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FROM DUTY TO CARE: A NEW LOOK AT THE MORAL FRAMEWORKS USED TO
GUIDE PREIMPLANTATION GENETIC DIAGNOSIS IN IRELAND

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ABSTRACT

The Catholic Church has held a special position as the moral authority in Ireland, influencing social views as well as policy and legislation. This is most pronounced in the Constitution of Ireland, where there is an ambiguous clause protecting the right to life of the unborn. Due to this clause, government officials have been reluctant to create policy for reproductive healthcare, and because of this lack of regulation, physicians have been hesitant to use reproductive technology. This has been problematic for the advancement of reproductive medicine, particularly for the technology known as Preimplantation Genetic Diagnosis, or PGD. While other countries have used PGD for over twenty years to detect fatal and severe genetic diseases in embryos before they are implanted into the uterus, Ireland has just recently adopted this procedure. As a result, Ireland has not yet had to address the controversial uses for PGD, such as using it to select for deafness. In many other countries there has already been a dialogue as to whether using PGD to purposely select for deaf embryos is morally permissible when deaf parents want to have a child who will share the deaf culture. However, with the recent adoption of PGD, Ireland will likely have to create guidelines for the technology and decide if it should be used to select for deafness. In order to make recommendations for policy and guidelines to using PGD, this paper has three goals. First, this paper aims to examine the traditional moral framework that has prevented the use of PGD in Ireland and explain why a new moral framework might be needed. This paper will address whether a change in moral constructs may permit physicians to use PGD to select for deafness. Finally, this paper will aim to provide suggestions on how Ireland may address these contemporary moral values through policy and guidelines to expand the uses for PGD and the advance the field of reproductive medicine.

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Chapter 1

An Introduction to Ireland, Preimplantation Genetic Diagnosis, and the Field of Assisted Reproductive Technology

Overview

Since the creation of the Constitution of Ireland in 1937 Ireland has been extremely conservative in rulings, policy, and legislation related to reproduction. This conservatism has developed from the Catholic Church's special position as the "moral authority" in Ireland (McDonnell & Allison, 2006). The Church has influenced both the written articles as well as interpretations of the constitution. This influence is especially pronounced in Article 40.3.3 where the state recognizes the "right to life of the unborn" (Article 40.3.3). The ambiguity of this clause has caused confusion as to what is defined as the unborn (McDonnell & Allison, 2006). Furthermore, there is no additional legislation on how this clause applies to modern reproductive medicine. However, due to the Catholic influence, policymakers and health professionals have erred on the side of caution when making decisions related to pregnancy and reproduction (McDonnell & Allison, 2006). This has slowed the acceptance of reproductive technologies that are commonly used for fertility treatments in other nations like the United States and the United Kingdom (McDonnell, 2017).

The technology known as Preimplantation Genetic Diagnosis, or PGD, is among one of the most controversial technologies and has rarely been used in Ireland (Cork Fertility Centre, 2017). This procedure involves collecting sperm and egg samples and fertilizing the eggs outside of the woman's body in a laboratory. Then, physicians will analyze the DNA of the newly created embryos to detect various genetic conditions (Harper, 2009). Most commonly these embryos are screened to detect fatal genetic diseases like Cystic Fibrosis or severely debilitating conditions like Spinal Muscular Atrophy (Sermon, Steirteghem, & Liebaers, 2004). After testing, only embryos without these health conditions are implanted into the woman's uterus (Harper, 2009). These embryos will continue to develop in the uterus for nine months and the rest of the

pregnancy should progress similarly to a natural conception (Harper, 2009). The ability to use PGD to screen and prevent fatal genetic diseases marks an important development in the field of reproductive medicine. Researchers have shown that PGD might increase the chance of a live birth, especially for women who are considered to be of advanced maternal age. A study conducted by Chang et al. (2016) showed that for women who were over the age of 37, using PGD to detect chromosome abnormalities resulted in a higher likelihood of having a live birth and reduced the chance of a miscarriage.

It appears that policymakers and physicians in Ireland have started to recognize this significance of PGD. Historically, the Catholic Church and religious organizations have resisted PGD. Despite this resistance, clinics in Ireland have started to use PGD to screen for fatal and severely debilitating genetic conditions since 2014 (McDonnell & Allison, 2006 and Cork Fertility Centre, 2017). Though PGD is starting to be used in fertility clinics in Ireland, there is little policy or guidelines to aid physicians.

Although PGD can be used to screen for genetic diseases and help increase the chances for a live birth, PGD can also select for and against certain genetically inherited disabilities. One of the most controversial debates is selecting for or against deafness (Robertson, 2003). Using the medical model of disability, implanting embryos with a trait like deafness would be disabling and cause harm to the child, and so selecting for deafness might be seen as immoral (Rosa et al., 2016 and Fahmy, 2011). However, ethicists who view selecting deaf embryos as morally permissible argue that there is a distinction between selecting deaf embryos and deafening a hearing child. While deafening a hearing child would cause harm, selecting deaf embryos allows a deaf child to be born (Hayry, 2004). In addition, those who view disability as a social construct may think that selecting for deafness is morally permissible. According to this view, deafness is not inherently disabling and only become an impairment due to the environment (Kara & Harvey, 2017). Using this model, deafness may be seen as a culture rather than a disability (Mand, Duncan, Gillam, Collins, & Delatycki, 2009). Furthermore, this view may permit physicians to use PGD to select for deaf embryos.

While Ireland has yet to be confronted with a case involving the use of PGD to select for deafness, it is likely that this is because the technology is just starting to be accepted and physicians are ambivalent to use it in cases other than to prevent severe disease or death. However, now that the technology is being used, Ireland will have to address the lack of clear guidelines and policies that have previously been ignored due to the ambiguity of the constitutional “right to life of the unborn” (McDonnell, 2017). There should be well defined policies that clearly state which genetic conditions PGD can be used to select for or against. This thesis will specifically examine whether physicians in Ireland might select for deafness in the future and what more immediate policy changes should be made to specify the circumstances in which PGD can be used.

However, in order to determine whether PGD should and could be used to select for deafness in Ireland, one must consider not only the attitude of the public and health professionals regarding PGD, but also the moral frameworks that guide decision-making and the beliefs of health professionals, policymakers, and the lay public. This thesis will argue that until recently the Catholic Church’s influence has guided ethical decision-making across Ireland. This Catholic framework emphasizes the duty to protect the unborn and is even evident in the Constitution of Ireland where it says the unborn has a right to life and that the state will “vindicate” that right (Article 40.3.3). This wording expresses a duty to protect the unborn, but does not consider relations within the family and between the unborn and the parents (McDonnell & Allison, 2006). Although the emphasis on the duty to the unborn in Ireland is derived from the Catholic influence, it is in many ways analogous to a Kantian ethical framework. This is because when using Kantian ethics, only actions that are performed out of duty are morally permissible (Kant, as cited in Olen, Van Camp, & Barry, 2007). Thus, if the unborn is interpreted to include embryos that are not implanted, which the Church believes should be included, then it can be argued that there is a moral duty to protect all of these embryos (Fasouliotis & Schenker, 1998). In addition, because some of the embryos are discarded, using PGD fails to protect the “unborn” that are not implanted. Thus, although Ireland’s ethical framework derives from the Catholic Church, because it bears

many similarities to Kantian ethics it is possible to use a Kantian moral framework to see how an emphasis on duty prevents the use of PGD.

While this previous framework with an emphasis on duty may have prevented the use of PGD, this thesis will argue that due to the fact that Ireland has started to use the technology, a different moral framework may be needed (Canavan, 2011). Furthermore, this thesis will argue that care ethics might be a valuable moral theory for the nation to adopt, since it would enable the use of PGD to expand by including the role of relationships and emotions in ethical decision-making (Held, 1990). It will be argued that when emotions are considered and care ethics and the social construction of disability are applied, selecting for deafness may be morally permissible. This is because when relationships are considered and deafness is thought of as a culture, one can begin to understand how parents might want to share this identity with their children and how these kids may benefit from this shared identity (Mand et al., 2009).

Thus, the central argument of this thesis will conclude that under a care ethics moral framework, using PGD to select for deafness may be morally permissible in Ireland. However, while the Church's role is diminishing, its influence is still likely to prevent the use of PGD for deafness in the near future. Instead, the immediate focus in Ireland must be to create policy for PGD that can be easily amended as moral frameworks and social views change. This is because it is unlikely that PGD will become widely accepted in Ireland until physicians have clear guidance on what conditions can be selected for and against.

A comprehensive policy and regulatory body similar to the United Kingdom's Human Fertilization and Embryology Authority (HFEA) would be an ideal model for Ireland to adopt. This is because HFEA includes a detailed list of what conditions can be selected for or against using PGD. If Ireland were to adopt this system, this would reduce the hesitation that physicians have towards PGD because they would have clear guidelines. In addition, as PGD continues to be accepted, Ireland would be able to expand the conditions tested for if policymakers use the HFEA model (Human Fertilization, 2017). Using this model and care ethics as the contemporary moral framework, Ireland may eventually allow physicians to select for deafness.

Data and Methodology

This thesis will use a textual analysis of historical documents to examine how Ireland's political and religious history has shaped the moral frameworks used to make decisions related to reproduction and PGD. This will include a detailed analysis of the role of the Catholic Church and how it came to have a strong presence in both social and political spheres in Ireland. A textual analysis will also be used to examine past cases where PGD or other forms of ART have been used to select for deafness. This will allow for a greater understanding of how physicians and parents came to their decision to select for deafness and may help indicate what moral frameworks were used in making this decision.

In addition, textual analyses as well as literature reviews will be used to closely examine the moral philosophies surrounding Kantian and care ethics. It is important to fully explain the theory of Kantian ethics to understand how the Catholic Church's influence is similar to this theory. In addition, the textual analysis will allow for a deeper understanding of care ethics. However, the literature reviews will be especially crucial, as they will provide contemporary interpretations of these moral theories. This will be important in order to gain a strong understanding of how both a duty-based approach and care ethics can be interpreted for modern scenarios, such as determining the morality of using PGD to select for deaf embryos.

Another key component of this paper will involve a policy analysis. The Constitution of Ireland will be one of the most important documents consulted. This thesis will specifically examine Articles 40, 41, and 44 of the constitution because these articles have impacted the use of PGD in Ireland. It will be critical to understand not only the wording, but also how these articles have been interpreted throughout history. This will allow for an understanding of why historically PGD has been resisted and is now starting to be used in Ireland. In addition, this thesis will look at the policies of fertility clinics to examine how they are currently using PGD. Lastly, this paper will examine the United Kingdom's policies and regulations for ART. This will allow

for a deeper understanding of how their regulatory body functions and what aspects policymakers and health professionals in Ireland might be able to adopt to create guidelines and regulation for PGD.

Using this combination of textual analysis, literature reviews, and policy analysis, this thesis will analyze how past policy has been influenced by the Catholic Church and is strikingly similar to a Kantian moral framework due to the emphasis on duty. Furthermore, using this methodology this thesis will argue that if policy and guidelines were to integrate a care ethics perspective it may permit the use of PGD to expand and even allow deaf parents to select for deaf embryos. Thus, this thesis will be able to provide a recommendation for how policymakers and health professionals in Ireland may develop and implement policies to regulate the use of PGD in the future through the use of a care ethics framework. However, before discussing how a new moral framework may expand the uses for PGD in Ireland, it is first important to understand how the technology developed. This cannot be understood without learning the historical context of PGD and how it developed from scientific breakthroughs in the field of ART.

History of Assisted Reproductive Technology and PGD

The field of assisted reproductive technology gained recognition in 1978 after the birth of the first “test tube baby,” Louise Brown. Brown was the first child to be born using a technique called in vitro fertilization (IVF), where eggs and sperm are retrieved and fertilized outside the body in a laboratory to increase the chances of a woman becoming pregnant (Kamel, 2013). IVF was one of the first of a now large group of technologies termed, “assisted reproductive technology,” or ART. ART is now defined by the Centers for Disease Control as any fertility treatment where both the eggs and the sperm are handled (What is Assisted Reproductive Technology, 2017).

After Brown’s birth, IVF became a popular procedure performed globally (Kamel, 2013). In addition, after the successful birth of Brown, scientists began to think it might be possible to use embryos created through

IVF and detect genetic diseases before any of the embryos were implanted into the uterus (Stern, 2014). If such a technique could be combined with IVF, then there would be a method to prevent at-risk couples from passing on certain genetic diseases to their offspring (Harper, 2009). In order to develop this procedure, researchers would first have to find a method to biopsy an embryo before it was implanted and test one of its cells for genetic diseases (Harper, 2009). While scientists discovered methods to biopsy animal cells in 1968, it was not until the late 1980s that scientists discovered a model that could potentially be applied to humans (Stern, 2014 and Harper, 2009). Using mice, Alan Handyside and Marilyn Monk showed that it was possible to biopsy a single cell to diagnose single-gene disorders (Harper, 2009 and Stern, 2014).

In 1990, Handyside was the first to use PGD in a human. He used the procedure to detect and prevent two diseases that were x-linked, meaning that the mutated genes causing the diseases were located on the X chromosome (Stern, 2014 and X-linked adrenoleukodystrophy, 2017). After this initial success, throughout the 1990s and into the 2000s researchers continued to develop techniques to detect diseases in developing embryos. These advancements expanded the types of conditions PGD could be used to detect from the original x-linked diseases to more common genetic diseases like Cystic Fibrosis and Sickle Cell Anemia (Sermon et al., 2004). Now, PGD is used throughout the world to detect a range of genetic conditions (Sermon et al., 2004).

Contemporary Definitions and Uses for Preimplantation Genetic Diagnosis

After the development of PGD in humans, the uses for the technology began to expand. PGD is now not only used to prevent genetic diseases, but also to select for traits. In order to understand the specific conditions PGD can detect, it is crucial to understand how the technology works. In addition, it is important to learn how PGD is used in order to understand that it can be used for purposes other than preventing fatal genetic diseases (Johnston, 2005). This knowledge will be critical for understanding how PGD has been used to select for deafness and could potentially be used for this purpose in Ireland (Mand et al., 2009).

First, PGD works in combination with other forms of ART. Usually, three days after the eggs have been fertilized through IVF, one or two cells are biopsied from each of the developing embryos (Khalaf, 2007). These cells are screened using one of three techniques to analyze their genetic composition and detect any genetic disorders or abnormalities. The first technique uses a procedure called polymerase chain reaction, or PCR, to amplify the DNA and analyze specific genes (Sermon et al., 2004). This can be used to detect single gene disorders such as Cystic Fibrosis, where the disease is caused by one gene (Harper, 2009 and Rechitsky et al., 1999).

Another method is called Fluorescence in-situ hybridization (FISH). This method can be used to analyze chromosomes for any abnormalities in the number or structure leading to conditions like Down syndrome (Sermon et al., 2004 and Conn, Cozzi, Harper, Winston, & Delhanty, 1999). In addition, it can also detect the sex of the developing embryo and screen for diseases that are related to the X chromosome and are considered “sex linked” (Harper & SenGupta, 2011). Lastly, the third method is called comparative genomic hybridization and is used to screen for similar conditions as FISH, but is able to analyze the both copies of each chromosome (Sermon et al., 2004). After one of these analyses has been performed, only embryos that do not have the genetic disease are implanted into the woman’s uterus. Once the embryos are implanted, they should continue to develop and a normal pregnancy should progress (Sermon et al., 2004).

There are two primary reasons physicians will use these techniques and perform PGD. The first is when a couple has a family history of certain genetic diseases and is at an increased risk for passing these diseases to their future child (Harper, 2009). In this case, PGD enables health professionals to screen for single gene disorders, x-linked disorders, and abnormal chromosome rearrangements (Braude, Pickering, Flinter, & Ogilvie, 2002). This screening is most commonly used when there is a high risk for transmission of genetic disorders like Cystic Fibrosis, Tay-Sachs, and Fanconi Anemia (Khalaf, 2007). Physicians will also commonly use PGD when patients have not been able to become pregnant or have suffered from miscarriages. In this case, physicians can screen for abnormalities that may be preventing the pregnancy from advancing (Harper, 2009).

While these are the most common uses for PGD, the technology can also be used for more controversial reasons. PGD can be used to select the sex of the embryo even when there is not a medical reason to do so (Braude et al., 2002). PGD can also identify controversial traits like deafness. This is because one type of deafness, called sensorineural deafness, is frequently genetically inherited as a single gene disorder (Taneja, 2014). Although it is more common to use PGD to select embryos that will not be deaf, there is movement within the deaf community to use forms of ART to purposefully select for a deaf embryo so that the child will share the same deaf culture and identity as his or her parents (Spriggs, 2002 and Hayry, 2004). Using PGD for conditions like deafness raises many questions as to the ethical implications of this technology (Mand et al., 2009). The next few chapters will go into greater depth as to how and why PGD has caused uneasiness and controversy.

Conclusion

This chapter aimed to provide an overview of the argument that will be put forth in the remainder of this thesis. It will be argued that the Catholic Church's influence in Ireland has led to a focus on the duty to protect the unborn that is analogous to the duty described in Kantian ethics (McDonnell & Allison, 2006). Furthermore, using this duty-based framework PGD may have been seen as immoral. However, now that clinics are starting to use PGD, there is a need for a new moral framework to guide the use of the technology. Care ethics would be a possible moral framework for Ireland to adopt because it would allow the uses of PGD to continue to expand and may even permit physicians to use the technology to select for controversial traits like deafness. While a care ethics framework would allow the uses for PGD to expand, health professionals still need policies and guidelines to provide clear instructions on how the technology can and should be used. Thus, Ireland could benefit from adopting professional guidelines and a regulatory framework similar to the comprehensive system used in the United Kingdom (Human Fertilization, 2017).

In order to understand why there is a need for a new moral framework and policies to guide PGD in Ireland, this chapter aimed to explain the history of PGD as well as how it is used today. PGD developed after the creation of IVF as a method to detect fatal genetic diseases (Sermon et al., 2004). However, the uses of the technology have continued to expand and PGD can now detect many traits, including deafness (Taneja, 2014). This has become one of the most contentious uses for the technology, and thus as clinics in Ireland begin to use PGD, policymakers and health professionals will have to address whether physicians are permitted to use the technology to select for deafness. The next chapter will further explain why Ireland is a good case study to examine moral frameworks and policy solutions for PGD. However, in order to understand why Ireland provides a relevant case study, the next chapter will begin by exploring the nation's religious and political history and how this has come to shape the use of ARTs.

Chapter 2

Explaining the Need to Study Ireland

Introduction

Having explored how health professionals can use PGD, this chapter will now examine why physicians and policymakers in Ireland have been hesitant to use the technology. This chapter will demonstrate how Ireland's political and religious history have contributed to these controversies and created ambiguity in how PGD and other forms of ART can be used. Furthermore, this ambiguity has prevented the country from developing policies (McDonnell & Allison, 2006). However, with the gradual acceptance of the technology, this lack of policy will likely lead to ethical issues such as whether it is acceptable to use PGD to select for deafness. In order to illustrate the problems Ireland will face using PGD without policy or legislation, it is first important to learn why policy has not been created. The chapter will begin by providing historical context on how the Catholic Church has come to have a dominating presence in Ireland, influencing legislation and moral values around PGD and preventing ART policies about PGD from being developed.

The Role of the Catholic Church in Ireland

Catholicism has become intimately associated with the Irish identity, and thus religion has come to shape attitudes and policies on many issues, including the use of PGD. It is important to understand how Catholicism first became ingrained in the Irish identity before subsequently becoming a moral influence guiding the creation of the constitution (Smyth, 2005). While the Catholic religion has been prevalent in Ireland throughout history, it became a strong sense of national pride following a period of Catholic oppression under the English rule (Smyth, 2005). This oppression grew rapidly throughout the 16th and 17th centuries when Ireland experienced an influx of "New English" settlers (Connolly, 1992).

Unlike the “Old English” who were often Catholic, these immigrants were Protestant and had a great disdain for the Catholics dating back to the former Catholic persecution of Protestants in England. Many of these Protestant settlers were sent to Ireland by the English Parliament to force the Irish to convert religions (Smyth, 2005). As this Protestant influence grew in Ireland and England, the English government began to oppress and persecute Catholics in Ireland. This was evident in the establishment of Penal Laws, which prevented Catholics from gaining land ownership as well as positions in parliament and other professions (Connolly, 1992). Such forms of persecution continued until 1829 when the Catholic Emancipation Act was put in place formally ending the oppression of Catholics in Ireland (Smyth, 2005).

Although Ireland did not gain independence from Britain until 1922, after 1829 Catholicism became a symbol of the Irish identity (Smyth, 2005). Murphy (1988) explained, “The powerfully interlocked Irish and Catholic ethos was an entity seen by its representativeness as invulnerable against attack” (p.134). In this manner, Catholicism became an identity for the Irish, symbolizing Ireland’s strength and differentiating the Irish from other Europeans. Furthermore, because Catholicism was part of the Irish identity, Ireland incorporated many aspects of the religion into the Constitution of Ireland (Smyth, 2005).

Catholicism and the Constitution

The Constitution of Ireland was created in 1937, and from the very first line the Catholic influence is apparent. The constitution opens by stating, “In the name the name of the Most Holy Trinity from Whom is all authority and to Whom, as our final end, all actions both of men and States must be referred” (Pmbl.) This Catholic influence was also evident in Article 44. Although the article began by acknowledging freedom of religion, it then recognized the “special position” of the Catholic Church and implied that Catholic morality would guide the creation and implementation of social policy (Article 44 and Smyth, 2005).

The special position of the Catholic Church was eventually removed from the constitution in the 1970s. However, this original clause had a profound impact on social policies for close to forty years. During this time, the Catholic morality was used to influence policies related to contraception and abortion (Smyth, 2005). McDonnell and Allison (2006) have argued that this religious influence created a “moral monopoly” where the church shaped initial perceptions of contraception and subsequently reproductive technology in Ireland.

Ireland’s position on ART did not derive solely from Article 44, but also from Article 40.3.3. This clause was added in 1983, and says, “The State acknowledges the right to life of the unborn... and, as far as practicable, by its laws to defend and vindicate that right.” (Article 40.3.3) This article reflects the Catholic Church’s view that from the moment of conception, an embryo attains the status of a human being (Fasouliotis & Schenker, 1998). Furthermore, the wording of Article 40.3.3 to protect the unborn put a constitutional ban on abortion that is still in place today and has continued to prevent abortions in all cases unless the mother’s life is at risk (McDonnell & Allison, 2006).

In addition to establishing a constitutional ban on abortion, the ambiguous wording of Article 40.3.3 has stagnated advancements in ART and PGD. The confusion has come from a lack of clarity as to what is defined as an unborn child according to the constitution. Although the Church has maintained that the unborn is granted the status of a human at the point of conception, the constitution does not clarify if this is the definition of unborn the country should use (Fasouliotis & Schenker, 1998 and McDonnell & Allison, 2006). If the unborn were granted the “right to life” at the moment of fertilization this would prevent the use of many types of ARTs, including PGD (McDonnell, 2017). As explained in the previous chapter, PGD and other forms of ARTs involve fertilizing multiple embryos, but most often not all of these embryos are implanted. The embryos that are not implanted are discarded (Robertson, 2003). If each embryo is defined as an unborn person and has a right to life, this makes storing or discarding embryos impossible and prohibits most forms of ART, including PGD.

Ireland's Minister for Health and Children attempted to address these issues in 2000 with the establishment of the Commission on Assisted Human Reproduction, CAHR, which was tasked with creating recommendations for policy on ART (McDonnell & Allison, 2006). The commission's report explained how different types of ART like PGD are used and why ethical issues often arise from the technology. Ultimately the commission recommended that legislation be passed to establish a regulatory body to monitor and license all clinics using ART (CAHR, 2005). However, five years after the commission ended and their report was released there was still little public political debate on how ART should be used and if policies should be created (McDonnell & Allison, 2006). McDonnell (2017) attributed this lack of progress to, "the State's ambivalence about the legal and bioethical complexities arising from ARTs." (p.153) This illustrates the fact that the Catholic influence in the constitution has continued to affect policy and cause great concern for how ARTs such as PGD can be used in Ireland. Furthermore, it is this ambivalence, religious influence, and lack of progress that make it necessary to study the ethical frameworks in place as well as the current and future uses of PGD in Ireland.

Family Values and the Need to Study Ireland

In addition to deeply ingrained religious beliefs, there is a strong value placed on becoming a mother and rearing a large family in Ireland. This has created a paradox where women feel pressure to have children, but may not be able to use reproductive technology to help them conceive (Allison, 2013). This is because while there is a religious objection to PGD and other ARTs, women in Ireland may struggle with fertility. Thus, their only option to become mothers might be to use the technology that their religion has banned. This creates a tension between women's religious beliefs and their desire to have children (Allison, 2013).

The emphasis placed on motherhood originated after the Great Famine in the 19th century. The famine primarily affected the lower class and eliminated much of the non-landowning population, resulting in a greater

proportion of small farmers (Smyth, 2005). This change in social structure influenced attitudes about farming and social status became tied to the amount of land one owned. However, farms were only passed down to the eldest son to ensure that the farms remained large (Smyth, 2005). Previously women would contribute to the farm labor as well as other household work. However, this inheritance method put women in a position where they were completely reliant on their husbands for financial stability (Hayes & Urquhart, 2001). A woman needed to marry a man with land and produce sons who could do the farm labor and later take over the land.

In this system, women's status became dependent on their ability to marry, and they became more restricted to household tasks (Smyth, 2005). With these restrictions, the gender equality gap continued to widen and sexual activity was restricted until women were married and attempting to conceive. This oppressive system encouraged male dominance and reinforced the patriarchal family structure (Smyth, 2005). Furthermore, this structure perpetuated the idea that women are tied to reproduction by placing value only on their ability to rear children. These initial ties between womanhood and motherhood initiated the family ideals that are still evident in today's society.

These family ideals were formally recognized in the 1937 Constitution of Ireland. Article 41 is titled, "The Family" and addresses the family as the "fundamental unit group of Society" (Article 41). However, the article goes further and states, "The State shall... endeavour to ensure that mothers shall not be obliged by economic necessity to engage in labour to the neglect of their duties in the home." (Article 41.2) This clause has been referred to as the "women in home clause" and reflects the fact that women are still viewed primarily in the realm of domesticity. Although there has been a push to remove this clause, at the present time it is still in the constitution, illustrating that the country has been slow to change views on motherhood (Hilliard, 2016).

This association between womanhood and motherhood has put pressure on women to reproduce. According to Allison (2013), mothers have been seen as the "keeper of domestic space, morality, and social values" (p. 42). However, this pressure to have children conflicts with the Catholic Church's ban on ART. In 2013 there were over 2,000 reports of couples in Ireland seeking fertility treatment, yet the Catholic Church

often does not approve of the methods used in treatment (Allison, 2013). Even with the Church disapproving of ART, fertility clinics have been established in many of the cities in Ireland (Cork Fertility Centre, 2017). This creates a unique conflict where there are strong social influences to have children, but also religious influences against using ART methods, such as PGD and IVF, which might be needed to conceive. Allison (2013) best explained the tension between religious views and family norms as “the paradoxical discourse on the part of the Catholic Church in which they condemned IVF on the one hand while continuing to promote motherhood and having children on the other.” (p. 46) This issue further reflects the need to study the use and attitudes towards PGD in Ireland because it is clear that there are conflicting policy, cultural messages, and religious beliefs about ART and PGD.

Understanding the Catholic Church’s Arguments Against PGD

Before discussing how PGD may raise controversies in the future, it is important to understand religious objections to PGD because these objections have slowed the acceptance of the technology in Ireland (McDonnell, 2017). Historically the Catholic Church has rejected most forms of ART because this technology violates the religious beliefs that life begins at conception, children should not be created in a clinical setting, and that people should not intervene with “divine intention” (Fasouliotis & Schenker, 1998 and Czarnecki, 2015). The rejection of ART dates back to 1956 when Pope Pius XII formally issued a proclamation stating that any form of artificial fertilization was immoral and illegal. This proclamation has continued to be echoed by popes and church documents throughout the past 65 years, prohibiting most forms of ART (Sallam, H. & Sallam, N., 2016). The Church has continued to disapprove of PGD and other forms of ART because the Church believes an embryo gains the status of a human being at the point of conception (Fasouliotis & Schenker, 1998). According to this view, any form of ART involving embryos is immoral because it disregards human life (Schenker, 2005). Thus, the use of ARTs such as surrogacy, IVF, and PGD are seen as immoral.

Furthermore, PGD is seen to disregard human life because the technology creates extra embryos that are never implanted into the uterus and are often discarded (Robertson, 2003). According to the Catholic Church, these extra embryos are human and should be respected and not discarded (Fasouliotis & Schenker, 1998 and Robertson, 2003). Thus, the Church believes that PGD is disrespectful of human life and views the technology in a similar manner as abortion (Schenker, 2005 and Cameron & Williamson, 2003).

The Catholic Church has also rejected the use PGD and IVF because of the belief that children are supposed to be “gifts from God” and not created in a clinical setting. According to Czarnecki (2015) the Catholic Church believes that a laboratory setting is disrespectful to “human dignity [and] divine intention” (p. 719). However, in order to use PGD eggs must be fertilized in a lab before they are implanted into the uterus (Khalaf, 2007). Furthermore, PGD is seen to intervene with “divine intention” because using this technology physicians decide which embryos are implanted and which are discarded (Czarnecki, 2015 and Scott, 2006). Scott (2006) explained how physicians are seen as playing the part of God because they choose between possible lives.

In order to formally address these issues with ARTs, in 2009 the United States Conference of Catholic Bishops released a statement that said couples need to “cooperate with God” in conception. The release explained that technology which “replaces the marital act” is “morally flawed” (Life-Giving Love, 2009, p. 13). According to this statement, PGD is immoral because it uses IVF, which replaces the act of conception and fertilizes the eggs outside of the body (Khalaf, 2007). This statement formally condemned the use of IVF and PGD and labeled the technology as immoral (Life-Giving Love, 2009).

While the Catholic Church has continued to maintain that PGD and IVF are immoral, it should be noted that some countries with a Catholic influence have started to find ways to justify the use of ARTs. For example, in Ecuador IVF is accepted by the Catholic Church and justified as a way to assist in “God's laboratory” (Czarnecki, 2015, p. 722). However, for devout followers in countries where there is little separation between church and state PGD remains morally impermissible. Thus, people who live in these countries often have

restricted access to ARTs like PGD and must choose between religious beliefs and the desire to have children. This has been the case for people living in Ireland, where the Church has continued to resist forms of ART (McDonnell & Allison, 2006). For example, in Ireland IVF was restricted to married couples and there was a ban on donor gametes and embryo freezing until 1989 (Allison, 2013). Furthermore, while PGD has been used in the United States and the United Kingdom since the 1990s, it was not used in Ireland until 2014 (Sermon et al., 2004 and Leogue, 2014). McDonnell and Allison (2006) explained how these bans and restrictions on the field of ART are a result of the Catholic Church's moral authority. Thus, by understanding the Catholic Church's objections to ART, it can be understood why PGD has been resisted in Ireland, where historically Catholicism has had a dominating presence (McDonnell & Allison, 2006).

The Rising Conflict Between Catholic Morals, Laws, and ART

As the use of ART becomes more common worldwide, there has been opposition against the Catholic Church and the constitution's protection to the right to life of the unborn through legal cases that have tried to expand women's access to reproductive services like abortion and contraception (Smyth, 2005). This resistance first gained mass attention in 1992 during the case of the Attorney General v. X, commonly referred to as the "X case" (Smyth, 2005). The case involved a 14-year-old rape victim who became pregnant and wanted to travel abroad to have an abortion. The Irish Supreme Court ruled that the right to life of the unborn gave the court the power to prevent the girl from traveling for an abortion and enforced restrictive travel for pregnant women (Smyth, 2005). However, when the girl returned to Ireland, a psychologist deemed her suicidal. After reviewing the case the court eventually ruled that travel was permitted if there was a significant risk to the life of the mother (Smyth, 2005). The X case represents one of the first steps towards reproductive freedom. Furthermore, it illustrates how citizens began to question the role of the Catholic Church and Irish laws.

However, it should be noted that while the X case recognized the right to travel, abortion remains illegal in Ireland in all cases except when the mother's life is at risk (Murray, 2016).

While there has been some clarity in regards to Article 40.3.3 and abortion services, the field of ART has been left unregulated by the courts and legislators. In 1989 the bans on donor gametes, embryo freezing, and restriction of IVF to only married couples was lifted. Although these bans were removed, there was no statement, policy, or regulatory body to decide how ART should be used (Allison, 2013). While some groups are advocating for regulation so the field of ART can advance, the Catholic Church has pushed for regulation to protect the right to life of the unborn (McDonnell, 2017). Allison (2013) explained that outside of Poland and Romania, Ireland has remained the only nation in the European Union without a regulatory body to examine the ethics and implement legislation on ART.

This lack of legislation and policy has caused much confusion and ambivalence towards PGD. While this technology was developed in the 1990s, the first baby born using PGD in Ireland took place in 2014, over 20 years after the technology was created. In this case, the family was able to use PGD because they were at an increased risk of having a child with Cystic Fibrosis (Leogue, 2014). The couple used PGD at Cork Fertility Centre, which only permits the technology for "serious genetic conditions". The clinic's website states, "We can carry out PGD for single gene disorders including; Cystic Fibrosis, Fragile X Syndrome, Duchenne Muscular Dystrophy and Myotonic Dystrophy, Tay-Sachs disease, Beta-thalassemia, Hemophilia A, and Sickle Cell Disease." (Cork Fertility Centre, 2017)

Although there is no legislation on how PGD can be used in Ireland, Cork Fertility Centre's website neglects to mention that PGD can identify sex or select for certain conditions like deafness. This illustrates the hesitation to use ART and a clear avoidance of using PGD for more controversial uses. The avoidance of PGD is further evident by the fact that even in 2015 Cork Fertility Centre was one of only two clinics in Ireland to perform PGD (Cork Fertility Centre, 2017). While Cork Fertility Centre has avoided even mentioning the use of PGD to select for deafness and other controversial traits, if PGD is going to become an acceptable form of

technology, there needs to be an open dialogue on how the technology can and should be used. It is problematic that clinics in Ireland have not addressed the use of PGD to select for deafness because without discourse on the controversial uses of PGD, there will continue to be ambiguity and a slow acceptance of the technology.

Furthermore, if a clinician or patient were to express a desire to use PGD to select for deafness, at the present time there would be no guidelines on whether this should be permitted (McDonnell, 2017).

Conclusion

This chapter shows how throughout history in Ireland Catholicism has influenced not only attitudes, but also policy for ART. This religious influence is problematic because it has created ambiguity on how PGD can be used. It is now important to study Ireland because without policy, the country will have to face the various ethical issues associated with this technology. Due to the limited number of cases where PGD has been used, Ireland has not had to address such issues. However, with the gradual acceptance of PGD in clinics like Cork Fertility Centre, more ethical issues will become apparent (Cork Fertility Centre, 2017). Thus, because there is no legislation or policies for how clinicians can use PGD, there needs to be a discourse on what types of conditions can be selected for and against. The next chapter will explore one of the most contentious uses for PGD, selecting for deafness, in order to demonstrate some of the critical issues Ireland must now consider if the technology is going to be used.

Chapter 3

PGD and Disability: Controversies and Objections

Introduction

Although PGD has been used for over twenty years as a method to prevent fatal genetic diseases, there are many controversies surrounding the use and specific applications of this technology. This chapter will address objections to using PGD to select for deaf embryos (Johnston, 2005). While there are numerous ethical concerns associated with the PGD, selecting for deaf embryos will be used as a case study because it highlights important ethical questions about when PGD can be justified and presents a case study of the medical versus social model of disability (Robertson, 2003 and Johnston, 2005). Furthermore, because using PGD to select for deaf embryos has caused disagreement among physicians, ethicists, and disability activists, it is likely that as Ireland gradually begins to use the technology, physicians and policymakers will have to address whether selecting for deaf embryos is morally permissible (Mand et al., 2009). There is also a growing sense of a deaf culture and deaf community that does not view deafness as a disability, but rather as a positive attribute (Tucker, 1998). Therefore, it is important to understand this issue with PGD as it will likely become relevant in Ireland in the future.

Although there are many controversial uses for PGD, selecting for deafness was chosen as a case study because it is highly debated among physicians and ethicists and can be used to illustrate what types of ethical questions will arise without policy to guide PGD. Selecting for deafness raises questions about what conditions should be defined as disabilities and forces physicians and policymakers to consider when using PGD is justified (Mand et al., 2009 and Johnston, 2005). For example, can PGD be justified to select for a disability? If deafness is constructed so that it is not a disability, then might using PGD to select for deafness be

permitted? As Johnston (2005) stated in reference to selecting for deafness, “The dilemmas...are likely to become a permanent feature of medical ethics, public policy, and moral philosophy as each newly discovered possible link with disease or disability in our genetic inheritance presents itself...for consideration: is intervention justified?” (p. 427). Thus, examining the ethics and controversies of selecting for deafness will raise questions about when PGD can and should be used.

Medical Model vs. Social Model of Disability

In order to explain why there has been controversy over using PGD to select for deafness, it is important to understand the two different views of deafness. Traditionally deafness has been seen as a disability because it prevents one from communicating and taking part in activities with the hearing population (Jones, 2002). This concept of deafness is part of the medical model of disability, where the disability is seen as an inherent part of the individual and assumes that medical intervention is needed to manage or correct the condition (Davis, 2013). In the case of deafness, the medical model has been applied to mean that deafness should be “cured” through medical interventions such as the use of cochlear implants (Sparrow, 2005). Sparrow (2005) explained that people who view deafness as a disability believe that “there are things that the deaf cannot do that ‘normal’ people can and that these incapacities place them at a disadvantage” (p. 137). Thus, when the medical model is applied to deafness, it assumes that deafness is always a negative condition that should be corrected.

However, there has been a growing body of literature indicating that deaf individuals do not want to correct their condition and would prefer to remain deaf (Sparrow, 2005). These deaf activists use the social model of disability to argue that deafness is not inherently disabling (Davis, 2013). According to the social model, it is the environment and social factors that prevent deaf individuals from fully participating in society (Davis, 2013). For example, using the social model of disability, Andrew Solomon (2012) argued that deafness limits communication because of discrimination and not because deaf people are inherently disabled and unable

to communicate. Solomon noted in his book *Far from the Tree*, “The issue of deafness in most societies is one of linguistic exclusion” (p. 83). In this manner, it is because most of the hearing population has not taken the proper steps to include deaf people that they are seen as disabled. If more people were to use captioning on audio material or provide interpreters, then those who are deaf would no longer be excluded from mainstream activities (Levy, 2002). Thus, according to the social model of disability, deafness is not inherently disabling and only becomes a disability when the deaf are excluded by the hearing population.

Furthermore, if deafness was a debilitating condition, then it would be expected that those who are deaf would want to correct the disability. However, devices like the cochlear implants have been created, yet are commonly rejected by the deaf community (Sparrow, 2005). Starting in the 1980s there have been strong protests against this technology, as many believe it is an attempt to “cure deafness” (Tucker, 1998). Protestors view cochlear implants as a form of genocide that will completely eliminate deafness and are especially hostile towards the idea of young children having the procedure before they can make the choice for themselves (Sparrow, 2005). These protests within the deaf community push back on the concept of deafness as a disability (Tucker, 1998). If deafness was a debilitating condition, then it would be predicted that adults would not only want to “cure” themselves, but would also want to protect their children from experiencing it.

In addition, when Solomon (2012) interviewed people who were born deaf, many said they do not wish they could hear. In one conversation a young boy wished his mother was also deaf. The idea that a young deaf child in a hearing community still values deafness illustrates that a lack of hearing is not always seen as a loss. Solomon (2012) equated deafness with sex, explaining that in both cases people do not experience loss for something they never had. For example, while a woman might question what it is like to be a man, most often she does not experience a loss for not being born male. Although this is an extreme comparison, it demonstrates the idea that people in the deaf community often do not express loss or feel disabled by their condition. Thus, within the deaf community deafness is not seen as a disability that needs to be corrected through medical intervention and the use of cochlear implants.

Deafness as a Culture

Once deafness is no longer seen as a disability, there must be a new and more accurate way to understand the community. This has been achieved by classifying deafness as a culture unique to those who are deaf (Tucker, 1998). Deaf activists have often described it in this manner because the deaf community has their own rich and diverse languages. For example, in the United States American Sign Language is common while in England British Sign Language is used (American Sign Language, 2015). While there are many different subsets, it is argued that everyone in the community shares a variation of sign language, which binds those who are deaf into a culture (Padden, 1998). Although oftentimes cultures do have their own language or lexicon, simply having this aspect of a culture is not enough to justify the use of PGD to select for deaf embryos. This is because if learning sign language is enough gain acceptance into the deaf culture, then deaf parents do not have to use PGD to have a child who is part of their culture. Instead, deaf parents could teach their children sign language so that the kids can have access to the culture. However, there are other aspects of the deaf culture that cannot be taught.

Deafness is viewed as a culture not only because of the rich language, but also because of the unique values and heritage of the deaf community. These values and insights cannot be gained just by learning sign language. For example, within the deaf community there is a greater value placed on vision (Hauser et al., 2010). Research has shown that people who are unable to hear often have enhanced visual cognition, especially related to periphery vision and movement (Bravelier, Dye, & Hauser, 2006). This increased visual awareness allows the deaf to observe visual cues and information that most hearing people will miss, resulting in the deaf having a different knowledge base and perspective of the world. It has even been said that the deaf live in a “visual reality” unlike the world of the hearing population (Hauser et al., 2010). In this manner, those who are not deaf cannot be part of the deaf culture because they will never have the same visual abilities, and therefore will never experience the visual world of the deaf community.

Deaf activists have also maintained that the culture has a rich heritage that cannot be fully appreciated unless one is deaf. Throughout history the deaf community has been oppressed: dating back to 355 B.C. Aristotle described the deaf as “senseless” and “incapable of reason” (Hladek, 2002). From programs aimed at eliminating sign language, to movements for all deaf children to have cochlear implants, deaf communities continued to face adversity (Padden, 2005). However, it was this oppression that created a strong sense of heritage and deaf pride that is a defining feature of the culture. A strong example of this deaf heritage is the deaf school system. These schools not only teach subjects in sign language, but also socialize students into the deaf culture by teaching the social norms, values, and traditions of the deaf community (Ladd, 2009). In this manner, the deaf community has created a system to continue to pass on the heritage and culture to future generations. Although history can be taught, those who are part of the hearing population will never be able to fully relate to the values and norms of the deaf community. Together the unique heritage, values, and language have led deaf activists to reclassify deafness as a culture rather than a disability (Sparrow, 2005). Furthermore, it is because this culture is exclusive that deaf activists and community members have expressed their desire to have deaf children (Mand et al., 2009).

Using PGD to Select for Deafness

When deafness is constructed as a culture rather than a disability, then it can be understood why deaf parents would want to use PGD to select for this trait. PGD would enable deaf parents to ensure that their future children share their cultural identity (Mand et al., 2009). Deaf children would have the heritage and visual abilities to be a part their parents’ deaf culture (Hauser et al., 2010 and Sparrow, 2005). However, if deaf parents have hearing children, the parents would not be able to share their unique values and heritage with their children. For example, while deaf parents can encourage their children to pay attention to small details, hearing kids will not have the same visual abilities as their parents. Thus, they will not be able to fully understand the world their parents live in and the value placed on vision (Hauser et al., 2010). If deaf parents

can only share their deaf cultural identity by having a deaf child, they may want to use PGD to ensure this shared identity (Mand et al., 2009).

While deafness has been constructed as a culture to argue for allowing physicians to use PGD to select for deaf embryos, those using the medical model have continued to object to this use. This is because using the medical model, deafness is seen as a disability that will cause harm to the future child (Fahmy, 2011).

According to this view, deafness will harm the child by giving him or her a lifelong disability that will diminish the child's quality of life (Fahmy, 2011). Opponents have also argued that the prospective parents should only select embryos that would give the potential child the most opportunities and ability to live a life with the highest level of well-being, or flourishing. Savulescu (2001) used this idea of flourishing to argue that that a hearing child would have more options later in life than a deaf child and thus more opportunities to achieve the highest level of well-being. For this reason, he argued that physicians should not select for deaf embryos (Savulescu, 2001).

However, deaf activists have rejected these arguments against selecting for deaf embryos. First, since activists use the social model of disability and do not view deafness as a disability, they have argued that it is possible for a deaf child to have a life that is just as satisfying and might even provide additional opportunities than if the child were born hearing. For example, Savulescu (2011) argued that by discarding an embryo because of a specific trait, one could be discarding the next Mozart. In a similar manner, because many deaf people have superior visual abilities, it is possible that by avoiding deaf embryos, one will be discarding the next Picasso. Thus, while a deaf child might have different opportunities than a hearing child, it is possible that both allow the child to achieve a maximum sense of well-being (Savulescu, 2001).

In addition to claiming that deafness is not a disability, activists have said that selecting for a deaf embryo does not cause harm to the future child. This is because there is a key difference between selecting for a deaf embryo and deafening a hearing child (Hayry, 2004). If parents were to deafen a hearing child they would be changing that child's existing conditions and harming the child. This is different from selecting

embryos that give a potential deaf person a life (Hayry, 2004). Due to the fact that PGD does not design embryos to be deaf, but rather can select for traits like deafness, it can be argued that using PGD to select a deaf embryo does not harm the future child (Hayry, 2004 and Sheldon & Wilkinson, 2004). This debate on whether using PGD to select for deafness actually harms the future child further demonstrates how contentious this use for PGD has become.

These conflicting views of PGD, deafness, and disability illustrate the complexities of deciding whether PGD should be used to select for deafness (Johnston, 2005). While those following the medical model have continued to object using PGD to select for deafness, the issue becomes multifaceted once a social construction of disability is applied. In this case, it is possible to construct deafness as a culture, which then permits a debate as to whether PGD should be used to select for deafness (Mand et al, 2009).

Conclusion

This chapter aimed to show how there are many controversies surrounding the use of PGD. It was important to discuss the ability for PGD to select for deafness because this is one of the most controversial uses of the technology. Furthermore, because selecting for deafness is so contentious, it is likely that Ireland will have to address this issue now that the nation is starting to use PGD. However, it is first critical to consider what ethical frameworks guide such moral decisions. The next chapter will address what moral frameworks have guided these past restrictions on PGD before exploring how a change in moral frameworks might allow for physicians to use PGD to select for deafness.

Chapter 4

Duty-Based Ethics in Ireland

Introduction

Given that PGD is increasingly being used for a wide variety of purposes, including selecting for and against disabilities, and that Ireland does not have clear policies about this technology, what moral frameworks guide PGD practices in Ireland? This chapter will explain one moral framework that appears to have guided past interpretations of Article 40.3.3 of the Constitution of Ireland. It will be argued that the religious history of Ireland has led to a focus on duty when creating and implementing decisions related to the “right to life of the unborn” (Article 40.3.3). This chapter will explain how the Catholic emphasis on the duty to protect the unborn is analogous to the idea of duty described in Kantian ethics. Furthermore, this chapter will explain that when only duty is considered in ethical decision-making, as is the case in Kantian ethics, PGD is immoral. However, in order to understand why PGD might be morally impermissible under a framework emphasizing duty, this chapter will begin with an explanation of Kantian ethics.

What is Kantian Ethics?

Kantian ethics is a deontological, or duty-based, moral theory from the writings of Immanuel Kant (Wood, 2008). According to this philosophy, the intention, or reason for an action, determines if the action is right or wrong (Sherman, 2014). Furthermore, only actions that are performed out of duty are morally permissible (Wood, 2008). Kant used the example of being truthful to illustrate this point. He stated, “to be truthful from duty...is an entirely different thing to be truthful out of fear of untoward consequences” (Kant, as cited in Olen, Van Camp, and Barry, 2007, p. 36) If one told the truth out of the duty to be truthful the act was moral, but if the truth was told to avoid a punishment, then the action is immoral. The result of the action is not

considered when judging morality. Instead, it is the reason for acting or the intention of the action that is important (Wood, 2008).

Using this theory, emotions and relationships do not impact morality and should not be considered when making an ethical decision. According to Kant, “Duty does not rest at all on feelings, impulses, and inclinations.” (Kant, as cited in Olen, Van Camp, and Barry, 2007, p. 39) For example, if an action was done out of friendship or love, then it is immoral because these aspects of humanity should not be relevant (Baron, 1995). Wood (2008) best described how Kantian ethics views emotion by stating that it is “hostile to human happiness, mercilessly unsympathetic to human weakness, allowing no place in life for natural human feelings and desires.” (p. 2) Thus, using a Kantian framework, situational factors like relationships or emotions are ignored. The only factor that should be considered is the intention for acting, and the only acceptable intention is to act out of duty (Sherman, 2014).

In addition to a focus on duty, Kantian ethics places emphasis on the inherent worth of human beings and respect for personhood. This was expressed in Kant’s writing where he stated, “rational beings are designated persons because their nature indicates that they are ends in themselves... Such a being is thus an object of respect.” (Kant, as cited in Olen, Van Camp, and Barry, 2007, p. 37) In this framework, rational beings must always be respected as an end and never used as merely a means to further another end.

While the definition of a rational being has been highly debated, some philosophers have argued that Kant’s formulation extends to those with the potential for reason. Oduncu (2003) claims that anything with the potential to become a human and later have the capacity to reason should be considered a person worthy of respect. According to Oduncu’s view, the entire species of *Homo sapiens* should be respected, including embryos. It is clear how using this view of a rational being Kantian ethics could be used to defend the Catholic Church’s position that embryos have a right to life because they have the potential to become rational human beings (Fasouliotis and Schenker, 1998 and Oduncu, 2003). However, it is important to note that this view of a Kantian rational being is highly contentious: for example, Manninen (2008) directly addresses Oduncu’s

argument and maintained that the idea of rational being is not automatically given to those with the capacity to reason in the future. Instead, she argues that beings must already have this capacity for reason to be respected as persons. Under this view, an embryo would not be granted the status of a rational being worthy of respect (Manninen, 2008).

These conflicting views reflect the fact that while Kantian philosophers often take a deontological, or duty-based approach, interpretations of Kant's writings may differ (Wood, 2008). While there may be discrepancies in the definition of a person, it is clear from Kant's writing that this moral theory emphasizes the importance of acting out of duty and respecting persons (Kant, as cited in Olen, Van Camp, and Barry, 2007). With this understanding of Kantian ethics, one can see how this theory is analogous to the moral framework that has been used in Ireland to protect the right to life of the unborn and prevent the use of PGD and other ARTs.

Similarities Between Kantian Ethics and the Catholic Morals Used in Ireland

Many reproductive decisions that have been made in Ireland reflect similar duty-based morals as Kantian ethics. This duty-based ethical framework may have evolved due to the Catholic Church's role in the creation and interpretation of the Constitution of Ireland. As explained Chapter 2, this influence is extremely pronounced in Article 40.3.3, where the State acknowledges the "right to life of the unborn" and promises to try and "vindicate" and "defend" that right (Article 40.3.3). The language used in this article reflects the idea that there is a duty to protect the unborn and that the government must act on this duty. Ireland's focus on the right to life of the unborn has even been referred to as a "duty-to-protect-unborn-life jurisdiction" (Siegel, 2013, p.523). This focus on acting out of a duty thus appears to be analogous to a Kantian framework and indicates that a focus on duty was used in the creation of reproductive legislation.

This Kantian-like focus on duty was also used to interpret the legislation in past court cases. This is most evident in the case of *Attorney General v. X*. In this case, the Supreme Court of Ireland initially ruled that

the right to life of the unborn could be used to prevent a 14-year-old rape victim from having an abortion (Smyth, 2005). This ruling was made with the knowledge that the girl was suicidal, indicating that court ignored the girl's mental and emotional health when ruling (Smyth, 2005). This demonstrates how the court was focused solely on the fetus and its right to life rather than the mental and emotional state of the girl, further reflecting a Kantian perspective where emotions are ignored (Wood, 2008).

Even after the court reversed their decision and allowed the girl to travel, their ruling still neglected the relationships involved in the decision to have an abortion. The court did not make their decision based on the fact that the girl was impregnated from a rape, but instead decided that an abortion should be permitted if the woman's life was at risk (Smyth, 2005). In this manner, the court did not consider the relationship between the girl and the father of the unborn child when ruling on the morality of the abortion. The case of *Attorney General v. X* reflects how historically the courts have acted out of a duty to the unborn, ignoring relationships and emotions when ruling on cases related to reproduction. These actions have illustrated Ireland's use of a framework that is analogous to Kantian ethics when making decisions in the field of reproductive medicine. Thus, although the emphasis on the duty to the unborn in Ireland was developed from a Catholic influence, because the framework Ireland has developed is strikingly similar to a Kantian framework, one can look to Kantian ethics to note how an emphasis on duty prevents the use of PGD.

Applying Kantian or Duty-Based Ethics to the Use of PGD

Applying this idea of Kantian ethics and the duty to protect the unborn to the case of PGD, it is clear why policymakers and health professionals in Ireland have been hesitant to adopt this technology. This is because according to the Catholic Church, even embryos that are not yet implanted in the uterus are considered "unborn" and worthy of protection (McDonnell & Allison, 2006). Therefore, if there is a duty to protect unborn, then all of the embryos created through PGD must be implanted into the uterus. However, because PGD discards embryos that are not implanted in the uterus, some of the "unborn" are not protected (Robertson,

2003). Thus, using PGD is immoral because the duty to protect the unborn is not fulfilled when this technology is used.

In addition to failing to protect the right to life of the unborn, using Kantian ethics and Oduncu's definition of human beings, it can be argued that PGD is immoral because it does not respect personhood. As previously explained, Oduncu defined Kantian human beings to include embryos because they have the potential to become rational (Oduncu, 2003). However, because PGD discards some of the embryos, the technology does not respect the potential for these embryos to become rational human beings (Robertson, 2003). Thus, PGD might disrespect the Kantian idea of personhood, and therefore the use of the technology may be seen as immoral when using Kantian ethics or the analogous form of duty-based ethics that is used in Ireland.

Conclusion

This chapter shows how in past cases involving reproduction, such as the *Attorney General v. X*, the Catholic emphasis on duty to the unborn has guided interpretations of the constitution (Smyth, 2005). Furthermore, this duty derived from Catholicism is analogous to the duty described in the theory of Kantian ethics. In both cases there is an emphasis on duty to respect personhood and a disregard for other factors like emotions (Wood, 2008). Due to the fact that the emphasis on duty in Ireland is analogous to a Kantian ethical framework, it is possible to use a Kantian perspective to see how an emphasis on duty may have prevented the use of PGD in Ireland. However, it now appears that this Catholic influence and emphasis on duty is starting to decline. This is evident in the fact that clinicians in Ireland are starting to use PGD even though it violates the Church's idea of protecting the unborn. Furthermore, now that Ireland is starting to use PGD, a new and non-religious moral theory may be needed to guide decisions related to reproductive medicine. The next chapter will argue that care ethics may be a useful ethical theory for Ireland to adopt, as it could expand the uses of PGD by considering the role of relationships in ethical decision making (Held, 1990).

Chapter 5

Adopting a Care Ethics Framework in Ireland

Introduction

Although the duty to protect the unborn has slowed the acceptance of ARTs such as PGD, there are alternative moral frameworks that Ireland could adopt to allow the uses of PGD to expand, especially to include selecting for traits like deafness. While the duty-based framework has ignored emotions and relationships, making PGD immoral, now that the nation has started to use the technology, this Catholic influence might be diminishing (Wood, 2008). Instead, it is important to consider other ethical frameworks that Ireland could adopt to allow the uses of PGD to grow. One theory in particular that would allow for the expansion of PGD in Ireland is care ethics. Unlike most ethical frameworks, care ethics does not rely on rules and principles, allowing health professionals and ethicists to have more discretion when determining the morality of an action (Held, 1990). Instead, care ethics recognizes the role of contextual factors such as emotions and relationships in ethical decisionmaking. Thus, if Ireland were to adopt a care ethics framework, there are many uses for PGD which might be morally permissible that would not otherwise be permitted using another moral theory (Held, 1990). This chapter will show that when care ethics is used to guide PGD practices and policies and there is less of a reliance on duty and abstract principles, PGD can be seen as moral and the uses of the technology can expand to include selecting for deaf embryos (Held, 1990).

Furthermore, as this chapter will demonstrate, due to the fact that care ethics considers relationships and emotions, this framework might permit physicians in Ireland to use PGD to select for deaf embryos (Baier, 1987). Thus, it is important to consider the use of a care ethics moral framework as this might allow the uses of PGD to expand and lead to an important dialogue about the potential to use of PGD to select for deafness in

Ireland. However, before explaining how this ethical framework can be applied to the case of selecting for deaf embryos, it is important to understand the theory behind care ethics.

What is Care Ethics?

Care ethics is a theory rooted in a feminist perspective that emphasizes the role of emotions and relationships in moral decision-making (Held, 1990). Unlike the individualistic duty-based theory used in Ireland, which views individuals in isolation, care ethics considers people to be interdependent (Sherman, 2014 and Held, 1990). Furthermore, care ethics examines how relationships between such interdependent people will be affected when making moral decisions (Baier, 1987). Held (1990) explained the concept of care ethics by stating, "Caring, empathy, feeling with others, being sensitive to each other's feelings, all may be better guides to what morality requires in actual context than...abstract rules of reason" (p.332) According to this view, abstract rules and principles should not determine morality or moral decision-making. Instead, philosophers should include the value of relationships and emotions in ethical decision-making.

Carol Gilligan was one of the first to recognize the importance of relationships and emotions in the field of ethics. In 1982 she published the book titled *In a Different Voice*, where she noted that the moral reasoning styles of women are different than the styles that have been described in past literature. Gilligan explained that past literature focused on the ethical and moral decision-making of men, often portraying women's decision-making as inferior and less developed than male decision-making (Tong, 2009). Gilligan recognized that women's decision-making was not less developed, but rather different than men's decision-making. She noted that women tend to focus on emotions, relationships, and the needs of others while men stress the importance of justice and rights when making moral decisions (Tong, 2009). Furthermore, past philosophers, like Kant, have constructed moral theories to emphasize the importance of duty, rights, and reason while ignoring emotions, relationships, and the interdependence between people (Held, 1990). By emphasizing the role of duty and

disregarding emotions and relationships, these philosophers did not construct moral theories from a gender-neutral perspective, but rather from a male point of view (Held, 1990).

Historically morality has been constructed from this male perspective because philosophers believed that only men were rational and therefore capable of moral reasoning (Tong, 2009). Women were thought to be too emotional to be involved in ethical decision-making. Held (1990) described how early philosophers viewed women by stating, “Women have been seen as emotional rather than as rational beings, and thus as incapable of full moral personhood. Women’s behavior has been interpreted as...driven by instinct, and thus irrelevant to morality and to the construction of moral principles.” (p. 325) Due to the fact that philosophers believed women were incapable of reason, females were completely excluded from discussions on morality. In addition, because qualities like compassion and care were associated with “femaleness,” such traits were historically thought to be irrelevant to ethics. Instead, there was a strong focus on reason and justice because philosophers believed these traits were associated with men and thus key to ethical decision-making (Held, 1990).

However, following Gilligan’s work showing that women develop a different reasoning style than men, philosophers began to embrace the idea of incorporating care into ethics (Tong, 2009). For example, shortly after Gilligan’s research the philosopher Nel Noddings elaborated on the concept of care ethics by explaining the definition of care (Tong, 2009). According to Noddings, in order to incorporate care into ethics the individuals must know each other and have a connection with one and other. Tong (2009) explained Noddings’ definition of care, stating, “real care requires an active encounter with specific individuals; it cannot be accomplished through good intentions alone.” (p. 168) Thus, for care to be incorporated into ethics, there must be an interaction and connection between the individuals involved. For example, Noddings contrasted the idea of a mother caring for her child with an affluent philanthropist donating money to a starving child in a foreign country. She explained that only the mother-child example reflects “real care” because while the philanthropist might have good intentions, this case lacks a personal connection between the two individuals (Tong, 2009). In this manner, care ethics not only considers people as interconnected, but also examines decision-making and

moral reasoning in the context of the relationships. By incorporating contextual factors such as relationships and emotions, care ethics is distinct from other moral frameworks. While traditional duty-based ethical frameworks like Kantian ethics focus solely on the individual and his or her duties, care ethics allows for a broader understanding of how relationships affect moral decisions (Held, 1990). Furthermore, because care ethics considers relationships and emotions, it is possible that this theory may view the morality of an action differently from other ethical theories.

This can be illustrated through the example of using PGD to select for deafness. As previously explained, using a duty-based ethical theory the use of PGD for any reason is immoral because it violates the duty to protect the unborn (Robertson, 2003). However, when emotions and relationships are considered and care ethics is applied, it is possible to understand how using PGD might be morally permissible. When care ethics is applied, health professionals must consider how using PGD would affect all of the relationships involved, including the relationship between the parents. If the prospective parents are experiencing infertility, this can be a major strain on their relationship. A systematic review conducted by Luk and Loke (2015) found that couples who suffer from infertility have reported increased marital problems, anxiety, and depression as well as decreased satisfaction in their sexual relationship. However, PGD can help resolve these infertility issues by allowing the pregnancy to progress. PGD can detect abnormalities in the embryos and selectively implant the ones with the best chance of developing into a fetus (Chang, 2016). Thus, using a care ethics perspective, PGD would strengthen the relationship between the prospective parents by resolving their infertility issues and thereby removing the factor that causes marital, sexual, and psychological distress (Luk & Loke, 2015). When the relationship between the prospective parents is considered, it is possible to see why PGD may be permitted in a care ethics framework. However, using care ethics as a moral theory may also expand the cases where PGD is permitted beyond the use of the technology for infertility treatment.

Applying Care Ethics to Selecting for Deafness

When the relationships between deaf parents and their children are considered, using PGD to select for deaf embryos might be morally permissible. This is because selecting for deaf embryos would enable deaf parents to share a common cultural identity with their kids. Furthermore, care ethics shows how this shared identity can strengthen family relationships, benefitting both the parents and children. As explained in Chapter 3, there is a strong deaf culture that can only be accessed by deaf individuals (Hauser et al., 2010 and Sparrow, 2005). For this reason, deaf parents can only share this cultural identity if their children are also deaf. Although hearing children can often communicate with their deaf parents through sign language, the inability to fully relate to the values and heritage of deafness prevents them from entering the culture (Mand et al., 2009). Using the feminist perspective of care ethics, it can be argued that because using PGD to select for deafness would allow for this shared identity between parents and children, this use of the technology is morally permissible.

Rather than view each person in a vacuum setting, care ethics recognizes that people are interrelated and that these relationships matter when considering if an action is moral. As the feminist philosopher Virginia Held (1990) explained, care ethics considers, “the actual relationships between embodied persons, and with what these relationships seem to require.” (p. 330) If this reasoning is applied to selecting for deafness, then using PGD for this purpose can be ethical because it would strengthen the child’s relationship with his or her parents. The ability for deafness to strengthen relationships is best reflected in the book, *Far From the Tree*, where one mother explained the joy she felt in sharing this trait with her kids. She stated, “they are part of the world that I’m in and they understand where I’m coming from.” (Solomon, 2012, p. 102) This example shows how deafness allowed the mother to have a special bond with her children that would otherwise not exist. By sharing the deaf culture, her children had a greater propensity to understand the values and heritage of deafness. Furthermore, using PGD to select for deafness enabled the children to enter the world in which their mothers lives.

If health professionals and philosophers only use a medical model of disability or consider the future child without relation to his or her parents and siblings, then they may not see the social value in deafness as a culture and selecting for deafness might not be an important trait to decide. However, care ethics examines relationships, so using this model one would have to consider how this decision would impact the relationship between the parents and children (Held, 1990). In the case of deaf parents, having a deaf child might actually benefit the future child by allowing him or her to be accepted into the same community as the parents. For example, Stebnicki and Coeling (1999) explained that deaf individuals tend to be socialized into the deaf community because the community “gives its members a feeling that they are understood and accepted” (p. 351). If the parents are socialized into the community but the children cannot fully enter, this could cause the kids to feel excluded from an important aspect of their parents lives. Even though the hearing children of deaf parents might know sign language, they still will feel that they do not belong in the deaf community. Singleton & Tittle (2000) explained this concept by stating, “Hearing children who are raised by deaf parents have the unique experience of being insiders, yet outsiders, in the deaf world.” (p. 228) Thus, the parent-child relationship might be strained because the hearing children feel as though they are outsiders in the deaf world in which their parents live.

In addition, hearing children of deaf parents might also struggle to form their own identity. Preston (1994) interviewed hearing adults who lived with deaf parents during their childhood. The researchers found that as these participants entered adulthood, they often questioned their identity. These participants developed an “uncertain adult identity” because they had trouble maintaining ties to the deaf community once they moved out of their parents homes (p. 49). Participants reported having trouble understanding how they could fit in with the deaf community once they were no longer living in a deaf household (Preston, 1994).

The issues hearing children of deaf parents face become even more complex if the parents already have one deaf child and want to use PGD for their second child. In this case, the entire family might already be immersed in the deaf culture, and a hearing child would then be isolated from the rest of the family (Mand et al.,

2009). For example, in an article published by BBC News, a deaf advocate explained, “it is those who are able to hear that are at a disadvantage in a world of deaf plays, deaf poetry, and deaf jokes.” (Murphy, 2008) In this manner, a hearing child would be at a disadvantage in a family of deaf culture and would not be socialized into the same community as his or her siblings and parents. Thus, in cases like this, a greater strain might be placed on the future child and all family members if the child is born hearing instead of deaf since the child cannot access the deaf culture (Mand et al., 2009). This illustrates that there are instances where the child might benefit from being deaf. However, these benefits can only be identified when care ethics is applied and the relationships among family members are considered.

In addition, when the entire family is considered, selecting for deafness might be seen as moral because it also benefits the family unit. Studies have shown that deaf parents with hearing children express many frustrations due to feeling left out of important areas of their children’s lives (Singleton & Tittle, 2000). For example, Harvey (1989) found that deaf parents with hearing children often said they did not feel informed about their child’s education. This is because educators commonly bypass the parents and talk directly with the child or other hearing family members when an issue must be discussed. When educators go to other family members, such as grandparents, or these relatives decide to intervene for communication purposes, deaf parents reported feeling that their parental authority was reduced (Harvey, 1989). This can also put a strain on relationships, as deaf parents feel they are not integrated into their hearing children’s lives. Furthermore, such a strain would directly affect the child, who might not be able to develop close relations with his or her parents due to constant interference by extended family members (Singleton & Tittle, 2000).

Using PGD to select for deafness can be justified in a care ethics framework when one considers the interdependence and relationships of the family as well as a social model of disability. When this is considered, selecting for deaf embryos would prevent both the deaf parents and their children from feeling isolated within the family. All parties would be part of the same culture and share a common identity (Mand, et al., 2009). Although using PGD to select for deafness has been highly contested by health professionals and ethicists, this

might be because professionals have not considered the future children in relation to their deaf parents (Robertson, 2003). However, when ethicists go beyond duties and the rights of the unborn, it is possible to see how selecting for deafness is morally permissible. It should also be noted that using this ethical framework where relationships and emotions are considered, it might be permissible for health professionals to use PGD to select for other controversial traits like sex. However, these other uses for PGD are beyond the scope of this thesis. Thus, the central argument for this chapter concludes that if ethicists and healthcare professionals apply the theory of care ethics, they can understand how relationships can be strengthened when PGD is used for a controversial trait like deafness.

Conclusion

While duty-based ethical frameworks like Kantian ethics have deemed PGD morally impermissible, this chapter aimed to demonstrate how this view of PGD can change when a different ethical theory is applied. By using the moral theory of care ethics, not only can PGD be used, but it can also be morally acceptable to select for controversial traits like deafness (Robertson, 2003). This is because care ethics does not just rely on rules and principles, but also considers how the action will affect relationships when determining morality (Tong, 2009). Furthermore, as this chapter demonstrated, when relationships are considered, it is possible to understand how allowing deaf parents to use PGD to select for deafness might be moral.

Although the Catholic emphasis on the duty to the unborn may have prevented selecting for deafness and all other uses of PGD, now that health professionals in Ireland are using the technology, there is a need for a new moral theory. This chapter aimed to demonstrate how care ethics might be a valuable framework to guide PGD use in Ireland. A care ethics framework would allow the use of ARTs like PGD to expand in new directions to keep up with the consumer demand and would also permit a dialogue to develop on how PGD could be used to select for deaf embryos. Furthermore, this framework would also allow for the implementation of policies that take into account relationships and families.

Chapter 6

Ireland Moving Forward and Concluding Remarks

Introduction

This thesis has argued that as the Catholic influence diminishes and more clinics in Ireland begin using PGD, a care ethics moral framework should be used instead of the duty-based framework that has previously been applied. This ethical framework would expand the field of ART by permitting PGD to be used in more cases, such as for deaf parents to select for deaf embryos. However, because care ethics would expand the uses of PGD, it is critical that Ireland creates policy and ethical guidelines to regulate the field of ART moving forward. This will ensure that health professionals and policymakers have guidance on how to use this technology as morals evolve from a focus on duty towards possibly a care ethics framework.

In order to address the need for policy, this chapter will provide concluding remarks on how Ireland should adopt a regulatory system and enhance professional guidelines to allow the uses of PGD to expand as morals evolve. It will be argued that Ireland should implement a regulatory system similar to the United Kingdom's Human Fertilization and Embryology Authority, or HFEA. This is because while HFEA is comprehensive, it can also be amended as new technology or issues emerge (Human Fertilization, 2017). If Ireland were to adopt this framework, the nation could create immediate policy to guide physicians, but also expand the uses of PGD as the technology becomes more widely accepted. However, such a regulatory body must also be supplemented with improved professional guidelines, as the current recommendations in Ireland do not specifically address how physicians should use PGD (Medical Council, 2016).

In order to show why Ireland should adopt such comprehensive policy, this chapter will first provide details on the role of HFEA before explaining how this system could be applied to Ireland. This chapter will also explain how a body like the HFEA should be supplemented with professional guidelines to aid health

professionals using PGD. Lastly, this chapter will conclude with a reflection on why there is a need for policy and guidelines given Ireland's political and religious history and declining religious influence.

An Explanation of the Human Fertilization and Embryology Authority

Before one can understand why Ireland might benefit from adopting a regulatory structure similar to the United Kingdom's system, it is important to learn the basics of the United Kingdom's HFEA. In 1982 the United Kingdom recognized that IVF and research on embryos needed to be monitored and created a committee to determine how the field of reproductive medicine should be regulated (Human Fertilization, 2017). This resulted in the 1984 Warnock Report, which stated that research on embryos and the use of IVF should be allowed, but a regulatory body should oversee this field (Human Fertilization, 2017). After the report was issued the Human Fertilization Act was passed, which established the HFEA in 1991 (Abdalla, 2009). Since its establishment, the HFEA has regulated reproductive technology and embryo research in the United Kingdom. Abdalla (2009) summarized the role of the HFEA by explaining, "the regulator's task is to find a balance between the needs of science and medicine and the concerns of patients and the public." (p. 53) In this manner, the HFEA is supposed to consider concerns of the public while still encouraging reproductive technology to develop. This framework is used with all technologies, including PGD (Human Fertilization, 2017).

In order to regulate PGD, the HFEA determines what genetic conditions can be tested for or against and also licenses and monitors clinics using PGD to ensure physicians are following standardized procedures (Human Fertilization, 2017). The HFEA has a comprehensive list of genetic conditions that can be tested using PGD and considers expanding the list after a clinic submits an application for a specific condition to be added (Houses of Parliament, 2013). Furthermore, health professionals in the United Kingdom are not permitted to use the technology for any conditions that have not been approved by the HFEA, including selecting for deafness (Human Fertilization, 2017 and Emery, Middleton & Turner, 2010).

While this regulatory system currently prevents the use of PGD to select for deaf embryos, the HFEA can amend regulation and periodically reevaluates the list of approved conditions (Houses of Parliament, 2013). The HFEA has a formal review process for conditions that have been denied approval to be reconsidered (Houses of Parliament, 2013). This allows for the list of approved conditions to be amended as research and social views evolve. Thus, it is possible that as morals evolve in the United Kingdom, this system could potentially allow deaf parents to select for a deaf embryo. It is because of this flexibility to expand the uses of PGD that the HFEA model should be adopted even though it currently does not permit for selecting deaf embryos.

The United Kingdom's Houses of Parliament has recognized that the uses of PGD continue to expand. In 2013, the Houses of Parliament released a document explaining the uses for PGD and stated that there has been "a broadening in the range of conditions authorized." (Houses of Parliament, 2013, p. 2) Thus, it is clear that the United Kingdom's regulatory system provides flexibility to allow the field of reproductive medicine to grow by creating a method for conditions to be approved and reevaluated. In this manner, it is possible that some prohibited uses like selecting for deafness could be permitted if public views change. This comprehensive system prevents ambiguity by clearly stating how PGD can be used, but also allows for changes in policy as research and public views evolve.

Applying the HFEA to Ireland

Before explaining how the HFEA could be adopted by Ireland, it is important to understand why it is reasonable to apply a regulatory system from the United Kingdom to Ireland. First, the United Kingdom is more religiously diverse than Ireland, which may prevent religion from guiding laws and policy. For example, while the 2011 Census data showed that 84 percent of the population in Ireland was Catholic, a 2007 study conducted in England and Wales that showed 28 percent of the population was Anglican and 27 percent was Catholic. This indicates a higher degree of religious diversity in the United Kingdom compared to Ireland

(Central Statistics Office, 2012 and Bruce, 2011). It is important that Ireland adopts regulation that does not have a strong Catholic influence in order to ensure that the field of ART and the uses of PGD can expand. Thus, the United Kingdom would be a useful model because the nation is more religiously diverse and therefore less likely to be influenced by any one religious organization.

In addition, the United Kingdom has significantly more fertility clinics currently using PGD compared to Ireland. While only two clinics in Ireland are using the technology, there are over twenty clinics in the United Kingdom offering PGD (Cork Fertility Centre, 2017 and Human Fertilization, 2017). As Ireland begins using PGD, the nation could benefit from adopting a system like the HFEA, which already has experience regulating the technology. Lastly, as explained in the previous section, the United Kingdom's regulatory system is extremely comprehensive and provides detailed regulations (Human Fertilization, 2017). However, unlike most European countries, Ireland has no comprehensive regulation of ARTs (McDonnell, 2017). For this reason, adopting a model like the HFEA would provide comprehensive information on how PGD can be used to aid health professionals currently using the technology in Ireland.

Due to the fact that the HFEA provides a regulatory system that is comprehensive and modifiable, if such policy was adopted by Ireland, the uses for PGD could continue to expand. A system similar to that of the HFEA would clarify the ambiguity that currently surrounds PGD in Ireland. As explained in Chapter 2, clinicians in Ireland are hesitant to use PGD because they are unsure if it violates the constitutional protection on the right to life of the unborn (McDonnell & Allison, 2006). While few clinics have started to use PGD, it is usually only offered as a way to prevent a narrow list of fatal and severely debilitating genetic diseases. For example, although Cork Fertility Centre in Ireland offers PGD, the clinic's website lists less than ten conditions they will screen for using the technology (Cork Fertility Centre, 2017). This is a very restricted use of PGD considering that the HFEA has approved the technology for over 250 genetic conditions (Human Fertilization, 2017). In addition, Cork Fertility Centre's website states that PGD is "not yet considered to be a standard technique" even though the technology has now been used in other countries since the 1990s (Cork Fertility

Centre, 2017 and Sermon et al., 2004). This illustrates how clinics in Ireland are hesitant to adopt PGD and use it as a standard procedure. Furthermore, it demonstrates the need for a regulatory system like HFEA, which would not only legitimize the conventional medical uses of PGD, but would also regulate the technology more like comparable nations such as the United Kingdom.

If clinics had clear guidance on the legality of PGD, health professionals would be more likely to use this technology because there would no longer be ambiguity as to whether it violates the constitution. In addition, by adopting a system like the HFEA, health professionals in Ireland would have a specific list of what genetic conditions can be selected for or against using the technology. This might allow clinics like Cork Fertility Centre to expand the use of PGD beyond the eight conditions that are currently permitted (Cork Fertility Centre, 2017). Furthermore, using this system would enable policymakers to revise rules and regulations as social views change and discoveries related to genetic diseases and disabilities are made.

In addition, if Ireland were to adopt a regulatory framework like the HFEA, it would open a dialogue to address the more controversial uses for PGD, including selecting for deaf embryos. Ireland would then have to decide whether or not to approve this use of the technology. Although a regulatory framework would force policymakers in Ireland to consider this controversial use of PGD, it is unlikely that such a system would permit physicians to select for deaf embryos at this time. First, it is unlikely that policymakers would permit such a liberal use of the technology when for the past twenty years the nation has been extremely ambivalent to use PGD at all (Cork Fertility Centre, 2017). Even in countries where PGD has been routinely used since the 1990s, the acceptance of new uses of the technology has been gradual. This is best evident in the United Kingdom, where initially PGD was only used to detect fatal genetic diseases (Houses of Parliament, 2013). However, gradually over the course of the last two decades more liberal uses of the technology have been permitted. For example, the United Kingdom now allows health professionals to select against nonfatal diseases and screen for genes that increase one's risk of a disease later in life, such as the BRCA1 and BRCA 2 genes, which increase the risk of breast cancer in adulthood (Houses of Parliament, 2013). This example

illustrates how policy expansion surrounding PGD has been gradual even when there is a regulatory body in place. Thus, it is unlikely that Ireland would immediately permit selecting for deafness, but would instead gradually expand the uses of PGD.

The Catholic Church would also be a major barrier impeding the use of PGD to select for deaf embryos. This is because although Ireland has started to move away from a framework emphasizing the duty to protect the unborn, the Church continues to have a presence in Ireland, slowing the acceptance of PGD (McDonnell, 2017). As explained in Chapter 2, the Church has held an extremely conservative position and rejected all uses of PGD and other forms of ART claiming it interferes with “divine intention” and allows physicians to play the part of God by choosing which embryos to implant (Czarnecki, 2015, p. 719 and Scott, 2006). Even though health professionals have started to use PGD despite this religious influence, it has only been for severe and fatal diseases (Cork Fertility Centre, 2017). If policy was implemented, it would likely expand the list of genetic diseases that can be tested for or against. However, it is unlikely that policymakers and health professionals would immediately adopt PGD for controversial uses like selecting for deafness because of the strong Catholic resistance (McDonnell & Allison, 2006).

The strength of this religious resistance is best evident in the fact that the Catholic Church successfully prevented clinicians in Ireland from using PGD for over twenty years (Cork Fertility Centre, 2017). Furthermore, the Church has continued to protest policy for PGD and other forms of ART because of a fear that this would potentially allow for more liberal uses of the technology. McDonnell and Allison (2006) explained that there is a “strong Catholic medical ethos fear that legislation will liberalise access to fertility treatments.” (p.826) Thus, it would be expected that the Church would adamantly protest the liberal and controversial use of PGD to select for deaf embryos, preventing policymakers from approving this use of the technology. While the use of PGD and pressure from fertility clinics would likely challenge the Church, the religious protests would still slow the acceptance of PGD for more controversial uses like selecting for deafness.

However, using a regulatory body would allow Ireland to reconsider uses of PGD as moral frameworks and public attitudes evolve. For example, while the Church does not support any use of PGD, this religious influence is declining and thus it is possible that as this influence diminishes there will be less opposition against using PGD to select for deaf embryos. The HFEA allows for a reevaluation for conditions that have previously been denied approval (Human Fertilization, 2017). Thus, if Ireland were to adopt this aspect of the HFEA, policymakers could reevaluate and expand the uses of PGD as this religious emphasis on the duty to the unborn declines.

Implementing Professional Guidelines

Although a regulatory body would best address changing moral frameworks and provide comprehensive rules on how PGD can legally be used, Ireland should also improve current professional guidelines to address ethical issues with the technology. Currently, the professional guidelines for ART are supplied by the Irish Medical Council (McDonnell & Allison, 2006). However the most recent edition of the Medical Council's ethical guide does not specifically mention PGD. The guide, which is titled "Guide to Professional Conduct and Ethics for Registered Medical Practitioners", contains only four paragraphs devoted to the field of ART and provides little recommendation on how such technology should be used. The guide states, "Assisted human reproduction... should only be used after thorough investigation has shown that no other treatment is likely to be effective." (Medical Council, 2016, p.34). However, the Medical Council gives no further recommendation. Thus, an update is needed to specifically inform and guide physicians handling ethical issues that may arise from using PGD.

It is important that Ireland update professional guidelines because even if the nation establishes a regulatory system, health professionals will still face ethical issues. It is possible that it may be legal to select for a genetic condition using PGD, but not ethical in certain cases. For example, the previous chapter showed how if care ethics is applied, selecting for deafness might be permissible if the parents are deaf. However, in

other contexts such as a family where no one is deaf, care ethics might not allow for deafness to be selected. This is because in the case of a hearing family, a deaf child would not have the same cultural identity as his or her parents and selecting for this trait would not be critical to the parent-child relationship (Hayry, 2004 and Held, 1990). Thus, even if selecting for deafness is allowed, there are cases where it might not be ethically permissible. For this reason, professional guidelines are needed to help physicians decide when it is ethical to use the technology.

The importance of professional guidelines is further exemplified by the fact that even countries with regulatory bodies have established ethical guidelines for PGD. For example, the Royal College of Obstetricians and Gynecologists in the United Kingdom publishes clinical guidelines to aid health professionals working in the field of women's health (Royal College, 2017). These guidelines cover many aspects of women's healthcare including ART and the use of PGD. For example, although the HFEA permits many uses of IVF and other forms of ART, the Royal College of Obstetricians and Gynecologists in association with the National Institute for Health Care Excellence recommends that all couples should be seen together for fertility treatments and properly informed that treatment can put stress on the couple's relationship (NICE, 2013). Thus, in this example the professional guidelines supplement the regulations by providing more specific details on how the health professional should interact with patients. In addition, the Royal College of Obstetricians and Gynecologists also holds conferences and training sessions to inform clinicians about PGD and the ethical issues surrounding the technology (Royal College, 2017). This illustrates how policy and legislation must be supplemented with professional guidelines so physicians are fully aware and trained to handle ethical issues that could arise from PGD. With this combined use of professional guidelines and a regulatory body, Ireland would have the systems in place to expand the uses of PGD moving forward.

Concluding Remarks

From a focus on a duty to the unborn, to the potential for care ethics, this thesis aimed to show how Ireland's moral frameworks continue to evolve. With these changing morals and the increasing demand and use of ARTs like PGD comes a need for regulation and professional guidelines. Under the Catholic framework there was ambiguity as to whether forms of ART like PGD could be used because of the lack of regulation and an emphasis on the duty to protect the unborn (McDonnell & Allison, 2006). Although this constitutional ambiguity and the Church's views of PGD have not changed, health professionals in Ireland are starting to use the technology, creating a need for policy and guidelines (Cork Fertility Centre, 2017). Furthermore, this indicates that the Catholic framework is diminishing and a new moral theory may be needed to guide reproductive medicine. This thesis explained that care ethics may be a useful framework for Ireland to adopt, as it will expand the uses for PGD. This idea was illustrated by using selecting for deafness as a case study to show that when relationships are considered, uses of PGD that once seemed controversial might be morally permissible. Thus, adopting a new moral framework like care ethics would allow the uses of PGD to expand in Ireland.

While a care ethics framework would permit the expansion of the technology, this is unlikely to happen without clear guidelines and policy as well as further research. Current studies on Ireland's use of PGD are limited and have focused broadly on the lack of regulation and the field of ART as a whole (McDonnell & Allison, 2006). However, future research should specifically examine the use of PGD in Ireland. Now that two clinics are using the technology, future studies could examine public attitudes about expanding the uses of the PGD (Cork Fertility Centre, 2017). For example, if more studies in Ireland were to examine public opinions on the use of PGD to allow deaf parents to select deaf embryos, policymakers and health professionals could assess if the public is open to this use. This information would allow health professionals and policymakers to create policy and recommendations that reflects public views and attitudes.

Additional research should also further examine the moral frameworks used to guide PGD in Ireland.

While this thesis aimed to illustrate the evolving morals, it appears that this might be one of the first studies to examine Ireland's moral frameworks in relation to the use of PGD. Furthermore, while this thesis made recommendations for Ireland to adopt a care ethics perspective, future studies should examine if this moral framework is actually adopted. It is important to continue to monitor the moral frameworks used in Ireland because as this thesis illustrated, different frameworks might allow for different uses of the technology. If future studies indicate that care ethics is in fact being used, this might permit for the uses of PGD to expand to include selecting for deaf embryos. Thus, there are avenues for future research that should be explored to advance the use of PGD in Ireland.

Although health professionals have been a catalyst in making PGD available in Ireland, there is still much work to be done to expand the use of the technology. Now, additional research must be gathered and health professionals and policymakers must consider how to address the use of PGD through policy and guidelines. If these actions are taken, it is possible for Ireland to expand the use of PGD. It is now up to researchers, health professionals, and policymakers to address the changing morals and create guidelines and policy that reflect this shift from duty towards care in Ireland.

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Sales Associate

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