 of 2006

⁴³⁴ *Op cit* note 429 239.

⁴³⁵ Australian Government: National Health and Medical Research Council Ethical guidelines on the use of assisted reproductive technology in clinical practice and research (2017) 20.

⁴³⁶ Ibid.

⁴³⁷ Ibid.

⁴³⁸ Ibid.

5. Medical personnel in the clinical practice of assisted reproductive technologies should have cognisance and respect the autonomy of all parties involved in the procedures. They have to comply with the requirements of valid consent.⁴³⁹

6. Decision making in clinical practice of assisted reproductive technologies must take cognisance of 'social relationships and social contexts,' which may affect individuals and be mindful of cultural and religious diversity.⁴⁴⁰

7. The procedures and policies which provide couples access to assisted reproductive technologies must be fair and transparent and be cognizant of a person's human dignity and other human rights.⁴⁴¹

8. The assisted reproductive technologies must be transparent and be open to scrutiny and ensure that the confidentiality of individuals, including children born using assisted reproductive technologies, is maintained.⁴⁴²

The guidelines provide that couples can use preimplantation genetic diagnosis to select against genetic conditions and create an embryo that would be a compatible tissue match for stem cell transplantation to a sibling.⁴⁴³ Before performing the procedures, clinicians must be approved by an independent body that is satisfied that the sibling's medical condition is severe and can only be treated with stem cell therapy.⁴⁴⁴ The independent body must be satisfied that the procedure will not affect the child's interests and welfare.⁴⁴⁵ The independent body is an institution or clinical ethics committee responsible for decision-making and able to give advice or opinions.⁴⁴⁶ In Australia, conceivingaviour siblings is only permitted if there is compliance of the above. The section below will, therefore, discuss the states that have legislation for assisted reproductive technologies and rely on guidelines.

⁴³⁹ Ibid.

⁴⁴⁰ Ibid.

⁴⁴¹ Ibid.

⁴⁴² Ibid 21.

⁴⁴³ Guidance 8.15.1 National Health and Medical Research Council: Ethical guidelines on the use of assisted reproductive technology in clinical practice and research 73.

⁴⁴⁴ Ibid 75.

⁴⁴⁵ Ibid.

⁴⁴⁶ National Health and Medical Research Council: Ethical guidelines on the use of assisted reproductive technology in clinical practice and research 6.

5.2.3 New South Wales

The Assisted Reproductive Technology Act regulates assisted reproductive technologies in New South Wales.⁴⁴⁷ Section 11 of the Assisted Reproductive Technology Act 69 of 2007 requires a medical practitioner to conduct and supervise reproductive technology procedures.⁴⁴⁸ Section 6(1) requires the registration of clinics with the Director-General in terms of section 7, who keeps a register in terms of section 9.⁴⁴⁹

Although there are no provisions that deal with assisted reproductive technologies like preimplantation genetic diagnosis in South Wales, they rely on the ethical committee guidance of the National Health and Research Council to create a saviour sibling.⁴⁵⁰ The Guidelines of the National Health and Research Council allows the use of preimplantation genetic diagnosis to select an embryo with compatible tissue for an existing sibling.⁴⁵¹

It is clear that in New South Wales, to conceive and use saviour siblings depends on the decision of the ethical committee.⁴⁵² When deciding whether to allow the creation saviour sibling, ethical bodies consider several factors, including determining whether the welfare of the saviour sibling will not be affected, the sick sibling's medical condition, the alternative treatment available to treat the disease, and why the parents want to conceive the child.⁴⁵³

The ethical committees are essential as the New South Wales regulatory framework does not establish a statutory body that has an oversight role in ensuring compliance with legislative provisions.⁴⁵⁴

5.2.4 Victoria

The relevant legislation applicable to the creation of saviour siblings in Victoria is the Assisted Reproductive Treatment Act (Vic).⁴⁵⁵ The Act requires the consideration of

⁴⁴⁷ 69 of 2007.

⁴⁴⁸ Ibid.

⁴⁴⁹ Ibid.

⁴⁵⁰ *Op cit* note 428 22.

⁴⁵¹ Ibid 21-22.

⁴⁵² Ibid 22.

⁴⁵³ Ibid.

⁴⁵⁴ M Smith *Regulating IVF and Pre-implantation tissue-typing for the creation of "saviour siblings": a harm analysis.* (Phd Thesis Queensland University of Technology,2010) 51.

⁴⁵⁵ Assisted Reproductive Treatment 76 of 2008.

the best interest of the child laid out in the international conventions and regional norms discussed in Chapter 3.⁴⁵⁶ The creation of saviour siblings is allowed as section 10(2)(a)(iii) states that the use of reproductive technologies is allowed where a woman has the potential of giving birth to a child with a genetic defect.⁴⁵⁷

The Act in section 5 stipulates the following guiding principles for the use of assisted reproductive technologies:

1. The consideration of welfare and interests of the child born using reproductive technologies;⁴⁵⁸
2. The need to protect the health and wellbeing of the persons undergoing the treatment procedure;⁴⁵⁹
3. To ensure no exploitation of the child born using reproductive technologies.⁴⁶⁰

From the analysis of the guiding principles, the interests and welfare of the donor child are essential, and there is oversight provided for this. The Act established the Victorian Assisted Reproductive Treatment Authority in terms of section 99 of the Act.⁴⁶¹ The purpose of the Authority is to ensure the consideration of the best interests in treatment procedures.⁴⁶² The Authority monitors and administers the registrations to conduct reproductive treatment.⁴⁶³

Section 7(a)(i) of the Act requires the conducting of assisted reproductive technologies by a doctor registered in terms of section 74(1).⁴⁶⁴ Section 7 provides that a medical practitioner, trained in assisted reproductive technologies, should conduct and supervise the procedure but should obtain advice from a geneticist or a medical practitioner who is a specialist in human genetics.⁴⁶⁵

⁴⁵⁶ R Thorpe and M Pitts 'New assisted reproductive technology laws in Victoria: a genuine overhaul or just cut and paste?' (2011) 18(4) *Journal of law and medicine* 838.

⁴⁵⁷ *Supra* note 456.

⁴⁵⁸ *Supra* note 456 S5(a).

⁴⁵⁹ *Supra* note 456 S5(d).

⁴⁶⁰ *Supra* note 456 S5(d)(ii).

⁴⁶¹ *Supra* note 456.

⁴⁶² *Supra* note 456 100 (1)(b).

⁴⁶³ *Supra* note 456 100 (1)(d)(iii).

⁴⁶⁴ *Supra* note 456.

⁴⁶⁵ *Supra* note 456 S 7(a)(ii).

5.2.5 South Australia

In South Australia, the Assisted Reproductive Treatment Act 1988 regulates assisted reproductive technologies. Section 4A requires that children born through assisted reproductive technologies have their welfare to be considered as primary importance.⁴⁶⁶

Section 5 requires providers of assisted reproductive technologies to be registered in terms of the regulations.⁴⁶⁷ Section 6 requires a health professional to register by making an application to the Minister in terms of Section 7.⁴⁶⁸ The Minister must be satisfied that they are fit and proper,⁴⁶⁹ have a licence and accreditation, possess educational qualifications as required by the regulations.⁴⁷⁰ The Minister can set conditions on accessing assisted reproductive technologies unless the licence is obtained to treat a severe genetic condition exists transmittable to the child.⁴⁷¹

The Act is read together with the Assisted Reproductive Treatment Regulations 2010. Regulation 5 requires a person conducting assisted reproductive technologies to be accredited with the RTAC and hold a licence.⁴⁷² Moreover, Regulation 7 requires that a medical practitioner be registered,⁴⁷³ and registration involves compliance with Regulation 8(4)(b) and the National Health and Medical Research Council Guidelines.⁴⁷⁴ The abovementioned illustrates that South Australia is reliant on the National Health and Medical Research Council for ethical guidance.⁴⁷⁵ It is a submission that in South Australia saviour siblings are allowed and whether to use them as donors depending on the ethical guidelines that consider the interests of the child.

⁴⁶⁶ Assisted Reproductive Treatment Act 1988 ,s4A.

⁴⁶⁷ Ibid s5.

⁴⁶⁸ Ibid s7.

⁴⁶⁹ Ibid s6.

⁴⁷⁰ Ibid s7.

⁴⁷¹ Ibid s9 (1)(c)(iii).

⁴⁷² Regulation 5 Assisted Reproductive Treatment Regulations 2010.

⁴⁷³ Ibid Regulation 7.

⁴⁷⁴ Ibid Regulation 8(4)(b)

⁴⁷⁵ Health Law Central available at <http://www.healthlawcentral.com> accessed 13 December 2019.

5.2.6 Western Australia

In Western Australia, the Western Australia Human Reproduction Technology Act regulates assisted reproductive technologies.⁴⁷⁶ In terms of section 8, the Australia Human Reproduction Technology Act establishes the Western Australian Reproductive Technology Council, which develops the Code of Practice.⁴⁷⁷

The Council ensures compliance with the Act and advises the committees that deal with assisted reproductive technologies on matters relating to licencing, administering, and enforcing the Act.⁴⁷⁸ The Council administers applications made by a clinical geneticist where there is a risk of a genetic condition that requires the use of preimplantation genetic diagnosis.⁴⁷⁹ The basis of decision for the application is on factors implemented by the preimplantation genetic diagnosis committee responsible for advising the council on clinical and aspects of the technology.⁴⁸⁰

Similarly to Victoria and South Australia, Section 14(2b)(ii) of the Human Reproductive Technology Act⁴⁸¹ allows the use of preimplantation genetic diagnosis where there is a risk of a genetic defect or disease.⁴⁸² The Western Australian Reproductive Technology Council allows preimplantation genetic diagnosis if it does not leave the embryo unfit to undergo implantation.⁴⁸³ Beyond this, the Code of Practice provides that before conducting diagnostic tests, obtaining a license needs in terms of section 27(3) of the Act.⁴⁸⁴ This is to ensure that the embryos are in suitable condition for implantation and performed at an authorised institution.⁴⁸⁵ The legislation and the Code of Practice cater for the creation of saviour siblings; however, to use them, they must seek guidance from the guidelines.

5.2.7 Consent to medical treatment in Australia

The legislation in Australia acknowledges children's evolving capacities for medical treatment like South Africa. In New South Wales, the Minors (Property and Contracts)

⁴⁷⁶ 22 of 1991.

⁴⁷⁷ *Op cit* note 428 28.

⁴⁷⁸ Western Australia Reproductive Council Annual Report (2016-2017) 7.

⁴⁷⁹ *Ibid* 11.

⁴⁸⁰ *Ibid* note 479.

⁴⁸¹ Human Reproductive Technology Act 1991.

⁴⁸² *Ibid* 428 28.

⁴⁸³ *Ibid*.

⁴⁸⁴ *Ibid* note 477.

⁴⁸⁵ Reproductive Technology Council : Policy On Approval Of Diagnostic Procedures Involving Embryos, Framework For Approval Of An Embryo Diagnostic Procedure Attachment (2017) 1.

Act⁴⁸⁶ requires that consent be obtained from a child if they are sixteen years or older and where they are younger than sixteen their consent to be obtained from their parents.⁴⁸⁷

Moreover, in South Australia, the Consent to Medical Treatment and Palliative Care Act 1995 stipulates that a child is legally competent to give consent if they are also sixteen years or older.⁴⁸⁸ However, in Western Australia, a child can give consent to medical treatment when they are eighteen years or older in terms of the Guardian and Administration Act.⁴⁸⁹

In Victoria, the Medical Treatment Planning and Decisions Act⁴⁹⁰ does not stipulate a specific age a child for when a child is legally competent to give informed consent. The Act has principles to determine when a child is mature enough to understand the medical treatment.⁴⁹¹

It is a submission that even in Australia, there is a violation of the of saviour siblings' rights until considered mature to consent to medical treatment. However, the National Health and Medical Research Council Guidelines provide guidance and set restrictions regarding the use of assisted reproductive technologies.

5.2.8 Summary of discussion

In conclusion, Australia is a federal country with different states and does not have uniform legislation for reproductive technologies. The National Health and Medical Council Act is federal legislation established the Australian Health Committee in terms of section 35 of the Act. The Australian Health Committee established the National Health and Medical and Research Council Guidelines, implemented to improve standards and maintain the good practice of assisted reproductive technologies. Although the guidelines are not legally binding, they offer soft regulation in federal Australia for states that do not individually regulate assisted reproductive technologies.

⁴⁸⁶ 60 of 1970.

⁴⁸⁷ S49 Minors (Property and Contracts) Act 1970.

⁴⁸⁸ S6 Consent to Medical Treatment and Palliative Care Act 1995.

⁴⁸⁹ 110P Guardianship and Administration Act 24 1990.

⁴⁹⁰ 69 of 2016.

⁴⁹¹ The Victorian Healthcare Association Discussion Paper Informed Consent for Treatment /Intervention (2009) 4.

With regards to the accessing preimplantation genetic diagnosis to createaviour siblings, couples will have to satisfy stipulated conditions.

Australia has the Fertility Society of Australia that has the RTAC committee, which administers clinical aspects of its assisted reproductive technologies on a national level and has a Code of Practice, which all states need to comply with to have accreditation.⁴⁹²

New South Wales, the Assisted Reproductive Act regulates assisted reproductive technologies except for preimplantation genetic diagnosis. There is a reliance on the National Medical and Research guidelines as there is no statutory body that oversees the use of the technology. The Act requires clinics that perform assisted reproductive technologies to be registered.

In Victoria, the Assisted Reproductive Treatment Act (Vic)⁴⁹³ regulates assisted reproductive technologies. The Act establishes the Victorian Assisted Reproductive Treatment Authority in terms of section 99 of the Act.⁴⁹⁴ The purpose of the Authority's establishment is to ensure the consideration of the best interests of the child in treatment procedures.⁴⁹⁵ Moreover, the Authority is established to monitor reproductive treatment⁴⁹⁶ and administer registration to conduct medical procedures.⁴⁹⁷ The Act requires that assisted reproductive technologies done by a doctor registered to perform such medical procedures.⁴⁹⁸ The section requires supervision of a registered medical practitioner trained in the field of assisted reproductive technologies when conducting the medical procedure,⁴⁹⁹ who obtains advice from a geneticist or a medical practitioner who is a specialist in human genetics.

In South Australia, assisted reproductive technologies are regulated by the Assisted Reproductive Treatment Act 1988. The Act requires providers of assisted reproductive

⁴⁹² Fertility Society of Australia available at <https://www.fertilitysociety.com.au/rtac/> accessed 2 January 2020

⁴⁹³ *Supra* note 456.

⁴⁹⁴ *Supra* note 448.

⁴⁹⁵ *Supra* note 448, s100 (1)(b).

⁴⁹⁶ *Supra* note 448, s100 (1)(d)(iii).

⁴⁹⁷ *Supra* note 448, s100 (1)(a).

⁴⁹⁸ *Supra* note 448.

⁴⁹⁹ *Supra* note 467, s7.

technologies to be registered and accredited with RTAC,⁵⁰⁰ hold a licence,⁵⁰¹ and have educational qualification as required by the regulations.⁵⁰² For accreditation to use assisted reproductive technologies, like creating saviour siblings, clinics, and health personnel ought to comply with the National Health and Medical Research Council Guidelines,⁵⁰³ RTAC, and hold a license.⁵⁰⁴

With regards to accessing preimplantation genetic diagnosis, that Act requires that children born through assisted reproductive technologies to have their welfare considered as primary importance, and the use of the technology is permitted, where a couple has a severe genetic condition that is transmittable to an infant.⁵⁰⁵

Western Australia regulates assisted reproductive technologies through the Western Australia Human Reproduction Technology Act,⁵⁰⁶ which established the Western Australian Reproductive Technology Council that developed the Code of Practice.⁵⁰⁷

The Council ensures compliance with the Act as it advises committees on matters relating to licencing, administering, and enforcing the Act.⁵⁰⁸ In terms of the Council, access to preimplantation genetic diagnosis is limited to situations where there is a possibility of transmitting a genetic disorder.

The council administers applications for preimplantation genetic diagnosis made by a clinical geneticist.⁵⁰⁹ The application is decided based on factors implemented by the preimplantation genetic diagnosis committee responsible for advising the council on clinical and aspects of the technology.⁵¹⁰

⁵⁰⁰ *Supra* note 467 s6.

⁵⁰¹ *Supra* note 473.

⁵⁰² *Supra* note 456.

⁵⁰³ *Supra* note 475.

⁵⁰⁴ *Op cit* note 473.

⁵⁰⁵ *Supra* note 467.

⁵⁰⁶ *Supra* note 477.

⁵⁰⁷ *Op cit* note 428 28.

⁵⁰⁸ *Op cit* note 479 7.

⁵⁰⁹ *Op cit* note 479 11.

⁵¹⁰ *Op cit* note 479 7.

5.3 United Kingdom

The United Kingdom has a long-standing history of regulating medical procedures and has incorporated the creation of saviour siblings with government involvement for a long time.⁵¹¹

Preimplantation genetic diagnosis is regulated by the Human Fertilisation and Embryology Act 1990, which was passed on 1 November 1990. Section 5 of the Human Fertilisation and Embryology Act 1990 sets up the Human Fertilisation and Embryology Authority.⁵¹²

5.3.1 Legislation

Similar to Australia, the Human Fertilisation and Embryology Act regulates assisted reproductive technologies like preimplantation genetic diagnosis.⁵¹³ The Act allows the technology for testing severe genetic conditions and for HLA tissue typing to create saviour siblings.⁵¹⁴

The welfare of the child in medical procedures is equally important, as s13(5) of the Human Fertilisation and Embryology Act and Human Fertilisation and Embryology Authority guidelines. The guidelines provide that before conducting any treatment procedure and require the consideration of the child's welfare.⁵¹⁵

Schedule 2 of the Human Fertilisation and Embryology Act requires fertility clinics to be licensed to create saviour siblings through preimplantation genetic diagnosis.⁵¹⁶ Additionally, the Human Fertilisation and Embryology Authority requires fertility clinics to obtain licenses for each genetic test they wish to conduct on embryos, and this allows the government to monitor and control the clinics.⁵¹⁷

⁵¹¹ ZE Shapiro 'Saviour siblings in the United States: ethical conundrums, legal and regulatory void' (2018) 24(2) *Washington and Lee Journal of Civil Rights and Social Justice* 449.

⁵¹²L Cherkassky 'Twenty-Seven Years of Controversy: The Perils of PGD' (2018) 2(1) *International Journal of Pediatrics and Neonatal Health* 01.

⁵¹³Human Fertilisation and Embryology Act 1990.

⁵¹⁴ Guidance 8.3 Human Fertilisation and Embryology Authority Good Code of Practice (version 10).

⁵¹⁵ Ibid.

⁵¹⁶ *Op cit* note 512 449.

⁵¹⁷ Ibid 451.

5.3.2. Consent to medical treatment in the United Kingdom

The United Kingdom also recognises the evolving capacity of children in medicine. According to section 8(1) of the Family Law Reform Act, a minor can only give consent to medical treatment and surgery when he or she is sixteen years and older.⁵¹⁸

5.3.3 Professional Regulations

The person involved in the medical procedures such as *in vitro* fertilisation must have completed training as a gynaecologist, be on the General Medical Council Specialist Register, and participate in the discipline's training.⁵¹⁹ Further to this, if the centre conducts insemination procedures, the medical practitioner should be registered as a medical practitioner and have substantial experience in working at a fertility clinic.⁵²⁰

The persons conducting the embryo testing for preimplantation genetic diagnosis should have a medical degree, be accredited to do diagnostic laboratory work, and registered with a body of clinical scientists.⁵²¹

Lastly, the Human Fertilisation and Embryology Authority stipulates the persons involved in the preimplantation genetic diagnosis procedures should have professionals from different disciplines. The team of professionals should include 'specialists, embryologists, clinical geneticists, genetic counsellors, cytogeneticists, and molecular geneticists.'⁵²²

5.4 Conclusion

In conclusion, the United Kingdom and Australia have mandatory statutory licensing and registration requirements for medical personnel and centres for the performing of preimplantation genetic diagnosis.⁵²³ The countries have legislation that establishes councils or statutory bodies that administer assisted reproductive. Despite having such bodies, the countries have national guidelines to ensure good practice for assisted reproductive technologies.

Children in Australia and the United Kingdom can give consent to medical treatment when they are slightly older than children in South Africa, where children can consent

⁵¹⁸ Family Law Reform Act 1969.

⁵¹⁹ Ibid note 444 Guidance Note 2 10(version 10).

⁵²⁰ Ibid Guidance Note 2.11.

⁵²¹ Ibid Guidance Note 2.28.

⁵²² Ibid Guidance Note 2.27.

⁵²³KL Trifolios 'Savior Siblings: The Ethical Debate' (2014) *Law School Student Scholarship* 16.

when they are twelve years of age. The use of preimplantation genetic diagnosis used to conceive saviour siblings, in Australia and the United Kingdom is limited to it having a beneficial effect and being in the best interests of the child,⁵²⁴ giving effect to the international conventions addressed in Chapter 3. However, the regulation in Australia and the United Kingdom still do not specify how to deal with competing interests of the sick sibling and the saviour sibling.

⁵²⁴*Op cit* note 166 230.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 Introduction and Background

Saviour siblings are children conceived through *in vitro* fertilisation and preimplantation genetic diagnosis to be a genetic match to their sibling suffering from a debilitating condition such as Fanconi anaemia to provide genetic material for their sibling.⁵²⁵ The created child comes from an embryo was selected found to be free of any congenital disease during the process of their creation and implanted in the woman for pregnancy.⁵²⁶ There is the extraction of hematopoietic stem cells and bone marrow when the child is born and during their life and given to the sick child to alleviate their condition and as the saviour sibling is a suitable match.

The dissertation aimed to explore the legal and ethical issues relating to saviour siblings. The research questions were whether it is ethically justifiable to conceive saviour siblings, whether international and regional instruments protect saviour siblings and whether South African law allows for the conception of saviour siblings.

The objectives of the dissertation were to determine whether it is ethically justifiable to conceive saviour siblings, to explore the rights protected by international and regional instruments, to explore the Australian United Kingdom regulation and to determine if South Africa can adopt any lessons.

The purpose of this chapter is to make a summary of the findings in the dissertation and to make recommendations for the South African legal framework.

6.2 Summary of key findings

6.2.1 The ethical dimensions of using saviour sibling as a donor for a sick sibling

The creation of saviour siblings and using the saviour sibling as a donor brings forth ethical challenges.⁵²⁷ In contributing to the existing literature, the chapter highlighted the ethical issues faced in the clinical field of medicine. Chapter 2 of the dissertation emphasized that medical practitioners are bound to the Hippocratic Oath⁵²⁸ and

⁵²⁵ SO Samardžić 'Saviour Siblings - Current Overview, Dilemmas and Possible Solutions?' (2019) 12(2) *Medicine, Law & Society* 99.

⁵²⁶ *Ibid.*

⁵²⁷ *Op cit* note 6 226

⁵²⁸ *Op cit* note 85.

biomedical ethics which require them to give beneficial treatment when the patient has consented to the treatment.

Chapter 2 highlighted violation of the biomedical ethics on the part of the medical practitioner as the saviour sibling's autonomy is threatened from the time they are born, and cannot exercise their right to self-determination as they also cannot refuse to be donors despite the procedures being highly invasive.⁵²⁹

The chapter and the discussions in the dissertation highlighted that saviour siblings are unable to give informed consent when they are younger than twelve years as they lack the capacity to consent and parents have to do so on their behalf as the principle requires patients to understand and give authorisation to the medical procedure they have to undergo.⁵³⁰ It is seen that a child can only have an input to decision-making when they are above the age of twelve years when deemed to have sufficient maturity. It argued that saviour siblings have their bodily integrity violated from birth until they are considered mature enough to decide to give their consent. It is argued that the law only provides protection for saviour siblings when they are twelve years of age or older and making them more vulnerable to human rights' violations until they reach an age can express themselves.

Moreover, there is a violation of the principles of beneficence and non-maleficence when using saviour siblings as donors. There is a violation because as the procedures performed on the saviour sibling are not beneficial to them, and there are risks associated with the medical procedures.

It is clear from Chapter 2 that the use of saviour siblings as donors is contrary to Immanuel Kant's respect for personhood, as there is a commodification of a saviour sibling who cannot consent which amounts to exploitation.⁵³¹ It is a submission using the child as a donor is contrary to the other ethical theories.

The chapter demonstrated that conceiving saviour siblings might be consistent with the ethical theory of utilitarianism as having a child created to save an ill child through bone marrow aspirations, therefore creating happiness for the family unit. However, it

⁵²⁹ *Op cit* note 166 229.

⁵³⁰ *Op cit* note 164 43.

⁵³¹ *Op cit* note 159 312.

is contrary to the ethical theory of deontology, which requires that a person is not used as a means to an end and need to have their human dignity respected. It is contrary to the theory of deontology because the saviour sibling is a commodity used to cure the ill sibling.

6.2.2 The international legal norms on saviour siblings are limited and do not offer significant guidance to domestic legal systems

There is a lack of regulation of saviour siblings in international and regional norms,⁵³² like the United Nations Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the child, as they are merely normative.

However, the norms given by the Universal Declaration on Bioethics and Human Rights 2005 are fundamental in bioethics and require states to protect the dignity and autonomy of patients, to ensure that medical treatment is not only beneficial but that there is a reduction of harm.⁵³³ Based on the analysis of South African law, there can be exploitation of a saviour sibling from the time that they are born until considered to have the capacity to express themselves when they are twelve years of age. Moreover, the sick sibling's right to dignity is afforded more weight and recognition than that of the saviour sibling subjected to non-beneficial procedures affecting their psychological health, which is contrary to the requirements of the Declaration of Bioethics.

6.2.3 The legal framework on saviour siblings in South Africa is inadequate

In South Africa, despite controversy between a woman's constitutional right to reproductive choices, parental responsibility and a saviour sibling's constitutional right to bodily integrity, there are no laws explicitly regulating saviour siblings. Section 129 of the Children's Act is vague as it only states that a child can consent to medical treatment or surgery from the age of twelve years,⁵³⁴ without specifying whether this includes procedures administered to saviour siblings.

There is a violation of the saviour sibling's right to bodily integrity as they don't have control over their bodies, and parents consent on their behalf. Moreover, the National Health Act does not stipulate the age children can consent to medical treatment.

⁵³² *Op cit* note 6 232.

⁵³³ *Op cit* note 273 363.

⁵³⁴ *Supra* note 7.

However, it requires obtaining consent before administering medical treatment. The omission is inappropriate as the Act is the main piece of concerned with health-related matters, and obtaining consent is essential in medical practice.

In South Africa, it is unclear whether the National Health Act⁵³⁵ regulates saviour siblings are. Section 56(1) does not provide for circumstances under which a person can have blood or tissue withdrawn from them,⁵³⁶ making it unclear whether this includes the withdrawal of stem cells or bone marrow done in the case of saviour siblings. Moreover, it is clear from the dissertation that the regulations do not state whether saviour siblings are allowed⁵³⁷ despite dealing with aspects related to technology. Regulation 13 of Regulations Relating to Artificial Fertilisation of Persons prohibits the use of preimplantation genetic diagnosis for sex selection⁵³⁸ but fails to address other aspects for the use of the medical intervention, such as the creation of saviour siblings.

Lastly, from the analysis of the Children's Act,⁵³⁹ it is evident that it only deals with one aspect of the use of assisted reproductive technologies, since it only covers surrogacy.

6.2.4 Lessons from the legal framework in Australia and the United Kingdom regarding saviour siblings

In the United Kingdom, the Human Embryology Act 2008 regulates saviour siblings as it establishes the Human Embryology Authority which provides guidelines and oversees the use of assisted reproductive technologies, require fertility clinics to have licences and set conditions which warrant the use of assisted reproductive technologies like preimplantation genetic diagnosis. Moreover, the guidelines are normative as they require the protection of the child's welfare.

Lastly, Australia has different states, where each has its regulatory framework besides the professional regulation provided on a state level established by the Fertility Society of Australia and the Australian Ethics Committee's National Health and Medical Research Guidelines. Despite the divergence in regulation in Australia, the guidelines

⁵³⁵ *Supra* note 35.

⁵³⁶ *Op cit* note 6 239.

⁵³⁷ *Op cit* note 36 35.

⁵³⁸ *Op cit* note 371.

⁵³⁹ *Supra* note 7.

and state legislation are normative, set the conditions for the use of assisted reproductive technologies and require protection of the child's welfare. In addition, there are registration and licensing requirements in Australia, which are the basis for accreditation to perform assisted reproductive technologies, such as the creation of saviour siblings.

6.3 Conclusion

In conclusion, the South African legal framework does not provide specific regulation for saviour siblings, making saviour siblings more susceptible to rights infringements.

6.4 Recommendations

Given the absence of an adequate legal framework for saviour siblings, it is a recommendation that there is an implementation of law reform by the parliament, and the following is required:

1. The National Health Act should be amended and made more comprehensive. Section 56(1) should specify conditions under which blood or tissue can be removed from an individual and whether this involves the removal of stem cells or bone marrow used in the case of saviour siblings.
2. The Regulations Relating to Artificial Fertilisation of Persons broaden its scope to deal with preimplantation genetic diagnosis used to create saviour siblings.
3. The National Health Act and the Children's Act should complement each other. The Children's Act should not look at one aspect of assisted reproductive technologies such as surrogacy, since artificial fertilisation is a related procedure used to create saviour siblings. The National Health and Children's Act should specifically recognize and incorporate legislation dealing with all assisted reproductive technologies, such as preimplantation genetic diagnosis and *in vitro* fertilisation, used to create saviour siblings.
4. The Children's Act should have provisions protecting saviour siblings from birth, as they are bearers of rights from the time they are born. The Act should deal explicitly with the rights of saviour siblings as it does for children born through surrogacy. Moreover, the term 'surgical treatment' should be

expanded on and state if it includes bone marrow aspirations performed on saviour siblings.

5. The National Health Act and the Children's Act should be uniform in stipulating the same age in which a child may consent to medical treatment and surgery.
6. The National Act should expand the mandate of the National Research Ethics Council and the Research Ethics Committee. The scope of work should include dealing with clinical applications of medical technologies which include *in vitro* fertilisation and preimplantation genetic diagnosis used to create saviour siblings.

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 - 2.1 Section 6(2)(a)
 - 2.2. Section 7
 - 2.3 Section 9
 - 2.4 Section 10
 - 2.5 Section 11
 - 2.6 Section 129(2) Section 129(4) and 129(5)
3. National Health Act 61 of 2003.
 - 3.1 Section 7
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 - 3.4 Section 55
 - 3.5 Section 56(1), Section 56(2)(a)(ii) ,Section 56(2)(b)
 - 3.6 Section 58 (1)(a), Section 58 (1)(b)(i) and (ii), Section 58(2)
 - 3.7 Section 59(1)
 - 3.8 Section 69, Section 69(3)(b),Section 69(3)(c).
 - 3.9 Section 72, Section 72(6)(c), Section 72(6)(e), Section 72(6)(f)
 - 3.10 Regulations

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