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Human Rights at stake: sacrificial separation of conjoined twins

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"Ruby is forever beside me.
I understand that I am *me*,
but that I am also *we*."¹

¹ Lori Lansens: *The Girls: A Novel*, (New York: Little, Brown and Company, 2006), 8.

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SUMMARY

What are the relevant lessons there for human rights law to learn in the legal-medical context relating to the figure of conjoined twins?

This thesis is a response to the highly debated judicial decisions regarding separation surgery of conjoined twins. As separation surgeries often result in the death of one or both twins due to a medical condition, the question whether there is a legal justification for separation is controversial among scholars.

The medical and legal discourses idealise the concept of “one body one identity” to articulate human rights and fail to notice that embodied personhood is fundamentally different for conjoined twins. The thesis argues that conjoined twins from legal and medical perspectives might be recognised as two individuals theoretically; however, in practice, they continue to be regarded as “monsters” shifted into medical terms and in need of “fixing” by separating them surgically. Such treatment also affects singleton people and human rights law in general terms.

The medical and legal treatment of conjoined twins, analysed in this research, is the vivid example of the need to adopt non-idealising approaches in legal, as well as, medical decision-making process related to conjoined twins.

This study demonstrates the essential character of addressing the issue of the legal personality of conjoined twins. From the combined perspectives of law and medicine, the thesis argues that conjoined twins, as they possess a separate brain, should enjoy legal personality and their right to life must be protected equally to others. Conjoined twins need legal protection which is impossible to provide without determining their legal personality, and so their right to life is not infringed either in separation surgeries.

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For the possible creative mistakes in this research, I am the only one responsible.

1. INTRODUCTION

1.1 Background

Which are human rights that are alerted when conjoined twins are born? What challenges does the figure of the conjoined twins pose to human rights law?

The body is a basis for people to make assumptions about each other. Human anatomy governs people's lives in many respects. Furthermore, there are many legal regulations regarding who can do what based on their anatomy, even, as discussed in the following thesis, who can have legal personality and claim a right to life.

Everyone goes through the process of "normalisation" daily to fit into socially accepted norms. However, some people are born with the anatomies that do not quite fit these normative standards. The thesis explores the construction of the conjoined body from the legal and medical perspective and how the related discourses and practices fail to deal with the legal challenges posed to them by the unique figure of conjoined twins.

Legal and medical discourses depend on normative presumptions of the body. More precisely, the concept of individuality that is used to articulate a coherent discourse of human rights is limited to singleton people. The cases analysed in this thesis shows how the figure of conjoined twins challenge medical and legal discourses that necessarily must "individualise" and "normalise" them. Besides, this research demonstrates how cultural imperatives of embodied individuality produced within the legal and medical discourses endanger the legal interests, as well as the bodies of conjoined twins.

The normalisation of the body and total dependence on the concept of individuality to articulate human rights to a person endangers not only legal interests of conjoined twins but also sets undesired legal standards for singleton people and affects human rights law in general terms.

1.2 Statement of the problem

The following thesis critically examines medical and legal discourses that construct and "normalise" the bodies of conjoined twins to articulate human rights. As argued in this

research, such construction and “normalisation” of the body of conjoined twins affect their legal interests in many ways.

The research explores the role of law and medicine in producing the dominant discourses of the “normalised” body and the concepts that define legal personhood. The normalisation of the conjoined body, i.e. court-sanctioned separation of the conjoined body and the lack of a definition of legal personhood, as demonstrated in this thesis, affects the right to life of conjoined twins.

This process of “normalisation” also affects people with singleton bodies. In other words, having legal and medical discourses that exclude conjoined twins from the protection of fundamental human rights also has a potential to influence singleton people’s treatment by setting undesired standards of treatment and having “mix-and0match” law system.

The limited construction of legislation not only produce the “monster” category out of conjoined twins but also limits the ways to accommodate physical differences in it. Although the category of a “monster” does not exist per se in legal terms, the thesis will demonstrate that conjoined twins are still treated as “monsters” shifted into medical terms.

A critical reading of the cases regarding surgical separation of conjoined twins will further lead to see the potential impact on subsequent case law. From that point, the thesis intends to provide general ideas about the influence of conjoined twins’ judgements and its significance for human rights law. Namely, this thesis shows the importance of the figure of conjoined twins for understanding the notion underlying all human rights law: the construction of legal personality which enables an individual to have human rights, including the fundamental right to life.

1.3 Significance of the study

By analysing legal and medical discourses, the study gives a practical overview of the problem of separation surgeries of conjoined twins and explores the potential impact of such surgeries on human rights law. This study examines why it is at all interesting to look at the figure of conjoined twins to advance human rights.

The study of this subject has revealed that there is a limited number of studies done in this regard. Usually, the legal researches related to conjoined twins is limited to medical law

review; however, a little has been done to discuss it from the perspective of human rights law adequately.

Even though recently more attention is paid to these issues from legal scholars, still the importance of conjoined twins' cases to better understand human rights is underestimated.

The following can be used by human rights lawyers to understand better human rights law and existing old assumptions still used in practice and the problems such pre-given rules can cause.

1.4 Research questions

Based on analyses of the empirical material, international human rights law standards, case law and literature review relevant to the topic, the thesis will focus the following two questions:

1. How the lack of legal personality affects the right to life of conjoined twins in separation surgeries from a legal point of view?
2. What impact conjoined twins' judgements have for human rights law?

1.5 Methodology and theory

The study uses the case study as a research method. While performing this analysis, the multiple-case design is preferred over one case design which allows to critically analyse medical and legal discourses related to the treatment of conjoined twins, draw general narrative and reach the conclusions.

In doing the case study, this thesis focuses on three main cases to form the idea how the conjoined twins are treated in medical and legal practices. Thus, this study illustrates the challenges they pose to human rights law that solely concentrates on accommodating singleton people and fail to accommodate biological differences.

The cases analysed in this thesis are (a) Case of Lakewood, (b) Case of Re A (Children) and (c) Case of Nolan. However, the main emphasis is the case of Re A (Children) since this case is the most well documented and significant for scholars to refer to in their studies.

There is a certain reason to select three cases mentioned above. As it is demonstrated in this study, these cases vividly illustrate of what this thesis tends to show: human rights law and

medicine are constructed on the idea of “one body, one identity” model which only accommodates singleton people. Therefore, in articulating legal personality and human rights, it is no surprise that the bodies of conjoined twins do not quite fit in the legal framework. Besides, there is no definition of the legal personality of conjoined twins in an accurate manner. Legal systems fail to offer precise rules to solve the conflicts between their legal interests. The other cases, for example, the ones that include removal of “extra flash,” i.e. there is no live-brain person present, do not seem to pose any legitimate doubts and need not be sanctioned by the court. So, by removing an “extra hand,” the doctors will not face criminal responsibility for the murder while separating conjoined twins surgically may arise such issue.

The three cases listed above and analysed throughout this thesis have often been the subject of discussions among scholars in different fields. However, there is a limited number of research done to investigate the figure of conjoined twins from a human rights law perspective. Usually, scholars focus on philosophical, ethical and other aspects of the cases. By looking at the three specific cases and critically examining them it is possible to draw general narrative how the courts review such cases in practice and analyse in what ways such treatment has potential to influence human rights law concerning singleton people as well.

Besides the case law invoked in this research, a set of international human rights instruments is used to define the right to life specifically for cases of conjoined twins in separation surgeries. In this age of human rights, separation surgeries, among other effects, also brings potential conflict with the right to life. This right protected in several international instruments is interpreted in many ways. The focus of this thesis is Article 2 of the European Convention on Human Rights (hereinafter the ECHR), as long as the case of *Re A (Children)*, among other issues, also analysed possible effects of Article 2 of the ECHR on Human Rights Act 1998. The Court of Appeal considered it as an inevitable part of national legislation. To be more precise, Article 2 of the ECHR is incorporated into Human Rights Act 1998, and The Court of Appeals has confirmed this during the decision-making process in the case of *Re A (Children)*.²

Article 2 of the ECHR imposes negative, as well as positive obligations upon the state to preserve the life of all within its jurisdiction. It is not an absolute right. However, it has been recognised as a fundamental one.³

² *Re A (Children) (Conjoined Twins: Surgical Separation)* [2000] 4 All ER 961.

³ Douwe Kroff, *The right to life: a guide to the implementation of Article 2 of the European Convention on Human Rights*, (Strasbourg: Council of Europe, 2006), accessed May 19, 2017.

As it is evident, the right to life protected under Article 2 of the ECHR, influences the national legislation, such as it did in the UK in case of *Re A (Children)*. In separation surgeries, the right to life seems to be protected more for one twin than the other's. No doubt, the decision to separate a live brain person knowing that she/he would die necessarily invokes the possible conflict with the right to life defended by the ECHR. Namely, in the case of conjoined twins when one twin's legal interests come into conflict with another twin's, how these interests are to be balanced? And, since the established law deals only with the interests of a singleton child, whose interests are to be paramount?

What is problematic is that the construction of a legal problem in that way is that twins are competing for life necessarily results in a legal conflict with the concept of the right to life reflected in Article 2 of the ECHR. Every individual, conjoined or singleton, must be protected equally before the law. This is very clearly established by the Article 2 of the ECHR. In the case of *Re A (Children)* the Court of Appeal acknowledged that both conjoined twins Mary and Jodie were separate persons, so how come that one's life matters more than other's? That seems to underline the problem in human rights law itself, a person's voice is heard in the legal world only in case the body meets certain criterions, i.e. being a singleton is a "must" to be protected.

Feminism is used as a guiding theory to critically analyse legal and medical discourses and evaluate how the thrive of idealising embodied personhood hinders the determination of legal personality of conjoined twins and affects the right to life.

Feminism as a theory focuses on the embodiment. As Christine Overall explains, by referring to Shildrick and Davis, different bodily characteristics and experiences, for example, health, disability, age and the appearance challenge people to consider how various kinds of bodies are treated as sites for oppression.⁴ She maintains, by referring to Weitz, that feminist theory questions embodiment in many respects, particularly if some bodies are more valuable than the others and whether there is a difference between what is or is not natural for human bodies.⁵ In other words, feminism focuses on the meaning and use of bodies, and how they reflect the culture in which they are rooted.

⁴ For example, see Kathy Davis, "Surgical Passing Or Why Michael Jackson's Nose Makes "us" Uneasy," *Feminist theory*, 4, no.1 (2003): 73-92, DOI: <https://doi.org/10.1177/1464700103004001004>.

⁵ Christine Overall, "Conjoined Twins, Embodied Personhood, and Surgical Separation," In *Feminist Ethics and Social and Political Philosophy: Theorizing the Non-Ideal*, ed. Lisa Tessman (Dordrecht: Springer, 2009), 69-84.

As a guiding theory of this thesis, feminism helps to critique a particular aspect of the ideal theory, namely the idealising portrayals of personhood employed in ideal theory which seems to be rooted in legal and medical discourses analysed in this research. Christine Overall, argues that ideal theory tends to ignore the fact that persons are embodied at all; feminist theorists do much better in this regard and regularly include considerations of racialised bodies and bodies that are shaped by abilities and disabilities.⁶ However, even feminists assume the embodied personhood of a singleton. Overall challenges this assumption by stating that the only and ideal ways of being embodied are considered to be a singleton which should not be taken as a universal for everyone.⁷

As demonstrated in this research, taking for granted the inevitability or the desirability of singleton embodiment leads to inadequate legal treatment of conjoined twins, who, as Overall argues, are not necessarily better off being “normalised,” that is, turned into singletons through surgical separation.⁸

Christine Overall explains feminist approach about the embodiment of personhood and suggests that one form of embodiment is subjected to feminist analysis and critique seldom: the state of what she calls *singletonhood*.⁹ Overall defines singlehood as (1) fundamental unattachment to any other individual and (2) having a one-to-one relationship between a single human body and consciousness.¹⁰ Furthermore, it includes three key features: (a) the individual’s physical independence, (b) the person’s ownership of and authority over her body and (c) the person’s self-awareness as a single body and sense of privacy on the body.¹¹

To apply feminist theory to the present study, one shall see that human bodies are not necessarily well-endowed with meanings and significance. Many physical features and values of bodies are applied or misapplied to the figure of conjoined twins in the legal and medical decision-making process in strive to manipulate and change their embodiment. The bodily experiences conjoined twins have, and the lack of determination and recognition before the law

⁶ See note 5 above.

⁷ See note 5 above.

⁸ The same position is shared by Alice Domurat Dreger. By referring to personal stories of conjoined twins, she states that there was only one case where the twins wanted to be separated. In her book “One of Us, conjoined twins and the future of normal” she states that they usually do not feel there is something abnormal about them and choose to stay conjoined.

⁹ See note 5 above.

¹⁰ See note 5 above.

¹¹ See note 5 above.

affects their right to life, as well as human rights law in general. It sets unnecessary standards of treatment for singleton people in the context of Article 2 of the ECHR.

By applying the feminist analysis of singlehood to this research, one can easily see that conjoined twins challenge the orthodox view of singletonhood's universality and that the properties of singletonhood ought not to be taken for granted as unexceptional or as ideal. The legal and medical discourses are so concentrated on physical unattachment to anyone else that conjoined twins are excluded from legal protection in practice.

Overall's feminist critique comes very useful to explain the legal issue of this thesis. The treatment of conjoined twins reflects one or both following errors: "the erroneous attribution to conjoined twins of the properties that constitute singletonhood, or the assumption that these properties are inevitably the only or at least the best way of experiencing embodied personhood."¹²

It is argued throughout this research that medical and legal discourses fail to consider the characteristics that make conjoined twins embodied personhood legally valuable. From the cases discussed below, it is evident that failing to understand the varieties of human embodiment, valuing some forms of embodiment more than others or over-generalising from one type of embodiment to another can lead to unjustified ethical and legal judgments and influence human rights in many respects. Hence, the examination of the legal personality of conjoined twins demonstrates the need of adoption for non-idealising approaches to the legal decision-making process.

In contrast to the previous researches done in the field, for example, Amy Campbell's work "Contestable bodies: Law, Medicine and the case of conjoined twins," this study analyses both: technical side of the proper legal decision and why separation surgery of conjoined twins is to be considered in the frame of law. Campbell's work analyses, not the problem of determining whether to separate conjoined twins at the cost of the life of one but focuses solely on problematic. In other words, Campbell's work is less keen to discover technical elements of a proper legal decision and more about finding out how it happened at all that conjoined twins and the issue of their surgical separation became a matter of law.

Furthermore, unlike other analysis, for instance, Adam Peter Bunting's "Guiding principles in medical law: the ability to treat," this thesis does not focus only on one of the branches of law rather it takes a broader approach. More precisely, rather than analysing the legal

¹² See note 5 above.

challenges the figure of conjoined twins poses to specific areas of law, such as medical law, criminal law, and so forth, this research takes a novel approach by framing the legal issues as a question of human rights.

What is more, this thesis argues that conjoined twins are considered as “monsters” in legal terms. Sharpe, for example, reaches the same conclusion. However, what is novel in this thesis is that it argues that although the category of “monster” does not exist per se in legal terms conjoined twins are still reviewed like that because this concept was shifted into medical terms.

1.6 Delimitations

This research focuses on the cases of conjoined twins where each twin possesses its separate brain. For this reason, this thesis excludes so-called “parasitic conjoined twins,” the births where extra “non-thinking” parts of the bodies are present and the ones where there is only one brain present.

The following thesis does not intend to condemn separation surgery or to argue whether any judicial decision was “wrong” or “right.” Alternatively, it argues that just because of the different body, conjoined twins should not be excluded from legal protection in practice and should enjoy their legal personality, along with the fundamental right to life, equally with singletons.

1.7 Structure

Chapter 2 provides clinical facts about conjoined twins and their documented history. The documented history shows how exactly law and medicine labelled conjoined twins in different times and geographical locations and what status they carry nowadays. This chapter provides Foucault’s analytical framework through which the reader understands how conjoined twins are still dealt as “monsters” shifted into medical terms in the contemporary legal world.

Chapter 3 chapter introduces the medical and legal discourses to unfold and analyse the legal personhood, the “normal/abnormal” body, and the right to life of conjoined twins. Besides, the relevance of the figure of conjoined twins to better understand human rights law is provided. This chapter analyses what impact these discourses of law and medicine have on judgements of separation surgeries and how these overall influences human rights law.

Chapter 4 analysis the legal personality for conjoined twins and the requirements one should meet to be considered as a human and a carrier of legal personality to claim the fundamental human rights, including the right to life, underestimated in separation surgeries.

Chapter 5 analysis the fundamental right to life in the light of the European Convention on Human Rights, in particular, Article 2. Therefore, the statements made in previous chapters are applied to three cases of conjoined twins to demonstrate the legal problems they face. Analysis of these cases helps to understand how exactly the understanding of one's individuality influences other human rights cases while misapplying fundamental principles.

Chapter 6 by drawing on the findings of the previous chapters provides the available options to conceptualise conjoined twins. Each possibility of conceptualization is analysed, and the chapter intends to answer which option would bare a practical value. Thus, this chapter provides a brief answer to the research questions to remind a reader once again what exactly is there for the human right law to learn from the figure of conjoined twins.

Chapter 7 summarises the thesis and provides the concluding notes.

2. UNDERSTANDING CONJOINED TWINS

Conjoined twins walk into a bar and one of them orders drink. The bartender asks for proof of her age. The other twin turns around so that she is the one facing the bartender. Because the second twin appears old enough to purchase alcohol, the bartender decides to serve the drink without seeing proof of age of the other twin.¹³

Historically, human body carries out an important role in distinguishing persons from each other. The basic legal, ethical and social presupposition “one body, one identity” guides persons in everyday dealings with others.¹⁴ However, the figure of conjoined twins challenges this Orthodox presupposition.

The phenomenon of conjoined twins has been a subject of discussion of many areas, such as medicine, philosophy, law, religion, sociology and so forth.¹⁵ To fully understand how modern legal and medical worlds construct and understand the body of conjoined twins, what status they carry and what legal challenges they pose, it is important to trace the extraordinary body through the lens of biology and briefly provide their documented history.

2.1 The biology of conjoined twinning

The process of division of a human zygote influences biological forming of conjoined twins. As explained by Medical Center of Maryland, twinning occurs in two different ways: when a woman releases two eggs, or she produces one egg that divides after fertilisation. In the case of conjoined twins, a woman produces only one single egg which does not separate entirely after fertilisation. The developing embryo starts division process during the first few weeks after conception into two identical twins. However, the process of division stops before it is complete and the partially separated egg develops into a conjoined fetus.¹⁶

¹³ Lori Schappell, in communication with Alice Domurat Dreger, December 9, 2002.

¹⁴ Geil Weiss, “Intertwined Identities: Challenges to Bodily Autonomy,” *Perspectives: International Postgraduate Journal of Philosophy* 2 no. 1 (2009): 22-37.

¹⁵ The list of academic literatures on the figure of conjoined twins in different areas are too vast to place in one place. For example, from legal perspective, one could consider the following literature: M. P. Battin, *Ending Life: Ethics and the Way We Die* (Oxford University Press, 2005); Lewis, *Assisted Dying and Legal Change* (Oxford University Press, 2007); J. Griffiths, H. Weyers and M. Adams, *Euthanasia and Law in Europe* (Oxford: Hart Publishing, 2008).

¹⁶ “Facts About The Twins,” *University of Maryland Medical Center*. N.p., 2016, Accessed May 19, 2017 <http://www.umm.edu/programs/conjoined-twins/facts-about-the-twins>.

Conjoined twins might be joined at different parts of the body. Classification of their bodies depends on the anatomical site of conjoinment. The Greek suffix *pagus* indicates the fixation of a particular part of a body. For example, fixation of the head (craniopagus), abdominal (omphalopagus), pelvic (ischiopagus), chest (thoracopagus) or coccyx and sacrum (pygopagus) fixation.¹⁷ Worth to note, that the term “conjoined twins” is favoured over “Siamese twins” and is considered as more proper form.

Conjoined twins are genetically identical. Thus, they are always the same sex.¹⁸ As it is evident and widely documented, conjoined twins are not limited to any ethnic or racial group. Thus, conjoinment is not restricted to humans but has occurred snakes, cats, dogs and so forth. However, for the thesis, only human conjoinment is relevant.

Nevertheless, the good general documentation of conjoined twins, it seems an impossible task to provide exact data on conjoined twins births as they differ from source to source. For example, J. David Smith claims that the incidence is “somewhere between once in every 50,000 to 80,000 births.”¹⁹ Alternatively, Alice Domurat Dreger provides that they “account for perhaps as few as one in 200,000 births and no more than one in 50,000.”²⁰ Data of conjoined twins births do not include undocumented cases or the abortions performed. To be more accurate, the figures provided are collectable data rather than a real number which should be higher.²¹

According to Maryland Medical Center, nearly 40 to 60 percent of conjoined twins are stillborn. About 35 percent survive a day. The overall survival percentage of conjoined twins is between 5 and 25 percent.²²

Conjoined twins do not necessarily involve two equally healthy bodies. In that case, usually, separation surgery comes into the scenario as a “solution” to the “problem.” Surgical separations often place one twin at greater risk of death than the other. At this point, the separation becomes not only a matter of medicine but life and death of the patient and involves

¹⁷ “From “monsters” to modern medical miracles: selected moments in the history of conjoined twins from medical to modern times,” *U.S National library of Medicine*, accessed February 9, 2017, <https://www.nlm.nih.gov/hmd/conjoined/embryology.html>

¹⁸ See note 16 above.

¹⁹ J. David Smith, *Psychological profiles of conjoined twins: heredity, environment, and identity* (New York: Praeger, 1988), <http://catalogue.nla.gov.au/Record/322500>

²⁰ Alice Domurat Dreger: *One of us: conjoined twins and the future of normal* (Cambridge, MA: Harvard University Press, 2004).

²¹ See note 20 above.

²² See note 16 above.

legal considerations by the courts, so the doctors do not face the charge of murder. Medical treatment does not include only medical ethics but lays at the crossroad of medicine and law.²³

Such separation surgeries are sometimes called “sacrificial” ones. There is no universally agreed definition of the concept of “sacrificial surgery.” However, Alice Domurat Dreger explains that there is an extraordinary form of separation in which doctors “intentionally sacrifice” one twin to save the other.²⁴ Increasingly common, these surgeries represent the only case in which surgeons are given explicit permission to separate live-brain person from the organs keeping her alive, so someone else may survive, states Dreger.²⁵

Before moving to the documented history of conjoined twins, one must answer a preliminary question: are conjoined twins one person or two people from a medical perspective? Shortly to say, two separate brains are the basis to consider conjoined twins as two individuals rather than one person. A brain, in the context of medicine, is the essence of existence.²⁶ However, the same question from a legal perspective is not answered adequately in relation to conjoined twins.

In the medical management of conjoined twins, one must keep in mind the fundamental tenets of ethical care as well, especially the principle of autonomy.²⁷ The particular importance of the principle of autonomy in cases of conjoined twins’ separation surgery, for the purpose of this thesis, is that it easily demonstrates how the misapplication of fundamental principles results in a depreciation of the right to life of the conjoined twins.

Many discussions have taken place about the figure of conjoined twins and the particular cases of separation surgeries within the of medicine. As claimed by Segal, “Nearly two hundred surgical separations of conjoined twins have been attempted, with approximately 90% occurring after 1950.”²⁸

²³ Mark Bratton and Susan Beryl Chetwynd, “One into two will not go: conceptualising conjoined twins,” *Journal of Medical Ethics* 30 (2004): 279-285.

²⁴ See note 20 above.

²⁵ See note 20 above.

²⁶ Leigh Atkinson, “Bioethical issues in caring for conjoined twins and their parents,” *Springer Link*, 20 no. 8 (2004): 504-507, DOI: 10.1007/s00381-004-0983-6.

²⁷ Richard Huxtable and Suzanne Ost, “Introduction – Medicine in the Courtroom: Judges, Ethics, and the Law,” in *Ethical judgments: re-writing medical law*, eds. Stephen W Smith et al., (Oxford; Portland: Hart Publishing, An imprint of Bloomsbury Publishing Plc, 2017): 1-37.

²⁸ Lynne Segal, *Why Feminism?: Gender, Psychology, Politics*, (New York: Columbia University Press, 1999).

The next step is to explore the documented history of bodily assumptions about conjoined twins and the debates surrounding separation surgery. In doing so, the contemporary characterization of the figure of conjoined twins from a legal perspective will be provided.

2.2 documentation of conjoined twins: from freak to patient

One of the earliest documented conjoined twins were Mary and Eliza Chulkhurst. Born in 1100, they lived for 34 years. Later, the most famous conjoined twin brothers, named Chang and Eng Bunker, were born in Thailand in 1811.²⁹ They married the sisters from North Carolina of the US, who gave birth to 21 children. Eng and Chang earned their living by attracting the audience in circus troupe and died at the age of sixty-three.³⁰

José van Dijck suggests, by referring to Fiedler, that for centuries people with different physical aberrations occupied the fairs and circus arenas.³¹ To exemplify, Dijck refers to, exceptionally large or small individuals, persons without clear-cut gender, or people with conjoined bodies, and states that they have always been the subjects of public attraction.³²

Exploring the documented history of conjoined twins shows a very rocky ride these twins had. They had different labelling in different times and geographical locations. They were seen as “freaks,” “monsters” and nowadays they are “saved” by medicine (or are they?). The unique body of conjoined twins and the ways medical and legal discourses construct and understand their bodies reveals the “normalisation” and “idealisation” of “normal body” practices that influence the legal decision-making process.

Besides, such “normalisation” is necessarily bound by the concept of individuality which is used to articulate human rights to a person. In this paradigm, it seems that mind/body problem remains to be the subject of discussion in conjunction with conjoined twins. Furthermore, the statuses they carried the problematises to distinguish human and “bestial creature” which has no moral value from the legal point of view.³³

²⁹ Sally Sheldon and Stephen Wilkinson, "Conjoined twins: the legality and ethics of sacrifice," *Medical Law Review*, 5 no. 2 (1997): 149-171. DOI: 10.1093/medlaw/5.2.149.

³⁰ Enas Qutieshat, "The Legal Personality of Conjoined Twins and the Coordination of Their Rights Conflict," *European Journal of Business and Management* 9 no.5 (2017).

³¹ José van Dijck, "Medical documentary: conjoined twins as a mediated spectacle," *Sage Journals* 24, no. 4 (2002): 537 – 556.

³² See note 31 above.

³³ This was one of the things the Court of Appeal discussed in separation surgery in the Case of Re A (Children).

The surgeries to separate twins are taking place often, and the media documents those surgeries widely.³⁴

To reflect more on the medical and legal status of conjoined twins nowadays and understand how they are labelled, more details about their documented history is vital to analyse.

A) Freaks

Conjoined twins were often used at so-called “freak show.” According to Elizabeth Grosz, conjoined twins were popular attractions in 19th-century fairs because they transgressed the boundaries of an ordinary human being. The “freaks” as conjoined twins were called, were the object of fascination and horror because “The Freak is an ambiguous being whose existence imperils categories and oppositions dominant in social life.”³⁵

In Europe and North America, “freak show” was a standard feature of circuses and travelling shows in the 19th century.³⁶ As Djick suggests, conjoined twins often displayed their bodies to the public; rejected by relatives and their communities, they were forced to surrender themselves with circus managers who exhibited their physical deformity.³⁷ “Freaks” were regularly imported from Asian or African countries, and their unusual bodies served as an integral part of the show. Thus, the “abnormality” was bound with racial or ethnic otherness and defined against the Western standards of normality.³⁸

To attract public attention and earn as much money as possible, “freak show” managers used many methods to accentuate the high scientific value of the show. The “freak’s” performance was accompanied by dressed-up “expert” commentary who explained this phenomenon to the audience. After the show, the audience could purchase autographed pictures of conjoined twins. Djick suggests that selling such pictures had two main aims: first, the sale of photographs yielded additional income and second, it also attracted new visitors who wanted to see the oddity with their own eyes.³⁹

³⁴ There are many documented stories that can be found online. For example, see <http://nytlive.nytimes.com/womenintheworld/2016/04/11/conjoined-twins-from-pakistan-undergo-free-separation-surgery-in-saudi-arabia/>.

³⁵ Elizabeth Grosz, "Intolerable Ambiguity: Freaks as/at the Limit" *Freakmaking. Constituting Corporeal and Cultural Others*, ed. R.G. Thomson, (1996): 55-65.

³⁶ See note 31 above.

³⁷ See note 31 above.

³⁸ See note 31 above.

³⁹ See note 31 above.

No doubt, such spectacles of “deformity” influenced the later labelling of conjoined twins in the medical and legal context. The details how conjoined twins were constructed and understood as “freaks” and “monsters” affected the way they are seen today. The explanation of this statement is provided as the next stage of this thesis.

B) Monsters

When speaking of a legal “monster”, one must note that the most questionable thing that is relevant to law, was and significantly is, whether they are one person or two people. As José van Dijck puts it, if the twins share a leg or when their heads are attached, their appearance invariably undermines the category of the “individual.” In legal terms, the “monster” caused difficulties, as it may not have been given the status of a person. This issue troubled, for example, the Court of Appeal in England in the case of *Re A (Children)*. The Court had to consider whether conjoined twins were “reasonable creatures” from a legal perspective and thus a person, or whether they were “monstrous births.”⁴⁰

During the Middle Ages and the Renaissance, individuals with such “abnormalities” were categorised as “monsters”, and the stories in which they figured were understood in mythical or religious terms, notes Dijck.⁴¹

Michael Foucault’s study of abnormality⁴² comes very useful as a framework to understand how the limited construction of laws and the depraved medical treatment’s dependence on the concept of individuality to articulate human rights, creates a space for “monster” category to exist in contemporary legal structures. To be more precise, although the category of monster does not exist per se in legal terms it is argued among scholars that the limited construction of laws allows a space of such category to exist.⁴³

Foucault in analysing the figures of the domain of abnormality creates three circles in which the problem of abnormality is gradually posed. He analyses three figures in his studies: (a) the human monster; (b) the individual to be corrected; and (c) the masturbating child.⁴⁴

⁴⁰ See note 2 above.

⁴¹ In 1573, Ambroise Paré published his famous tract *Des Monstres et prodiges*, in which he classified “monstrous people” on the basis of pseudoscientific terminology, notes Dijck.

⁴² Michel Foucault, *Abnormal: Lectures at the College de France 1974-1975*, (New York: Picador, 2003).

⁴³ For example, see Andrew N. Sharpe, *Foucault’s Monsters and the Challenge of Law*, (Abingdon: Routledge, 2010).

⁴⁴ See note 42 above.

The first of these figures, a “human monster” accommodates conjoined twins.⁴⁵ As Foucault highlights, “human monster” can be found in the law. He further explains that the notion of the “monster” is essentially a legal notion since what defines the “monster” is a double violation of law and nature so the field in which the “monster” appears can thus be called a “juridical-biological” domain.⁴⁶

Foucault’s study comes very useful to unfold medical and legal discourses, and “normalising” practices to create “one body one identity” out of conjoined twins. As stated by Foucault, when the “monster” violates the law by its very existence, it triggers the response of something entirely different from the law itself. It provokes either the will for suppression or medical care or pity.⁴⁷ However, the law itself does not respond the “monster's” existence; the “monster” is a breach of the law that automatically stands outside the law.⁴⁸

Foucault explains that conjoined twins also are a violation of nature. The “monster” is the natural form of the unnatural.⁴⁹ He furthermore states that this double ambiguity of law and nature are present, however, muffled. Thus, the legal and medical techniques that revolve around “abnormality” in the 18th and 19th century seem to be present. What is very important in Foucault’s study of “abnormality” is that he does not conclude that the monster seized to exist in legal or medical practices.⁵⁰

The full idea of the contemporary characterization of conjoined twins from the legal and medical perspective must be provided. To do so, the next stage is to briefly reflect how conjoined twins are shifted into medical world.

C) Patients

There are different explanations among scholars about why “freak show” diminished. For example, as explained by Robert Bogdan, the growing medicalization of society during the first

⁴⁵ Although Foucault analysis the existence of “monster” according to the three circles, this thesis focuses on the first category of other “monster” as the other two circles are beyond the scope of this thesis.

⁴⁶ Foucault, *Abnormal*, 55.

⁴⁷ *Ibid*, 56.

⁴⁸ See note 47 above.

⁴⁹ See note 47 above.

⁵⁰ The same opinion is reach for example by Alex N Sharpe in Andrew N. Sharpe, *Foucault’s Monsters and the Challenge of Law*, (Abingdon: Routledge, 2010).

decades of the 20th century resulted in decreasing interest in the figure of conjoined twins.⁵¹ Rather than being accepted as facts of life, congenital deformities were increasingly looked upon as handicaps that could be alleviated or solved through medical intervention.⁵²

Alternatively, as Djick suggests, Gerber criticises Bogdan's explanation of the gradual disappearance of the "freak show" in the early decades of the 20th century. According to Djick, Gerber suggests, the reason for its decreasing popularity was a general change in mentality; people began to feel social embarrassment at the public exploitation of "handicapped people."⁵³ Gerber argues that the disappearance of the "freak show" requires a more complex explanation than the one Bogdan provides.⁵⁴

Whatever the reason is for diminishing the "freak show" one fact can be observed clearly: medicalisation caused a change in public perception to the extent that conjoined twins are not regarded as "freaks" nowadays but as unfortunate individuals who are in need of medical help. Furthermore, the growth of medical knowledge resulted in a substantial increase in the number of "successful" operations aimed at separating conjoined twins.⁵⁵ In other words, conjoined twins could be liberated from their predicament with separating them surgically.

As already noted, it can be argued that the limited construction of laws and its dependence on the concept of individuality make the category of "monster" to exist in legal terms. As it is demonstrated in this thesis medicalization did not cause the disappearance of the "legal monster." Instead, it changed the character of a "monster" and focused on conjoined twins from a medical perspective, and the public attention shifted from the "monster" to the surgeon.

As van Dijck argues, in the 19th century, conjoined twins prominently figured as live attractions entertainment context; However, in the 20th century, their cultural role changed radically. They became part of a mediated spectacle in which the medical specialist takes centre stage as the cultural hero who seeks to liberate the poor twins from their physical confinement.⁵⁶

⁵¹ Robert Bogdan, *Freak Show: Presenting Human Oddities for Amusement and Profit*, (Chicago: The University of Chicago Press, 1998).

⁵² See note 51 above.

⁵³ See note 31 above.

⁵⁴ See note 31 above.

⁵⁵ See note 51 above.

⁵⁶ See note 31 above.

Even nowadays the way conjoined twins should be regarded is not clear. The vague labelling of conjoined twins in medicine and law questions whether conjoined twins are still “monsters” shifted into legitimate forms by being medicalized?

When it goes to the definition of their contemporary legal status, it must be noted that there is still ambiguity. As Sharpe notes, there has been no indication that conjoined twins seized to be “monsters” in the eyes of modern laws.⁵⁷ Thus, the construction of law in a very limited way is the basis to produce a “monster” out of conjoined twins as it leaves the room for such category to exist.

To sum up, the legal “monster” never actually disappeared, but took on a new coat; it evolved into medical terms, the appeal of which is based, to a large extent, on the convergence of medical and legal techniques, as Foucault argued it. However, becoming patient does not mean that they are not considered as “monsters” from a legal perspective anymore.

⁵⁷ See note 27 above.

3. NORMALISATION OF BODIES

3.1 Introduction to medical and legal discourses

The ethical coordination, in this thesis, is demonstrated by extraordinary form of separation surgery in which doctors with intention “sacrifice” one twin to save the life of the other. These surgeries recently increased in number. Thus, it represents the only case in which surgeons are given explicit permission from courts to separate brain-live person so someone else may survive. Because such surgeries are motivated by the belief that both children will die unless there is an intervention, such surgeries are turned into an ethical-legal battle.

Seen from the judgements analysed in this thesis the category of the “monster” still exists in the medical and legal discourses. This is where the discourse of law and medicine tend to show itself the most: treating a person with “abnormal” body not as a human, but as a “monster” based on the physical difference. Observation of Margrit Shildrick reveals that conjoined twins are not only “privileged signifier of the monstrous”⁵⁸ but also “limit case of the disabled body.”⁵⁹ The statements in medicine and law seem to be axiomatic. For this reason, it is difficult to question what appears to be already well-rooted. However, certain medical and legal notions of what human beings are intended to be, are problematic.⁶⁰

The law and medicine produce the discourses about human bodies and fail to accommodate bodily differences. As already noted, individuality is necessarily equalled with being a singleton. Dreger notes that the Western emphasis on physical separateness is so powerful that the medical profession is unable to grasp the concept of worthwhile conjoined life.⁶¹ Furthermore, Dreger observes that many conjoined twins, old enough to do so, express a desire never to be separated.⁶² Consequently, Dreger questions the fundamental: whose sake is the operation carried out? Although Dreger asks the questions from a sociological perspective, it makes a difference for human rights law too as the same issues challenge the legal world.

Should one agree with Mr Justice Johnson of the High Court, who said that prolonging one of the conjoined twin’s life would be “very seriously to her disadvantage”?⁶³ With Lord Justice

⁵⁸ See note 42 above.

⁵⁹ Margrit Shildrick, “Transgressing the Law with Foucault and Derrida: Some Reflections on Anomalous Embodiment,” *Critical Quarterly* 47, no.3 (2005): 30-45.

⁶⁰ See note 23 above.

⁶¹ Dreger, *One of us*, 11.

⁶² *Ibid*, 10.

⁶³ See note 2 above.

Walker of the Appeal Court, who suggested that Mary would gain from separation in acquiring bodily integrity, even in death? This way of conceptualising of conjoined twins is misconceived from a legal perspective, and it is easily demonstrated by the cases analysed in this research.

The drive to separate twins at all costs may be referred to evince a deeper unease with bodily configurations. As noted by Bratton MQ and Chetwynd SB, “that appear to threaten the premium that the Western ethical and legal tradition places on individuality and the physical circumscription that such sovereignty assumes.”⁶⁴

3.2 Bodies and the persons

Before examining specific aspects of the life of conjoined twins, an introductory note must be provided: it is important to understand how the conjoined twins’ body is constructed in the legal and medical world, how “abnormality” affects them to be considered as humans and to fit into the legal system. Furthermore, these concepts have practical importance in understanding human rights law as they necessarily affect legal personality and right to life of conjoined twins, as well as singletons.

People expect that an individual they meet will be the only person inhabiting in his/her skin. In other words, the concept of individuality requires anatomical individuality. People who lack such anatomical individuality are considered as “trapped,” and incapable of having a “normal” life.⁶⁵ Furthermore, the only “solution” to this “issue”⁶⁶ is to separate conjoined twins surgically; in other words, set them free by separating them.

The experiences of life are inevitable from the bodies. As Goffman puts it, the very ability to intervene in social life depends on the management of bodies in time and space.⁶⁷ Furthermore, historically, as Chris Shilling suggests, the body has dual status and has been something of an “absent presence.”⁶⁸ It is not present because researchers rarely focus on embodied human person. However, the body has been present at the very heart of sociological imagination, for instance, by the study of health and illness, life and death, and so forth.⁶⁹

⁶⁴ See note 23 above.

⁶⁵ See note 20 above.

⁶⁶ As noted by Lori Schappell in personal communication with Dreger, she does not live a conjoined life in the terms of individuality. Therefore, physical conjoinment is integral part of her life.

⁶⁷ Allan Graham, *Friendship: Developing A Sociological Perspective* (New York: Harvester Wheatsheaf, 1989).

⁶⁸ Chris Shilling, *The Body and Social Theory* (London: SAGE, 2003).

⁶⁹ See note 68 above.

The reason why body matters to human rights law is simple: human rights are designed for humans and body which fails to be human's body is also excluded from legal protection and is unable to claim human rights.⁷⁰ In analysing species and speciesism in conjunction with “moral value” of a person, Stephen W Smith notes that historically membership of species determined moral worth. Those things which were classed as human beings were morally relevant, says Smith. Besides, as he notes, large populations of entities which were human beings (e.g. women, slaves, and so forth) were not classed as morally relevant, so it was not as easy as being human. However, what was an essential part was that the entity must have been a human being to be considered as morally relevant. So, while not all human beings may have always been morally relevant, only human beings were ever morally relevant.⁷¹

Dreger in her book introduces the idea of anatomically based rules. These rules are the unspoken, however, the normative idea of what a body “should be.” Dreger notes that these restrictions and norms both formally and informally sanction across the eras and cultures. These rules, while helping to maintain order and protect those who are vulnerable, also exclude some people while providing privilege to (most) others. She discusses a stigma imposed on children born with what she calls “non-normate bodies” or those bodies that defy conventional “normalising” practices and states that the notion that a conjoined twin must individuate to the same degree singletons sets unjustifiable standards for everyone.

3.3 What influence the figure of conjoined twins has on human rights law?

The cases of conjoined twins are mainly mediated within the medical law; however, a little has been done to reflect how they influence human rights law in the bigger picture.⁷² The main question relevant to the human rights law context remains without answer: what are the most important lessons there for human rights law to learn by looking at the figure of conjoined twins?

⁷⁰ Stephen W. Smith, *End-of-Life Decisions in Medical Care. Principles and Policies for Regulating the Dying Process*, (Cambridge: Cambridge University Press, 2012).

⁷¹ See note 70 above.

⁷² Usually, the researchers analyse how various human rights instruments impact conjoined twins and not vice versa. For example, see Austen Garwood-Gowers, John Tingle and Tom Lewis, *Healthcare Law: Impact of the Human Rights Act 1998: A tool for changing health care law and practice*, (London: Cavendish Publishing, 2001).

As it has already been made clear in this research, human rights law system depends on the concept of individuality to articulate human rights to a person. But who can be considered as a person in legal terms? As explained in this thesis, to be a carrier of legal rights one must be a human being; however, being only a human does not seem to be enough from a legal point of view. This is precisely where the legal and medical discourses tend to show themselves very well. To be more precise, human rights law can learn something fundamental about its own presumption about what the "human" in human rights law is: a singleton.

The concentration solely on singleton bodies by the human rights law system is very well demonstrated by the case of *Re A (Children)* analysed in this thesis. In returning to the reasoning of the Court of Appeal in the case of *Re A (Children)*, as to why separation surgery is to be considered as a lawful one, it is important to emphasise bodily integrity from a legal perspective.

As Sharpe explains, liberal law's differential deployment of concern over bodily integrity across the singleton/conjoined twins divide.⁷³ Sharpe notes that while law fails to guarantee the right to life in the case of conjoined twins, it prohibits encroachments on the bodily integrity of singletons even where they pose no threat to life. Therefore, in the context of criminal law, singletons are protected from even minimal invasions of bodily integrity.⁷⁴ Sharpe clarifies, by referring to Goff, that "the fundamental principle, plain and incontestable, is that every person's body is inviolate. It has long been established that any touching of another person, however slight, may amount to a battery."⁷⁵

Sharpe further points out that this is consistent with liberal law's claim that it seeks to protect the physical autonomy of subjects and to promote the value of life as intrinsic worth. This contrast in the legal protection afforded finds further expression in civil law.⁷⁶ To illustrate this point more clearly, she refers to a case of *McFall v Shimp*.⁷⁷ A case where a competent adult refused to donate bone marrow in circumstances where he was the only suitable match for his cousin who was suffering from aplastic anemia. While the operation represented the only

⁷³ Andrew N. Sharpe, *Foucault's Monsters and the Challenge of Law*, (Abingdon: Routledge, 2010).

⁷⁴ See note 73 above.

⁷⁵ See note 73 above.

⁷⁶ See note 73 above.

⁷⁷ *McFall v Shimp*, 10 Pa.D. & C. 3d 90 (1978) in Andrew N. Sharpe, *Foucault's Monsters and the Challenge of Law*, (Abingdon: Routledge, 2010).

chance of survival, the court insisted that a person could not be coerced into undergoing a surgical procedure.⁷⁸ The Court put the point more forcefully:

For a society which respects the rights of *one* individual, to sink its teeth into the jugular vein or neck of one of its members and suck from it sustenance for *another* member, is revolting to our hard-wrought concepts of jurisprudence. Forcible extraction of living tissue causes revulsion to the judicial mind. Such would raise the spectre of the swastika and the Inquisition, reminiscent of the horrors this portends' (Authors emphasis).⁷⁹

In analysing the language of law, Sharpe points out that Gothic language is interesting, especially because the similar language was employed by the Court of Appeal in the case of *Re A (Children)*.⁸⁰ She finds the similarity in the languages used in those two cases and notes that in *McFall v Shimp* the vampire metaphor is invoked in the face of horror provoked at the prospect of bodily invasion of a legal subject while in *Re A* it is Mary, precisely a victim of bodily invasion and, moreover, one whose life is certain thereby to be extinguished, who is presented in blood-sucking terms.

In other words, the sanctity of bodily integrity appears limited to the “normal” situation where the law must weigh the interests of legally separate individuals. In doing so, the legal interests lie in the embodied space and the principle of autonomy loses its true value. At that point, and in qualifying Mary’s right to life, Kantian imperatives are abandoned, states Sharpe.⁸¹

It seems that conferral of a full set of legal rights is conditional on a particular mind/body conjunction, i.e. one must be “normal” to qualify for the enjoyment of fundamental human rights. In relation to conjoined twins, even the most fundamental human right, the right to life which is central to this study, cannot be guaranteed. Ironically, this is despite the legal assumption that conjoined twins are separate legal persons for the purposes of analysis of human rights.

The medical and legal discourses reveal that bodily integrity is premised on separation. Cases analysed in this research leaves no space to conclude otherwise. For example, in case of *Re A (Children)* the judges concluded that bodily integrity was precisely what Mary would gain from separation, even by paying with her life.⁸²

⁷⁸ See note 77 above.

⁷⁹ See note 77 above.

⁸⁰ See note 2 above.

⁸¹ See note 73 above.

⁸² *Re A (Children) (Conjoined Twins: Surgical Separation)* [2000] 4 All ER 961, p 1069 and 1052

Watt advocates that “the suggestion that a conjoined twin should be given a more “normal-looking” body at the cost of her life represents a new low point in the way we see the disabled.”⁸³ By separating conjoined twins surgically to “normalise” them to the degree that they are rendered to singletons so they can fit into “justice” system is something that human rights law should consider.

The figure of the conjoined twins challenges contemporary understandings of human rights about how to accommodate rights to individuals who have a distinct kind of body. To afford human rights to conjoined twins as having an integral body - shared by the twins - rather than consider the twins as two competing rightsholders whose one right to life must override the other twins seems to go against the fundamental principle of human rights of right to life.

What is more, the separation of conjoined twins that necessitate killing one twin to save the other does push to the limits of the human rights law. Moreover, at that limit, judges tend to reach constructed decisions mediated by physicians. In other words, such struggle of human rights law to accommodate the figure of conjoined twins under its protection creates the basis to think about the limits of law and the limits of life in legal terms. It seems that there are severe limits to the judicial decision-making process in complex life and death decision making.

It seems axiomatic that physicians should be able to make life and death decisions, and if they want to go to court, that is fine, because courts almost uniformly bless whatever physicians want to do. How has medicine gotten such a hold on the judiciary that judges authorise and promote almost anything physicians want to be done, even if the judges must use analogies to the Nazis, people jumping out of airplanes, and monsters to authorise doctors to do what they want to do? This question is answered by George Annas in his study, who says that “it is because of the power that doctors have over our lives, the power science and medical technology have over our lives, and our hope that medicine and science will become even more powerful and help us achieve virtual immortality.”⁸⁴

Another significant shortcoming of the decision to separate conjoined twins at any cost is that there is no legal principle on which the decision of these judges rested⁸⁵. Such kind of

⁸³ Helen Watt, “Conjoined Twins: Separation as Mutilation,” *Medical Law Review* 9 no. 3 (2001): 237-245, DOI: <http://dx.doi.org/10.1093/medlaw/9.3.237>.

⁸⁴ George J. Annas, *American Bioethics: Crossing Human Rights and Health Law Boundaries*, (Oxford: Oxford University Press, 2005).

⁸⁵ See note 84 above.

ambiguities leads to “mix and match” type of law which, of course, will have its impacts on subsequent case law.

Perhaps, there are many other lessons for human rights law system to learn from the cases of conjoined twins. However, two more points that seem to be relevant in the context of this thesis are to be stressed out:

(1) the legal principles formulated in the judgments of conjoined twins will apply to subsequent cases of conjoined twins;⁸⁶

(2) Less similar cases will also arise, to which the legal principles might apply.⁸⁷

To reflect more deeply on each point one must note that it is unlikely that future cases might concern the fates of conjoined twins, but legal principles formulated in the prior judgments would surely apply to the future ones.⁸⁸ Furthermore, in the case of *Re A (Children)*, Ward LJ noted that the case would set no precedent for other cases.⁸⁹ However, this point is highly arguable since the doctrine of *stare decisis* is binding in nature and one must envisage even the most carefully contained principle being applied in future cases.⁹⁰

After considering two main legal implication conjoined twins might have on human rights, a question of core value is to be posed: are all humans from legal perspective worth a basic respect human rights intend to provide?

Human rights are recognised as universal in their nature due to the simple fact: people who have those rights are human beings and the right to life, addressed in this thesis, is recognised as fundamental human right because it is fundamental for people’s existence, a basic attribution of human dignity.

One must also consider, that while humans have these rights, this does not necessarily mean that such rights are unlimited in nature. In other words, the right an individual does not deserve more respect than the right of another person. Such equality is based on the logic that because all human beings are equal, there is no legitimate basis to distinguish between individuals in respect of their basic entitlements.⁹¹

⁸⁶ See note 27 above.

⁸⁷ See note 27 above.

⁸⁸ See note 27 above.

⁸⁹ See note 2 above.

⁹⁰ See note 27 above.

⁹¹ David Hoffman and John Jermyn Rowe, *Human Rights in the UK: An Introduction to the Human Rights Act 1998* (Pearson, 2006): 11.

Another alarming issue that the figure of conjoined twins poses to human rights law is the potential to create not stable and reliable form of law (so called „mix-and-match“ law). It seems that the search of legal principles to guide with through complicated legal issues in cases of conjoined twins have been especially difficult. Besides, under such laws, judges can choose to avoid the conclusions undesirable for them. Those judgments have implications for the way the courts and society at large look at human rights law, life and death issues and so forth. No doubt, the caution of the adoption of well-established principles to guide with need to be urged.

To sum up this chapter, the challenge of legal system is again apparent in relation to the legal regulation of conjoined twins. As demonstrated throughout this research, law refuses to view conjoined twins as possessing bodily integrity or dignity in practise. Rather, the privileged, and rights-bearing, subject of the law is clearly a singleton. It is, of course, for this reason that medicine and law insist on separation surgery, even to the point of death of one or both twins. This is something to think of from human rights law perspective: how to accommodate conjoined twins under its system.

4. LEGAL PERSONALITY OF CONJOINED TWINS

One can ask what is the most valuable practical function legal personality has for conjoined twins? To answer that question very briefly: legal personality forms the basis for claiming other rights, including the right to life, which is a fundamental one.

An ethical dilemma of separation surgery results when the siblings do not equally contribute resources, but rather one is considered “parasitic” by the fact of total dependency on the sibling.⁹² In this regard, the main legal and ethical question have always been, “should doctors be allowed to sacrifice one of the conjoined twins to save the other.”⁹³ However, the issue of whether to sacrificing one twin to save the other would be legally valid only if there are two individual human beings. In other words, one without legal personality cannot claim to be a carrier of the right to life or any other human right. Despite physical conjoinment, conjoined twins must be legally distinct individuals to assert their rights.

The legal battle whether there is one person or two people involve a variety of opinions among medical and legal scholars. Some scholars argue that physical conjoinment does not influence legal status of conjoined twins and they are two people. For instance, Helen Watt analyses case of conjoined twins and their separation surgery as a mutilation. She points out that even infant conjoined twins are “human moral subjects ... not reducible to his or her experiences, which come and go.”⁹⁴ Watt argues that the process of identifying someone as a human being (i.e. living human organism) necessarily involves keeping in mind that human bodies look and perform in different ways. Furthermore, the concept of an organism needs to be revisited to count how many living organisms were presented in the case of conjoined twins: “It was clear from the physical behaviour attributed to Jodie and Mary that there were two separate systems of self-organization, despite some overlap in the parts controlled by each system.”⁹⁵ To illustrate what she means, Watt brings the contrasting example where a baby is born with an extra leg, and this leg is not a part of an alternative self-organising system. Therefore, she concludes that it is simply an unusual part of the baby from whom it is protruding. In other words, extra leg poses no legal problems while excising a conjoined twin reveals to be problematic for a legal system which fails to accommodate twin’s interests and rights in it.

⁹² Oksana Jackson, David Low, and Don LaRossa, "Conjoined twin separation: lessons learned," *Plastic and reconstructive surgery* 129, no. 4 (2012): 959.

⁹³ Barbara Hewson, "Killing off Mary: was the Court of Appeal right?" *Medical law review* 9, no. 3 (2001): 284.

⁹⁴ See note 83 above.

⁹⁵ See note 83 above.

Bratton and Chetwynd reach the same conclusion, the scenario where one twin is “just some extra flesh attached ... would pose no ethical problems relating conjunction.”⁹⁶

Alternatively, John Harris argues that the infant conjoined twins are not persons at all and that the weaker twin has a certain life expectancy which he labels as “biographical life rather than a life of a person.”⁹⁷ The position of Harris is highly arguable from a legal perspective. However, both scholars miss the point that is addressed by Richard Hull and Stephen Wilkinson. Neither scholars, as noted by Hull and Wilkinson, differentiate conjoined twins from singleton twins, and they restrict their research to infants.⁹⁸ The comparison with singleton twins is necessary to ensure that conjoined twins have the same legal personality and their right to life is defended on the same level as of the singleton ones.

Obviously, one reason why the issues raised by cases of conjoined twins appear so intractable is that law and ethics have developed along the concept of individuality which is equated to a physical separateness, i.e. individual human beings with competing needs. It is individuality which often provides a basic unit in considering the ethical and legal rights and wrongs.⁹⁹ The ordinary meaning of "individual" itself emphasises physical separateness that necessarily excludes conjoined twins from the protection of human rights.

In constructing individuality, “normal” and “abnormal” bodies play a vital role to demonstrate how conjoined twins are excluded from the justice system. People think that the “abnormal” is defined in the light of the “normal.” However, it is in the face of what is unfamiliar that we are prompted to define more clearly what is “normal.”¹⁰⁰ Perhaps, this explains the strong affirmation of the connection between physical separateness and personal dignity expressed by the Court of Appeal in the case of *Re A (Children)*.

The unusual anatomy of conjoined twins could be taken as a starting point to question that connection, and challenge the ways of thinking about individuality and autonomy that necessarily affect the legal personality of conjoined twins.

One can easily see that two main ambiguities cause the deficiency in human rights law. First, is the dilemma whether there is one person or two people present. Second, is the absence of a determination of their legal personality. In other words, there is a lack of jurisprudence

⁹⁶ See note 23 above.

⁹⁷ John Harris, “Human Beings, Persons and Conjoined Twins: An Ethical Analysis of the Judgment in *Re A*,” *Medical Law Review* 9 no. 3 (2001): 221-236, DOI: <https://doi.org/10.1093/medlaw/9.3.221>

⁹⁸ See note 29 above.

⁹⁹ See note 29 above.

¹⁰⁰ See note 23 above.

providing guidelines for how to conceive the legal personhood for conjoined twins. The lack of regulation of legal personality conjoined twins have affects them in many aspects. This thesis concentrates on the right to life which is the most fundamental one for claiming other rights. However, these other rights that cannot be attributed and maintained without resolving the issue of legal personhood.

One must consider that there are many different viewpoints regarding whether conjoined twins are one person or two people. This point is something to stress on as it influences the construction of legal personality, consequently right to life and of course is decisive in conceptualising them. Out of many, there are four main opinions: inhuman theory, one-person theory, two people theory and mixed humans' theory.

In the case of separation of conjoined twins, can they be separated by the surgery? This question is answered differently by each of the theory listed above. These theories are analysed by Harper who states that, per one-person theory, the law must allow for saving one's life by sacrificing another's. Because one is regarded as one parasite to another, he/she does not have the legal personality and cannot qualify to be a person before the law. Thus, he/she does not have the right to life.¹⁰¹

Harper further explains that per two-people theory, the law must allow them to be separated by surgery and to own their independent life respectively, even if this kind of separation may eventually cause the death of one or two of them. However, according to the standpoint of mixed person theory, the law does not allow them to be separated by surgery because a mixed person is an independent person and is one of the shapes of the legal subjects as well, notes Harper.¹⁰²

Still, the question whether conjoined twins are two people or one person remains without the answer. Legally speaking, the answer to this is quite clear. The brain death has been taken as the appropriate standard to determine the death of an individual. It seems logical to assume that "life of brain" should be the decisive criterion for judging there to be a living legal person.¹⁰³

Furthermore, the doctors who have treated conjoined twins relate to them as two patients rather than one. Conjoined twins are reported as having separate activities, patterns, personality, and so forth. In some cases, such Eng and Chang, non-separated twins can live

¹⁰¹ R.G. Harper *et al.*, "Xiphopagus Conjoined Twins: A 300-year Review of the Obstetric, Morphopathologic, Neonatal, and Surgical Parameters," *American journal of Obstetrics and Gynecology* (1980): 617.

¹⁰² See note 101 above.

¹⁰³ See note 101 above.

long and fulfilled lives with some degree of independence from each other. Indeed, differing personalities are the rule among conjoined twins with two conscious minds.¹⁰⁴

Still, why is it so important to have a legal personality for conjoined twins? A “legal person” is recognised by a legal system and holds rights and can exercise rights, appear before the court and operate as a legal actor. In other words, a legal person’s voice is heard in law. Those individuals who lack legal personality are unable to function in dimensions of law. Similarly, if stripped as a person before the law, a person can no longer act in the legal universe.

In the light of explanations provided above, one shall assume that each of conjoined twins has a legal personhood. Conjoined twins addressed in this research should be assigned the same status of legal personality as separate infants of the same age.

The analysis of legal personality of conjoined twins leads to the next point of the thesis which is the right to life affected by the failure to accommodate physical difference of twins in medicine and law.

To sum up, legal personality shapes the concepts of life and death analysed in the next chapter. The language of life and death is bifurcated in legal discourse. In one respect, life and death reflect the biological status of a creature, whether that creature is a legal person or property. However, at a more conceptual level, the language of life and death reflects the conferral or denial of the ability to be an actor in law, i.e. to be a legal person.

¹⁰⁴ As Smith noted in his psychological review of the histories of conjoined twins, the fact that such twins have distinct personalities and although, they appear to share same genetics and environment, they are still individuals (smith, psychological profiles).

5. RIGHT TO LIFE

5.1 Legal construction of life and death

The legal construction of life and death necessarily involves legal personality as there is no right to life without having “moral value” from a legal point of view. The uncertainty about how many patients are there presents against some fundamental assumptions about legal personhood, individuality, embodiment and the right to life which is acknowledged as a fundamental right on international level.

The following thesis examines the right to life in the light of the ECHR since the Court of Appeal in the case of *Re A (Children)* relied on the ECHR as on the key document incorporated in domestic legislation, namely in Human Rights Act 1998.

There are key international instruments regulating the right to life, such as International Covenant on Civil and Political Rights in Article 6 and Universal Declaration of Human Right in Article 3 as well as the ECHR, Article 2.¹⁰⁵

The ECHR in Article 2(1) provides that everyone’s right to life shall be protected by law. Furthermore, it prohibits intentional deprivation of life “in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.”¹⁰⁶ The ECHR also clarifies that deprivation of life shall not be regarded as inflicted in contravention of Article 2 when it results from the absolute necessity. Absolute necessities for the purposes of the ECHR are listed in Article 2(2) of the ECHR and reads as follows: “(a) in defence of any person from unlawful violence; (b) in order to effect a lawful arrest or to prevent the escape of a person lawfully detained; (c) in action lawfully taken for the purpose of quelling a riot or insurrection.”¹⁰⁷

After considering who has “moral value” and assuming that conjoined twins who possess separate brains should have legal personality, one must note that in separation surgeries of conjoined twins often the best interests of children are of a primary consideration to take further “end-of-life decision.”

¹⁰⁵ As the main focus is on the ECHR the detailed review of other key documents is beyond the scope of this thesis.

¹⁰⁶ Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14, 4 November 1950, ETS 5, Article 2 available at: <http://www.refworld.org/docid/3ae6b3b04.html> [accessed 20 May 2017]

¹⁰⁷ See note 106 above.

As Smith correctly puts it, the “end-of-life decisions” take the form of a debate between two sides. One side refers to its position on the “sanctity of life”, and the other refers to its position as the “quality of life.” These two positions are seen as being mutually exclusive, meaning one must accept one of the two positions but cannot accept both.¹⁰⁸ Smith notes that John Keown has characterised the debate over quality versus sanctity of life in some publications where he considers three distinct positions one can take.¹⁰⁹

The first position Keown provides is so called Vitalism. Vitalism holds that life is an absolute value. Consequently, it should never be taken or even lessened.¹¹⁰ Thus, if it is possible to extend the life of a morally relevant individual for a second it should be done, no matter the cost in resources, time or energy. On the other side of the spectrum from Vitalism is the Quality of Life position.¹¹¹ The Quality of Life position holds that there is no value inherent in life. Instead, life is only valuable because it allows a person to do things which are valuable. Smith points out that to Keown this is an extreme position.¹¹²

Keown advocates the second position, what he calls the middle position of Sanctity of Life. The Sanctity of Life position holds that life is a basic or inherent good, but not an absolute one. It, therefore, should not be intentionally taken away, although one need not do everything possible to extend life when treatment is futile.¹¹³ What those taking the Sanctity of Life position do instead is to look at whether the value of the treatment is worthwhile.¹¹⁴

One must note that “the best interest test” might not be the best way for making the end-of-life decision from the legal point of view. To illustrate, the Court of Appeal in the case of *Re A (Children)* used exactly that test. Can one say that the operation was really in the best interest of Jodie knowing that she might be severely disabled and would need further operations?

Gillon acknowledges that, as a result of the separation, Jodie would grow up knowing that her life was a result of a decision she never took, namely „that would kill her sister.”¹¹⁵ Dealing with Jodies’ best interest also demonstrates the try to fit her into socially accepted norms about the body. The medics concluded that “prolonging her life is an obvious benefit to her. In general

¹⁰⁸ See note 19 above.

¹⁰⁹ Keown, *Euthanasia, Ethics and Public Policy: An argument against legislation* (Cambridge: Cambridge university Press, 2002).

¹¹⁰ Keown, *Euthanasia, Ethics and Public Policy*, 39.

¹¹¹ *Ibid*, 43–44.

¹¹² For example, see S. Pattinson, *Medical Law and Ethics* (London: Sweet and Maxwell, 2006).

¹¹³ Keown, *Euthanasia, Ethics and Public Policy*, 40–41.

¹¹⁴ *Ibid*, 42-43.

¹¹⁵ Raanan Gillon, „Jodie and Mary, Conjoined Twins: A Case of Judicial Moral Hubris?” *Medico-Legal Journal* 72 no. 3 (2004):6.

terms, she will live a normal or fairly normal life.” This assessment of “normal” life does not seem to fit the concept of the right to life. Furthermore, can anyone claim that it could be a reliable argument to end life? Are not all the humans designated to die at some point?

The problem of the separation was even less clear with regards to Mary’s best interests. Johnson J, in assessment Mary’s best interest, took into account the length and quality of life and concluded: “keeping Mary alive be very seriously to her disadvantage.”¹¹⁶ The reasoning of such kind is greatly unsuitable to the situation of conjoined twins. As Harris writes, individual, whatever the life expectancy is, it would be incredible to kill such person “against their will by a decision of the courts.”¹¹⁷

In *F v West Berkshire Health Authority* the court well-thought-out the definition of treatment in the best interests of the patient and came to a conclusion that the operation or treatment will be in patient’s best interests only if, it is carried out in to save their lives, to ensure improvement or prevent deterioration in physical or mental health. However, none of these potential goals were met in the case of Mary. The surgeon was frank in acknowledging there was no benefit for Mary in operation. In light of this precedent, one can argue that the Court of Appeal had no other choice rather than to reject Johnson’s reasoning regarding the right to life. However, the Court of Appeal, through differing reasons found lawful to “sacrifice” Mary to save Jodie.

The test of best interest failed the Court for one more reason: everyone is designed to die, no matter conjoined or singleton. For example, in the case of *Re A (Children)*, one can argue that the best interests of conjoined twins were analysed in medical terms and moral principles of judges rather than what is required by the law. It must be noted that the best interest is not limited to “best medical interests.”¹¹⁸

Separation surgeries bring it into potential conflict with the right to life. It does not seem a decision taken within the scope of the law, but a decision including moral considerations of the judges in it. Therefore, the question arises: who has power to decide who must live and who must die? Once again, in this type of decisions, by acknowledging conjoined twins as two separate individuals having the right to life, the problematic seems to formulate the legal issue in a way that two people are competing for one life while there are two lives.

¹¹⁶ *Re A (Children) (Conjoined Twins: Surgical Separation)* [2000] 4 All ER 961., p 175.

¹¹⁷ See note 97 above.

¹¹⁸ *F v West Berkshire Area Health Authority* [1990]

Taking into consideration the bodily difference of conjoined twins, one can easily see where the problem lies: human rights law is about singleton bodies only. Would it be two singletons the court would not construct the legal issue in that way, the doctors would not apply for operation either. In the light of the right to life, reflected in Article 2 of UDHR, the legal and medical discourses reveal the deficiency in human rights law itself: a failure to hear the voice of conjoined twins or as someone might put it, to muffle their legal interests.

Article 2 of the ECHR imposes negative and positive obligations upon the member states to preserve the life of all within its jurisdiction. One must note that this right is far from being an absolute. However, the legality of decisions to cease life-sustaining measures in the circumstances such as the conjoined twins, should not be in doubt. Unfortunately, the tendency of national judges to downplay the significance of the Human Rights Act 1998 has led to a problematic reconciliation of such treatment decisions with the patient's right to life. Rather than engaging fully with the intricate interests and responsibilities implied by Article 2, domestic courts have been content to read into the right to life a potentially wide-ranging exception where continued life-sustaining treatment is no longer in the patient's best interests.¹¹⁹

The relationship between the withdrawal of life-sustaining treatment and the positive obligation on the state to take reasonable steps to preserve life requires more advanced study than the test of best interests. The best interests test, at least as previously utilised, is an unsatisfactory solution to this potential conflict. Besides, the doctrine of double effect, used in case of *Re A (Children)*, further fuels the discussion about contestable bodies of conjoined twins, namely the nature of the identity of conjoined twins. There remains uncertainty about how many persons are present. This presses against some fundamental assumptions about legal personhood, individuality, embodiment and the right to life.¹²⁰

5.2 Cases of conjoined twins

The ethical dilemmas and legal battles surrounding the surgical separation of conjoined twins have been significant, especially after the development of technology.¹²¹ A growing number of cases have come before the courts where the decision whether to permit medical treatment is a

¹¹⁹ See note 2 above.

¹²⁰ See note 27 above.

¹²¹ See for example, the study performed by Louisiana State University Health Sciences Center, School of Medicine, New Orleans, USA "Ethical issues surrounding separation of conjoined twins."

matter of life and death for the patient. In this paradigm, one of the most outstanding are the cases of conjoined twins. Without a doubt, such unique cases involving “sacrificial” surgeries are exceptionally difficult to decide because of the conflict between ethical and legal values. Furthermore, from a legal perspective, it is challenging because the search for the settled legal principle to guide with the situation has been especially harsh.

As already noted in an analysis of what “normal” and “abnormal” bodies mean, the concept of individuality is central. As law and medicine are constructed on the idea of individuality¹²² to articulate legal personality and human rights, it is no surprise that the bodies of conjoined twins do not fit in the legal framework. What is more, the law does not determine the legal personality of conjoined twins accurately and fails to offer precise rules to solve the conflicts and disputes between their legal interests.

This legal awkwardness is especially significant in cases of separation surgeries. A biologically unavoidable separation is needed if the twins stayed conjoined, would lead to the death of both primarily because of the biological functioning of one, namely shared circulatory mechanisms.¹²³ As claimed by Johnson and Weir, in such circumstances, there is a deep-seated intuition to save life where conceivable, even if this leads to quickening the death of the other twin. In this regard, medically necessary detachment openly contradicts the two twin’s right to life, which therefore necessitates ethical and legal justification for the involved “sacrifice.”

The following three cases showed this kind of legal awkwardness: Lakewood case, the case of *Re A (Children)* and a case of Nolan. To provide a comprehensive answer to the central issues of the thesis the first step is to provide a short background of the cases.

Case of Lakewood

The 1977 *Lakewood* case appears to be the first case in which court approval was sought before “sacrificial” separation surgery. The twins shared a liver and one fused six-chambered

¹²² i.e. singleton bodies

¹²³ Reuben Johnson and Philip Weir, "Separation of Craniopagus Twins," *Cambridge Quarterly of Healthcare Ethics* 25, no. 01 (2016): 41 in Enas Qutieshat, "The Legal Personality of Conjoined Twins and the Coordination of Their Rights Conflict," *European Journal of Business and Management* 9 no.5 (2017).

heart. The parents agreed to separation surgery, knowing that one twin could not survive the procedure.¹²⁴

The surgeon's concern was that he might face charges of premeditated murder. He refused to perform surgery without the Court's sanction. Family Court of Philadelphia, with a three-judge panel, proceeded the case. The lawyers argued that the greater good would be served by saving one child instead of letting both die. In other words, "one of two greater evils" was preferable. Another argument of lawyers was that there would be no crime if a court ruled that the good outweigh the bad.¹²⁵

The lawyers used an analogy of a mountain climber who falls but is saved because he is roped to another climber. However, the second climber's hold is not secure enough to prevent both from plunging to their deaths, and he would, therefore, be justified in cutting the rope to save himself. The Family Court agreed with the logic in this argument and, after a few minutes of deliberation, authorised the surgery.¹²⁶

There is no written record of the hearing or decision.¹²⁷ The weaker twin died during the surgery, and the survivor died 47 days later after contracting hepatitis B from a blood transfusion.¹²⁸

Case of Re A (Children)

Rina Attard was about four months pregnant when an ultrasound scan showed that she was carrying conjoined twins. Seeking medical assistance unavailable on the Maltese island of Gozo, Michelangelo and Rina Attard had arrived at St Mary's Hospital, Manchester.

Born on 8th August 2000 Jodie and Mary were ischiopagus (joined at ischium) tetrapus (having four lower limbs) conjoined twins. Each of twins had their brain, heart, lungs and other vital organs. However, the twins shared their circulatory system at the main artery through which Jodie's heart supplied oxygenated blood to both children. Mary was severely "abnormal"

¹²⁴ Fred Rosner, "Contemporary Biomedical Ethical Issues and Jewish Law," (Jersey city: KTAV Publishing House, 2007): 32.

¹²⁵ See note 124 above.

¹²⁶ "The Twins Decision: One Must Die So One Can Live," Donald C. Drake, The Philadelphia Inquirer, October 16, 1977, <https://profiles.nlm.nih.gov/ps/access/QQBBXZ.pdf>

¹²⁷ Richard Berkman in communication with Colleen Davis (21 August 2009) in Colleen Davis, "The spectre of court-sanctioned sacrificial separation of teenage conjoined twins against their will," *Journal of Law and Medicine* (2004).

¹²⁸ J. David Bleich, *Bioethical Dilemmas: A Jewish Perspective* (New Jersey, Ktav Publishing House, 1998): 294.

in three aspects. Firstly, she had a primitive brain. The second problem was with her heart. Thirdly, there was a virtual absence of functional lung tissue. As claimed by the doctors, if she had been born a singleton, she would not survive birth.

After a medical examination by the doctors, they provided three available options to deal with Mary and Jodie. The first choice to leave twins conjoined would result in the death of both twins. Second option to perform separation surgery would preserve Jodie's life but prematurely end Mary's since her lungs and heart were deficient to oxygenate and pump blood through the body. In other words, in the case of separation Mary's death was foreseen. The third option, separating only in an emergency would diminish a successful outcome for Jodie significantly.

While not underplaying the operational complexities, one must note the nature of operation did not involve any organ transplant nor the donation of any bodily parts from one child to the other.¹²⁹

The parents, who were devout Roman Catholics, opposed separation surgery. They could not accept that one of their children would die to enable the other one to live. As they stated, everyone has the right to life, so why kill one daughter "to enable the other to survive."¹³⁰

Under many jurisdictions, the refusal of parents to operate their children would be the end of the issue since the parents' wishes would have prevailed. Nonetheless, the medical experts, unable to acquire the necessary parental consent, applied to the High Court for a declaration that surgical separation of the twins would not be unlawful.

Johnson J of High Court granted the declaration. According to the declaration, to operate twins would be lawful for two reasons. Firstly, it would be in the best interest of both twins. Secondly, cutting off the blood supply would be analogous to removing artificial nutrition and ventilation under the *Bland* principle.¹³¹

The parents of Mary and Jodie appealed the declaration in Court of Appeal on three grounds: (1) The separation could not be in Mary's best interests; (2) the separation could not be in Jodie's best interests; (3) The separation would constitute an unlawful act.

¹²⁹ When asked if the separation operation impinge on the bodily integrity of Mary the doctors suggested that the separation of the twins would necessarily involve exploration of the internal abdominal and pelvic organs of both twins and particularly the united bladder. It was expected however that each twin would have all its body structures and organs.

¹³⁰ Although, acknowledging that they would be governed by the law of England and everyone has the best interests of their daughters, they still did not want to allow the operation and kill one to save another twin.

¹³¹ Johnson argued that surgery would not only be in Jodie's but also in Mary's "best interests" since it would be her disadvantage to prolong her very short and hurtful life.

In the light of competing interests of Mary and Jodie, the court analysed the best interest of each twin. Regarding Jodie, the Court of Appeal did not take much effort to conclude that for her welfare, and her best interest lied upon being separated. As the Court of Appeal concluded, Johanson J. was plainly right to find that the operation would be in Jodie's best interest. Each of the three judges,¹³² with massively differing reasonings, established that the separation surgery would be lawful

Case of Nolan

On 3rd of May 2001, Alyssa and Bethany Nolan were born in Brisbane. The twins were joined at the head. They had separate brains but shared cranial draining veins, and Bethany had no kidneys or bladder. On 25 May, Bethany's health declined, and her death appeared imminent. The twins' parents gave permission for the girls to be separated, knowing that surgery would be fatal for Bethany.¹³³

Queensland applied to the Supreme Court for an order that the surgery would be lawful.¹³⁴ Chesterman J granted the declaration, relying on the duty imposed by s 286 of the *Criminal Code 1899* (Qld) on people who have the care of children under 16 years, in conjunction with the excuse in s 282, to find the surgery would be lawful. Section 282 relieves doctors from criminal responsibility if they perform, in good faith and with reasonable care, surgery for the benefit of the patient provided it is reasonable under all of the circumstances.¹³⁵

After providing a brief review of the cases, the crucial part is to understand what is at stake in those judgments. Many questions have to be answered, for example, did the courts based their decisions only on law or they included other considerations, and if they did, should they apply the other values of their own to the cases? Was it in the best interest of any of the twins to perform surgical separation? Are those cases a demonstration of court's failure of legal reasoning? Were the twins treated like less than animals? Should one twin pay with her life to normalise the other? What implications had this particular case for further judgments?

Despite the difference in facts of the cases, controversial issues and reasoning to perform sacrificial surgery on twins these cases and in general cases involving "sacrificial" separations

¹³² Lords Justice Ward, Brooke and Walker.

¹³³ *Queensland v Nolan* [2002] 1 Qd R 454, p 456.

¹³⁴ See note 133 above.

¹³⁵ *Queensland v Nolan* [2002] 1 Qd R 454, p 459-460.

have some features in common that enable to generalise criticism towards such practices. Conjoined twins can be used as a starting point to illustrate how limiting individuality to singleton bodies affect the right to life reflected in the ECHR.

While all three cases had different factual circumstances, reasonings, principles applied all there have something in common: the law showed itself at its limits of the right to life by being constructed along the model of singleton bodies. These three cases demonstrate the failure of human rights law to accommodate bodily differences in it.

As shown by the cases analysed in this chapter, law characterises the relationship between conjoined twins as conflict rather than cooperation. It seems that a conflict arises from the fact that legal systems are incapable of acknowledging conjoined twins as distinct legal persons. As Sharpe puts it, “valid ontological experience” cannot be accommodated by legal world.¹³⁶ The same conclusion is research by Overall in analysing feminism as a theory that the ontological status of conjoined twins is not welcomed from a legal perspective.¹³⁷

As Clark and Myser note, stated Sharpe, “both conjoined twins and singular bodies can only approximate this ideal condition.”¹³⁸

¹³⁶ See note 73 above.

¹³⁷ See note 5 above.

¹³⁸ See note 73 above.

6. CONCEPTUALISING CONJOINED TWINS

6.1 Conceptualisation possibilities of conjoined twins

All types of conjoined twins have their physical differences, and each situation should be a matter of case-to-case analysis from medical, as well as legal perspective. However, the minimum legal guardianship system should be provided to eradicate the human rights problems described in this research. The creation of such system would inevitably involve conceptualisation of conjoined twins and determination of their legal personality. Regulation of legal personhood issue would ensure the protection of the right to life of conjoined twins on the same level with singletons.

Bratton and Chetwynd provide three available options for conceptualising conjoined twins.¹³⁹ Although, they primarily consider the potential possibilities of the conceptualisation of conjoined twins with respect Jodie and Mary's particular situation. Still, the options provided in their article can be generalised and can be useful for wide-ranging guidance in legal and medical decisions.

Without a doubt, each of the conceptualization options has its advantages and disadvantages. The question is which of the three options provided above have a practical use? To answer that question, one must consider each case in turn.

The first possibility described by Bratton and Chartywnd is that only Jodie is a person from a legal perspective and that the weaker twin, Mary is just an extra flesh attached to her sister. This scenario would present no legal or ethical issue for separation since there would only be Jodie to consider. In other words, Mary is not a human, but a "monster" and consequently is not a carrier of legal personality, her voice would be muffled in the legal world.

Bratton and Chartywnd state that there are reasons for rejecting the first scenario. Whether Mary should have been considered as a part of Jodie's body was not open to either court as a matter of law. However, Mr Justice Johnson, in the High Court, drew attention to Mary's "very poorly developed primitive brain" and "reduced cortical development." Nevertheless, from a legal perspective, both twins were to be afforded all the legal protections appropriate to "liveborn" children. Bratton and Chetwynd point out that, either both twins would count as

¹³⁹ See note 23 above.

persons (i.e. *Homo sapiens*) or neither would yet be a person due to a lack of the ability to make moral decisions.¹⁴⁰

The second option, Bratton and Chetwynd provide, is that the conjoined twins, by rights, be two physically separate people, who are conjoined by some accident. Such conceptualization tends to see both twins as competing for the possession or use of body parts.

Bratton and Chetwynd argue that the philosophical justification is hard to find for that option, and it also results in prioritising one twin to the detriment of the other.¹⁴¹ It seems that the Court in the case of *Re A (Children)* preferred to view conjoined twins as two individuals who meant to be physically separate. The facts of the case reveal that Jodie and Mary were never physically independent of each other until they were separated through the “sacrificial” surgery that resulted in Mary’s death. This is precisely a scenario where discourses of law and medicine tend to show itself most clearly. It seems that The Court of Appeal could only think of Jodie and Mary as singletons, physically separate individuals, to make an appropriate response to the legal challenges posed by the body of conjoined twins. In other words, The Court has considered the only way to think of conjoined twins as two separate individuals who were unfortunately conjoined. The only model the courts appear to have for thinking about people and their best interests is that of physically distinct individuals at any cost.

The third option, Bratton and Chetwynd claim, labels all conjoined twins as two individuals, psychologically separate, but with a shared body. Here, the body of conjoined twins is not something they are competing for, but something they both have interests in, without exclusive rights over it. Further, they note that although they are “psychologically” individuals, part of what makes them the individuals they are, is their conjoined state. This option opens discussions over the concept of individuality. Both authors support the third scenario as the most “workable” option out of three provided.

This thesis reflects the same view. The logic behind supporting the third option of conceptualisation can be well described by applying Dreger’s work to this thesis. She argues that the paradigm needs to be shifted in the way lawyers and doctors view conjoined twins. Dreger claims that the medical profession’s lust for interaction is driven by dominant cultural assumptions about what it takes to be an individual, which often work against the best interests of conjoined twins.¹⁴² Following Dreger’s suggestion, the same can be said about the legal

¹⁴⁰ See note 23 above.

¹⁴¹ See note 23 above.

¹⁴² Dreger, *One of us*, 25.

construction of individuality. The law “expects” to have “one body, one identity” model to articulate legal personhood and other human rights to a person. However, Dreger suggests that the paradoxical fact is that *being conjoined is part of conjoined twins’ individuality* [her italics].¹⁴³

Dreger’s analysis comes useful to reflect the hidden assumptions that may have underlain the decisions of the courts in cases analysed in this research. In particular, the association between individuality and physical separateness is culturally mediated and, in particular, mediated by the medical profession, states Dreger.¹⁴⁴

Medicine plays a crucial role in deciding what the connection is between anatomy and identity. Furthermore, the medical profession is regulated by legal rules, and these two discourses work together around the orthodox view about the concepts that have a crucial role in ascribing legal personality and the right to life to conjoined twins.

By referring to Dreger’s work, Bratton and Chetwynd note that rather than looking at how much or how little autonomy conjoined twins possess, usually they are eliminated.¹⁴⁵ In other words, law and medicine eliminate conjoined twins instead of questioning the very concept of human individuality.

In conceptualising conjoined twins, one can easily trace the double breach of law and nature explained above. As demonstrated by this research, the court in the case of *Re A (children)* tried to argue that there is no place for the “monster” in modern English legal system.¹⁴⁶ Alternatively, the opposite conclusion is reached in this thesis. It can be argued that by sanctioning the separation The Court has conceptualised conjoined twins as “entangled singletons” requiring medical intervention to make them physically separate “as they were meant to be”, notwithstanding the death of the weaker twin.¹⁴⁷ Following that explanation, legal world leaves a gap where the “monster” exists in its dimensions.

It has to be highlighted that the model that should be adopted to react about the orthodox view about bodies has to protect the rights of the conjoined twins and has to advocate for a definition of legal personality. The model that is supported in the following thesis is the one that considers conjoined twins as two psychologically separate individuals sharing a body but not competing

¹⁴³ Ibid, 26.

¹⁴⁴ Ibid, 4.

¹⁴⁵ See note 142 above.

¹⁴⁶ *Re A (Children) (Conjoined Twins: Surgical Separation)* [2000] 4 All ER 961, p 1054.

¹⁴⁷ See note 23 above.

for it rather than having equal rights on it. Thus, the sharing of a body is integral to the individuality of each twin. Consequently, once the legal personality is ascribed the right to life of conjoined twins are equal with others in practice as well. More precisely, the third picture, analysed by Bretton and Chetwynd offers the best way of understanding the reality of conjoined twins' lives.

The third option, advocated in this thesis, i.e. viewing conjoined as separate persons with a shared body calls for recognition of what is lost in separation surgeries. Furthermore, such position supports the idea that the best interests of each twin are not to be automatically balanced as one person's interests against the other's grounding this separation with legal and medical discourses.

To sum up, the model advocated in this thesis is the one that conceives conjoined twins as two individuals who are legally separate but “happen to share a body, the sharing of a body being integral to the individuality of each twin.”¹⁴⁸

6.2 Answering research questions

The focus questions of this thesis are answered briefly once again in this chapter. The first focus question was how the lack of legal personality affects the right to life of conjoined twins in separation surgeries from a legal point of view?

One can easily see that deficiency in human rights law is caused because of two reasons. First, there is the dilemma whether there is one person or two people present. Second, is the absence of a determination of their legal personality results in conflict with the concept of the right to life in practice. In other words, there is a lack of jurisprudence providing guidelines for how to conceive the legal personhood for conjoined twins.

As it is demonstrated in this study, legal personality is the basis for having the fundamental right to life. Without having clear legal guidance whether there is one person or two people, if they have legal personality or not it becomes impossible to have a trustworthy legal system in general.

Not only conjoined twins are affected by such normalisation practices but singleton people as well. This statement takes a reader to the next main research question of this study: What

¹⁴⁸ See note 23 above.

impact conjoined twins' judgements have for human rights law? There is a lesson to learn for human rights law by looking at the figure of conjoined twins. In particular, human rights law's own presumption about what the "human" in human rights law is, a singleton, reveals the problematic character of its own. Human rights law should be able to adopt an approach neutral to the bodily difference. The neutrality does not necessarily mean to ignore the bodily differences but to acknowledge that embodiment is different for conjoined twins and regardless that difference, they should not be excluded from something as fundamental as it is right to life.

The concentration solely on Singleton bodies by the legal systems is very well demonstrated by the three cases analysed in this thesis. The figure of the conjoined twins challenges contemporary understandings of human rights law system about how to accommodate rights to individuals who have a distinct kind of physical body.

To afford human rights to conjoined twins as having an integral body - shared by the twins - rather than consider the twins as two competing rights holders whose one right to life must override the other twins seems to go against the fundamental principle of human rights of right to life.

7. CONCLUSIONS

The concern of the following thesis was to explore “two in one body” type of conjoined twins. As demonstrated, there is another legal way to think about “abnormal” conjoined twins, other than as a medical tragedy that necessarily needs fixing through separation surgery.

Feminism as a theory came very useful to explore the legal personality of conjoined twins as it focuses on the body and the examination of the ontological status of conjoined twins. Christine Overall’s explanations of the feminist critique of the embodiment seem to be true in the light of the things analysed above.

Feminism as a theory not only helped to draw general conclusions about the role of the body in human rights but also to emphasise the problematic nature of the very essence of human rights law: the concept of individuality is necessarily equated with being a singleton and therefore, excludes conjoined twins from its protection. Thus, the figure of conjoined twins and the discourses analysed in this research shows the most important lesson human rights law can learn about itself: the human is not only a singleton, but the bodily differences also must be accommodated in the protection system, especially for such a fundamental thing as the life is.

By using the feminist critique, this research demonstrated the importance that feminists have placed upon understanding the true range of variations of a human embodiment to understand its significant role for legal personality determination for conjoined twins.

Feminist critique, used in this thesis, helped to reach a conclusion and a few main points that should be emphasised. First, feminist critique contributed to exemplify the need to adopt non-idealising approaches in the medical and legal decision-making process. As claimed by Christine Overall, failing to understand the varieties of the embodiment, and over-generalizing one type of embodiment to another can lead to the imposition of inappropriate treatments that presume that one form of embodiment is ideal.¹⁴⁹ By contrast, an accurate understanding of the nature of human beings’ embodied personhood is the essential basis for making medical and legal decisions without questioning the basic that underlines all human rights: the legal personality.

As it has been demonstrated throughout the thesis, during 18th and 19th centuries conjoined twins were treated as “freaks,” “monsters,” one person and not two people having their own

¹⁴⁹ See note 5 above.

interests. Maybe they are more readily recognised as two human individuals. However, it is also assumed that their conjoinment must be “fixed” and “normalised” by surgically separating them, even if it costs a life of one of the twins. The desire to create singleton embodiment with “sacrificial” separation seems to be regarded as the most adequate legal and medical response which endangers human rights law, and in particular, the right to life reflected in Article 2 of the ECHR.

As it is seen from the cases analysed in this thesis, conjoined twins are still “monsters” in legal terms. Such approach seems to be very flexible and convenient for decision-makers because if there is no human being in the eyes of the law to kill, there is no legal issue either. Noting that both twins are equal in the eyes of the law and stating that “there is no place in English law for monster anymore,” seems misleading.¹⁵⁰ If there are two humans, two equals before the law, and they both have the right to life, sanctioning the separation knowing that one twin would die, disgraced and goes against such statements. As a result, “mix-and-match” law is presented which questions not only trustworthiness of The Court but human rights law in general.

Conjoined twins continue to be seen as being inherently impaired and therefore in need of repair with surgical separation, regardless the conjoinment itself is life-threatening or not. Thus, Christine Overall notes by referring to Hull and Wilkinson, that the “normal species functioning” refers only to the situation of singletons.¹⁵¹ Such practices inevitably result in excluding conjoined twins from human rights law framework.

As noted by Overall, unjustified assumptions about conjoined twins’ embodied personhood may also lead to inappropriate decisions about their medical treatment for singleton people. For singletons, the preservation of bodily integrity and autonomy means the protection of the one body that is one’s own from non-consensual contact of any sort by another person. But for conjoined twins, the preservation of bodily integrity and autonomy often means the protection of their *shared* anatomy. For them, embodied personhood inevitably departs from singleton norms with respect to physical independence, bodily ownership and authority, and self-awareness and privacy, states Overall.¹⁵²

¹⁵⁰ It was noted in case of *Re A (children)* by judge

¹⁵¹ See note 5 above.

¹⁵² See note 5 above.

From a feminist perspective, each twin is a permanent part of the “environment” of the other.¹⁵³ Each twin is, in effect, an “integral part” of the other.¹⁵⁴ In the light of these statements, separation surgery is not only a matter of separating one person from another, but it is also a creation of person via separation which creates the platform of other legal and medical discussions.¹⁵⁵

As pointed out by Overall, the separation of conjoined twins should be recognised for what it is: the creation of a new type of embodied personhood. Whether that replacement is an improvement is a judgment that only former conjoined twins can make.¹⁵⁶ Furthermore, human rights law is limited to the extent to exclude conjoined twins from the understanding of “human” and treat them as “monsters.” Such treatment is the result of the underlying assumption in human rights law about a body as a singleton, as being in a particular way.

To point out once again the main message of this study, which challenges the old assumptions existing in human rights law, one must keep in mind the underlying assumption about the body in human rights law. The innovative way of looking at the figure of conjoined twins, as it has been done in this research, signals a very important lesson to human rights lawyers and researchers: they need to be more sensitive and humane in relation to life than that, and be as careful as possible not to exclude conjoined twins from basic human rights, e.g. the fundamental right to life. Besides, human rights law as a system should avoid recognising the only body as a singleton, as being in a particular way and be more inclusive to bodily differences.

Hence, the implication of the reflections in this thesis is not that the separation surgery of conjoined twins is never justified. Alternatively, surgical intervention must be evaluated in the light of a non-idealised understanding of conjoined twins’ actual embodied personhood and not to the limited singleton bodies.

The lessons mentioned above that are learned from feminist critique have to be taken further in the context of human rights law. Namely, what human rights based approach carries in itself and how can defining legal personhood would eliminate this problem? The fact that these challenges are raised by the existence of conjoined twins should perhaps be treated as a challenge to construction of laws that fail to accommodate bodily differences of conjoined

¹⁵³ See note 19 above.

¹⁵⁴ See note 20 above.

¹⁵⁵ See note 5 above.

¹⁵⁶ See note 5 above.

twins and make the rest of us rethink our understanding of the concepts analysed in this thesis more generally.

It may seem that law, medicine and human rights are working separately. However, there is mutual concern and overlap that demand the application legal and medical rules. When the law and the medicine are applied at the same time, a gap in the legal area immediately. One must remember that it indicates interest in preserving the fundamental human values: life, bodily integrity, health and dignity as a paramount consideration in the field of human rights. As Nikola Tupanceski and Dragana Kiprijanovska correctly state medical law is not a closed system of norms systematised in a single legislative act, but a corpus of different ethical standards and legal rules. The legal regulations of this kind are a certain guarantee of the right to life, health, and so forth.¹⁵⁷

The opportunity to cover the legal deficiency discussed in this research is to use the corresponding values of the code of human rights and medical ethics in conjunction with historical and biological events before. As explained by Gould, cases of conjoined twins are “fact-based” code, and the human rights code is a value-based code. Facts cannot answer value questions, but these two “universal” human codes reinforce and inform each other on the fundamental question of human rights law.¹⁵⁸

The symbolic relationship between human rights, medicine and law, and the relevance of international human rights law for health care has become increasingly apparent in recent years. Some international documents articulate a right to life, which is central for this thesis. Furthermore, the ECHR in medicine has become an important basis for human rights in health in Europe. Some scholars in the United States have also argued for greater awareness of international human rights to life and health, while others have explored its concrete application to particular contexts.¹⁵⁹ Perhaps, the cases and discourses analysed in this thesis expose the inability of human rights law to deal with complex matters of healthcare. Human rights lawyers and researchers need to be more sensitive and humble in relation to life and health of a person, than that. Medical law issues should be investigated, starting with the need for respect of the human rights law and the fundamental rights to life. That is why the legal issues formulated in

¹⁵⁷ Nikola Tupanceski and Dragana Kiprijanovska, “Medicine, Law and Human Rights - A Symbiotic Relationship,” *Medicine and Law*, 33 (2014): 40-63.

¹⁵⁸ See note 84 above.

¹⁵⁹ See note 157 above.

this research is not solely medical issue but necessarily involves human rights law considerations.

To conclude, physical entanglement should be considered as a shared condition of two individuals rather than problem posed by one twin to the other. Moreover, if the separation surgery is the "least detrimental alternative" or the "lesser of two evils", then the careful consideration of what twins will lose and gain is unavoidable. Human rights law system should be focused more on integrating conjoined twins in its protection and not to exclude them from basic rights, i.e. the fundamental right to life.

The limits of individuality in the case of conjoined twins extend beyond the boundaries of the "standard" body. Referring to the work of Mary Douglas¹⁶⁰ and Stephen Jay Gould,¹⁶¹ Dreger argues that the body is a flexible concept that cannot be characterised into a discrete category.

¹⁶⁰ Mary Douglas, *Purity and danger: an analysis of concepts of pollution and taboo*, (London: Routledge and Kegan Paul, 1966): 122.

¹⁶¹ Stephen Jay Gould, *The flamingos smile: reflections in natural history* (New York: Norton, 1987).

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