DEMANDING IDENTITIES: HOW MEDICALIZATION AFFECTS INFERTILE WOMEN'S LIVES AND SENSE OF IDENTITY IN IRELAND AND THE UNITED STATES

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ABSTRACT

Demanding Identities:
How Medicalization Affects Infertile Women's Lives and Sense of Identity in Ireland and the United States

Doctor of Medical Humanities Dissertation by

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For women who are unable to have children naturally, the medicalization of infertility has created an opportunity to become biological mothers. This medicalization shapes the experience of involuntary childlessness in the Republic of Ireland and the United States due to all that fertility treatment demands and the changes in female identity that result. The goal of this dissertation is to understand through women's personal stories how the experience of medicalized infertility disrupts women's lives and alters their sense of identity.

The early chapters explore medical system structures, the fertility clinic setting and governance, and public opinions about fertility and infertility. Medical system structures are explored to show how the inconsistencies in the Irish and American medical systems make seeking help for infertility difficult, which creates added burdens for individuals. The way the fertility clinic setting is designed, fertility practices are governed, and care is delivered introduces more burdens women must navigate. Public views of fertility and infertility contribute to the beliefs women form at an early age and the experience they encounter when unable to have children on their own. The chapters

on medical system structures, fertility treatment governance, practices, and policies, and public perceptions provide background and context to prepare readers for later chapters and show that there are many layers of complexity women encounter when seeking medical help for reproductive problems.

Through interviews with women who went through fertility treatment, I explore the demands of treatment and the identity changes that result from the medicalization of infertility to show the gravity of the experience. The demands consume patients' lives, which leads to shifts in the people they are.

This type of research is important to understand how the medicalization of infertility affects women's lives. Through this interdisciplinary approach, and viewing the topic through the lens of medical humanities, I conclude that the medical community must take specific steps to make the way fertility treatment is designed and delivered more humanistic for those who must rely on the field of medicine to achieve the desire of becoming biological mothers.

Dedication

For those who shared their stories with me
and for those who have stories yet to be told

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Chapter One

Introduction

All cultures emphasize the importance of childbearing as a normal part of life. Particularly, women carry the burden of reproductive responsibility. The absence of pregnancy and children in cultures that deem reproduction necessary creates the need for a "cure." The desire to find a solution to a problem that affects individuals, families, and societies led to the medicalization of infertility in modern society. Medicalization creates a sense of order to infertility (Lloyd 1997, 194).

The way in which infertility is medicalized depends on one's position in the system. Medicalization dominates the process, but local cultures determine how medicalization occurs within specific societies (Ginsburg and Rapp 1991). Medicalization leaves the medical community with control of a socially constructed problem. The field of medicine offers a cure, and societies embrace all that medicine offers (Zola 1972, 500).

The medicalization of infertility focuses on female reproduction, and male reproduction is more of a non-issue (Lloyd 1997). The medical control of infertility leaves men in a role of providing comfort, demonstrating power, and doing little work, while women are the object of medicalization (Bell 2016) and endure the brunt of fertility treatment.

Medicalization identifies biological motherhood through fertility treatment as the most acceptable method for addressing infertility. Becker and Nachtigall wrote,

> In the case of infertility, the medicalisation process effectively limits acceptable outcomes to one, the biological production of a child. Alternative social solutions, such as remaining childless, adoption, and other modes of incorporating children into daily life, such as fostering others' children, are apparently viewed as more undesirable once a biomedical approach is initiated because they symbolise a dual failure: the failure to conceive and the failure to be cured. (Becker and Nachtigall 1992, 468)

Medicalization attempts to normalize issues but highlights the abnormalities at a higher level in the process.

Interestingly, medicalization took a condition that involved feelings and personal experience and turned it into a robotic process of medical intervention. This is not entirely negative, as medicalization has tried to create a cure for infertility. However, the personal experience gets lost in some cases.

While some may resist the process of medicalization, those who are infertile are likely to embrace it as their only option for having biological children.

For women and men who desperately want children, the absence of babies interferes with a part of life that many people experience naturally. Infertility affects seventeen percent of couples in the Republic of Ireland (Mum.ie 2017) and twelve percent of couples in the United States (RESOLVE 2015); yet little is known about the effects of the infertility experience on the large number of Irish and American women who encounter involuntary childlessness.

The first treatment to address infertility as a medical condition became available in 1967 when the fertility medication clomiphene became available widely for use after Frank Palopoli and his team discovered the medication in 1956 (Dickey and Holtkamp 1996, 483-485). A revolutionary type of medical intervention emerged in Europe in 1978 with the birth of Louise Brown, the first IVF baby, changing the landscape of infertility to one of scientific exploration. Three years later, in 1981, Elizabeth Carr was born through the first successful attempt at in vitro fertilization in the United States. While artificial insemination was used in the years prior to Brown's birth, the births of Louise Brown and Elizabeth Carr opened the floodgates to the medicalization of infertility in Europe and North America.

BRITAIN'S BIGGEST EVENING SALE
Evening News
LATE SPECIAL CITY PRICES
Meet Louise, the world's first test-tube arrival
SUPERBABE
Wide-eyed Louise Brown pictured in hospital 18 hours after she was born. Today she's doing well. See Page Three

LIFE
'CATS' LEAPS ONTO BROADWAY
The hottest theater ticket in the country
SAVING AFRICA'S BIG ANIMALS
A radical plan to butcher some of them and sell their meat
November 1982 $2.00
TEST-TUBE BABY BOOM
Elizabeth Carr, America's first in vitro baby, at the lab where she was conceived

Figure 1. Louise Brown and Elizabeth Carr Enter the World. Sources: Bowater 2012; NCCRM 2017.

The emergence of IVF as a method to intervene in cases of involuntary childlessness recognized infertility as a condition manipulatable within the medical domain. The added classification of infertility as a disease in 2008 by the World Health Organization (Zegers-Hochschild et al. 2008, 2686) confirmed infertility to be a medical diagnosis.

In this dissertation, I propose that the way in which infertility is constructed and controlled within each medical system contributes to varying degrees of life interference for women and causes changes in the female sense of identity. The aim of this research is to identify ways to improve the journey of infertility for the women who find they must travel it and to provide those who have not experienced involuntary childlessness with insight into the condition to improve general understanding.

The Republic of Ireland and the United States have been selected because, in these countries, fragmented healthcare systems lead to people lacking financial resources and treatment options. This fragmentation results in difficult or impossible access to fertility services for many. The Republic of Ireland and the United States address the medicalization of infertility in slightly different ways.

Research on this topic through the lenses of specific academic disciplines limits existing discussion, making the current medical humanities approach valuable. The field of medical humanities creates an avenue for an interdisciplinary analysis. By incorporating various academic disciplines, I have conducted research that provides a holistic assessment of a life-altering condition.

Methods

Women and men who have experienced infertility and completed fertility treatment were recruited through electronic communication. Men and women were required to express interest by email, which resulted in a follow-up email with a questionnaire. By examining the completed questionnaires, I selected individuals with former infertility experiences per country with differing outcomes, years of education, and income levels to participate in a thirty-to-sixty-minute, one-on-one, open-ended interview. Upon consent, interviewees met with me at a convenient location, answered questions they were comfortable with, and were audio recorded when permitted for documentation purposes. All participants are represented by alphanumeric identifiers in the text. Twelve women and two men were interviewed in Ireland, and eight women and one man participated in the interviews conducted in the United States. The research was conducted and analyzed using a grounded theory approach. Grounded theory, often used in social science research, is an inductive and open-ended approach for qualitative research collection and analysis. The researcher builds the theory through the collection of empirical data (Charmaz 2003).

Limitations

There are limitations of this research. Firstly, due to the method of recruitment, the number of women and men, outcomes of treatment, level of education, and age were not identical between Ireland and the United States.

Secondly, the number of participants was adequate for the research, but a larger sample may have provided additional information not included in this dissertation.

Thirdly, the interviews were a fixed amount of time for interviewees with time constraints and limited to one per participant. Additional communication occurred after the interviews for clarification in some cases. Planning for follow-up interviews would have been helpful to allow for extra time and to clarify questions that arose during the writing process.

Fourthly, healthcare is undergoing change in the Republic of Ireland and the United States. Future changes may alter health insurance offerings, health policy, fertility clinic structures, medical community governance, and media coverage relating to infertility, which may affect the relevance of some aspects of this research.

Outline

This dissertation will look at the medicalization of infertility in each country from four different aspects: medical system structures, fertility treatment governance, practices, and policies, public perceptions, and personal experiences. The information discussed in the early chapters provides background for the interview data discussed in later chapters. The participants' stories provide real examples of the information introduced earlier in the dissertation.

Chapter two provides a review of the literature regarding infertility and its medicalization.

Chapter three discusses current medical system structures and their connection to reproductive medicine. Through existing literature, medical system structures in the Republic of Ireland and the United States are evaluated to determine how access to medical services within countries contributes to the infertility experience.

Chapter four provides information about fertility treatment governance, practices, and policies shaping the infertility experience in the Republic of Ireland and the United States. Literature on fertility treatment governance, practices, and policies is examined to show how the medical community's governance of medical intervention for reproductive issues contributes to the experience and interferes with women's lives. My observations and analysis of four fertility clinics (two in Ireland and two in the United States) show the medical community’s governance in practice. The medical community’s control of fertility assistance results in patients viewing medical professionals and clinics as sources of information, support, and expertise.

Chapter five addresses public perceptions of infertility. Public knowledge of reproductive difficulty and the information available to the public contribute to infertility understanding and women’s personal experiences. The current state of sex education, fertility awareness, media coverage, and popular culture representation facilitates infertility education and awareness. Each of these factors are explored to show how public perceptions contribute to personal belief formation and fertility understanding. Public views affect the lives of women who must seek medical assistance.

Through analyses of the personal accounts collected from interviews, chapter six examines the demands of treatment and chapter seven explores the changes in female identity that result from the medicalization of infertility. Perspectives from people who have experienced infertility are essential to this dissertation. Women and men who experience reproductive difficulty and seek medical assistance are the only people who know the medicalized infertility experience personally. After examining medicalization’s impact on involuntary childlessness by looking at medical systems, fertility treatment governance, and public perceptions, I turn to women and men for their stories to understand how the treatment process disrupts women’s lives and alters their sense of identity.

Chapter eight discusses the many ways in which the chapters and elements of this dissertation connect to show the overall impact of the medicalized infertility experience

on women’s lives. The dissertation concludes with recommendations for the medical community and future research. Women who experience infertility find that life is interrupted and the identities they embody change, but the medical community has the ability to ease some of the burdens. This can be achieved by employing more humanistic medical practices in the delivery of fertility treatment.

Chapter Two

Literature Review

Cultural Reproductive Beliefs

Ample research within the social sciences on various aspects of infertility relates to the topic of this dissertation. Renowned medical anthropologist Marcia Inhorn spent many years researching infertility. In a comprehensive article, Inhorn looked at the topic of women's health and argued that medicalization surrounds the female body in many societies, cultures play a role in defining expectations of women, and an essential part of being a female family member entails reproduction (Inhorn 2006, 350). Inhorn's research on reproductive expectations aligns with Oaks' findings regarding the essentiality of reproduction and motherhood (Oaks 2003). The importance of motherhood dominates societal expectations of women in most if not all societies (Letherby 2002).

Ulrich and Weatherall suggested that womanhood and motherhood go hand in hand. Women who are unable to have children naturally feel a sense of inadequacy. The terms used and the societal expectations result in negative feelings for those affected (Ulrich and Weatherall 2000). Letherby found in her research in the United Kingdom that women unable to have children feel as outsiders, question their identities, and are viewed as different or deviant (Letherby 1999).

Inhorn discussed the importance of reproduction in Egypt in her book *Quest for Conception*, where having children is viewed as a female requirement. She discovered the lengths women go to to become pregnant. Inhorn found that women who encounter fertility difficulty experience added hardship because the husband's family blames the woman for the inability to have children, husbands may leave infertile wives to find wives who can have children, and communities alienate involuntarily childless women (Inhorn 1994).

Whittaker discussed the familial expectation to bear children in Thailand, where women must consider the family's wishes when making the decision whether to seek fertility assistance. That is, personal desires are not sole determinants of seeking medical help. Instead, women must pursue treatment despite their own views on seeking help to satisfy family. Men desire children, specifically sons, to carry on the family name. Male partners' families encourage women to conceive and permit men to leave their wives if unable to have children, creating added pressure for women (Whittaker 2014).

Since the emergence of assisted reproductive technologies (ART), research on the topic has increased. Inhorn and Birenbaum-Carmeli examined the presence of ART within societies. They concluded that social, moral, and religious components determine how cultures implement these biomedical advances, and reproductive expectations vary depending on local cultures (Inhorn and Birenbaum-Carmeli 2008). An example of the impact of social, moral, and religious factors influencing ART is found in Israel, where conservative rabbis encourage sperm donation from men who are not Jewish to eliminate potential issues of adultery or incest within Jewish society. Inhorn wrote, "For women around the world, local moralities, often religiously-based, have major effects on women's health decision making, particularly when the moral stakes are very high" (Inhorn 2006, 364-5).

Becker found that social and religious acceptance of ART shapes cultural thinking regarding these technologies as something that women and men consume. These technologies change the culture of childlessness, reinforce the need for normalcy of parenthood through fertility assistance, and create hope. Desperation to find a solution to infertility results in a market for assisted reproductive technology consumption in the United States (Becker 2000) and beyond.

Greil et al. found a connection between religiosity and seeking fertility assistance. Religion plays two major roles in individuals seeking assistance. First, religions tend to promote procreation and the role of women as mothers. Second, religion dictates what treatments are appropriate within specific belief systems (Greil et al. 2010).

McDonnell and Allison explored the role of religion in the medical design and ethics of fertility within society. They argued that religion and politics are key factors in cultural acceptance or denial of reproductive policies and technology. They found that the Catholic Church controlled many aspects of Irish society historically, including reproduction, whereas other societies tend to be more pluralistic (McDonnell and Allison 2006). The Catholic Church has determined and controlled aspects of the social construction of infertility in Ireland, contributed to the silence that surrounds involuntary childlessness, promoted the importance of having children in Irish society, and worsened the paralysis experienced when unable to conceive or carry a baby (Allison 2013).

Kahn explored the use of reproductive technology in the pronatalist country of Israel. Judaism and the state's recognition of the need for fertility policies and coverage shape Israel's views on infertility. Kahn has shown how rabbis have helped shape the policies and taught that procreation is necessary to create more members of the Jewish faith (Kahn 2000).

Greil and McQuillan found data regarding infertility beyond the biomedical setting. They believe medicalized infertility fails to account for women who may be infertile but do not consult, or have not consulted, a medical opinion. They concluded that involuntary childlessness affects far more women, and at various degrees, than can be determined and understood in the clinical setting (Greil and McQuillan 2010).

Johnson and Simon found in their study of women with and without medical diagnoses resulting in infertility that women who desire to have children with a biological roadblock to motherhood are increasingly likely to embrace biotechnology to become mothers (Johnson and Simon 2012).

Shanley and Asch argued that infertility is not a medical problem affecting individuals, but an often-unrecognized social issue. Societal expectations create this female responsibility and the burdens of undergoing ART, but finances prohibit individuals and couples from seeking medical assistance. Financial means determine the level of treatment patients receive, if any, because fertility treatment is costly and lacks coverage by most insurance companies in the United States. Shanley and Asch suggested the need to look at social factors contributing to infertility, such as delayed motherhood to establish careers and the failure to address environmental factors associated with reproductive difficulty (Shanley and Asch 2009).

Ginsburg and Rapp found that reproduction is a stratified condition in which some women are encouraged to reproduce and others are not based on economic status and stereotypes (Ginsburg and Rapp 1995). Greil, McQuillan, and Slauson-Blevins found that this leads to a subset of women reaching out for help when unable to have children.

Furthermore, individuals identify as infertile only when having children is desirable (Greil, McQuillan, and Slauson-Blevins 2011).

Infertility Health Policy and Treatment Access

In an article on the importance of legislation, regulation, and medical coverage, Adashi and Dean suggested that inadequate reproductive policies and health insurance benefits create economic and access barriers. Those who seek fertility services in the United States encounter inconsistent medical coverage. Coverage varies depending on the geographic location in which a person lives, her employment status, and the employer's inclusion or exclusion of fertility treatment because there are no federal government mandates regarding coverage (Adashi and Dean 2016).

> This state of affairs is socially unjust: the right to build a family in the face of infertility is now tied to economic prowess. Improving the state of underwriting of general infertility and ART services must be embraced as a central moral imperative and as an unwavering strategic goal of the professional societies entrusted with the reproductive health of women and men in the U.S. (Adashi and Dean 2016, 1117)

A survey of 1,003 participants concluded that more than half of the Irish public support various forms of ART and believe there needs to be better medical coverage offerings and legislation addressed by the Irish government (Walsh et al. 2013). Walsh, Ma, and Sills believe there is a need for greater government involvement and regulation of assisted reproductive technology. The failure to implement adequate regulations affects those who need medical intervention (Walsh, Ma, and Sills 2011).

In addition to the legislative and regulatory inconsistencies, the infertility experience differs for individuals depending on social class. Members of the lower class may have fewer treatment options for involuntary childlessness than middle or upper-class individuals, or none at all (Bell 2014).

Emotional, financial, and educational factors also contribute to the decision to seek treatment. There is a tendency for better educated, higher earning, and less depressed individuals to seek assistance. Overall, Eisenberg et al. found that these factors act as barriers to treatment for involuntary childlessness (Eisenberg et al. 2010).

Furthermore, research shows fertility treatment access varies depending on where a person lives. Healthcare system variations result in the control of ART access and wellbeing for women and men. The commercialization of ART and level of government involvement results in unequal access, which requires additional efforts to make access to these advanced technologies more equal (Balabanova and Simonstein 2010).

Medical Professionals and Infertility

Data suggest that physicians require better education generally to provide more in-depth information to patients who have trouble getting pregnant. Additionally, female physicians tend to be better aware of infertility issues than men, which results in better discussion, awareness, and recommendations for patients under the care of female clinicians (Ceballo, Abbey, and Schooler 2010).

Mourad et al. concluded that patients want physicians to share more details and information regarding treatment, and patients prefer to be more involved in the process. Individuals feel better about medical intervention when a small group of healthcare professionals with whom the patient is familiar delivers their care. A larger number of medical professionals' involvement in care delivery results in added stress for patients (Mourad et al. 2010).

Souter et al. found in their study that patients feel as though clinicians inadequately understand the emotions accompanying infertility and should increase counseling options within the clinical setting. Physicians fail to involve male partners equally in the treatment process. Patients want male partners to be invited to attend visits and included in conversations regarding care. Although relatively happy with fertility treatment delivery, patients would like physicians to communicate about treatment in more detail by providing more information about the causes of infertility and medication therapy (Souter et al. 1998).

Boivin and Lancastle believe medical professionals may be able to alleviate some emotions experienced throughout fertility treatment and periods of time waiting between treatments through the implementation of coping and self-help methods. The wait for pregnancy test results when being treated by medical professionals leads to feelings of anxiety and depression, a general sense of uncertainty, and a lack of control (Boivin and Lancastle 2010).

In conversations with five allopathic physicians, Kothari discovered that medical providers feel as though there needs to be better general education about reproduction, factors associated with infertility, and knowledge regarding when a thorough medical investigation is necessary. The author suggested that while infertility is situated within biomedicine in the clinical setting, there are lifestyle factors that contribute to infertility that people may not understand. The factors include work conditions, sexually-transmitted diseases, nutrition, and smoking (Kothari 2012).

Infertility Elements

While the biomedical model places emphasis on controlling reproduction, there is a level of uncertainty that accompanies infertility, which affects the infertility experience. Couples embark on the fertility journey together in many cases, but women carry the responsibility of treatment primarily. A sense of cultural and physical failure and an altered identity accompany infertility, regardless of whether treatment results in children. “For some couples, infertility was akin to having a chronic disease with intermittent illness episodes, a dysfunction that was always there despite any child they might have had or adopted, but an illness event exacerbated only when another pregnancy was attempted” (Sandelowski, Holditch-Davis, and Harris 1990, 211).

Parry’s research has shown that fertility services empower women. Through the experience of infertility and subsequent treatment, women find they become stronger personally. Women feel as though they gain some level of control, but continued social change such as better education about the effects of delayed childbearing must occur to improve the experience. Parry suggested social reform is needed to address women’s ability to have children and a career at the same time (Parry 2005). Chachamovich et al. found in their literature review that infertility affects and decreases women’s quality of life. They suggested that better intervention methods need to be put in place to address and alleviate some of these quality of life issues for individuals and couples (Chachamovich et al. 2010).

A study by Finamore et al. concluded that women tend to be secretive about fertility treatment with employers. Women choose to disclose or not to disclose their infertility issues to employers for several reasons, including a desire for privacy, concerns of position advancement, and fear of potential judgment. Some treatment requires more time away from work necessitating disclosure, and other women choose to share with employers to feel less perceived stress about the situation. Additionally, education plays a role. Higher education results in lower disclosure (Finamore et al. 2007).

Allison also addressed secrecy regarding ART and argued that patients find secrecy is difficult to maintain due to regular clinic visits and the physical effects of treatment. Additionally, silence surrounds infertility generally. Women, men, families, medical professionals, and societies avoid discussions about infertility (Allison 2011). In interviews with infertile women, Sternke and Abrahamson found the presence of silence is related to the stigma that accompanies involuntary childlessness. This refusal or inability to discuss infertility leads to women feeling isolated throughout the experience and encountering many other emotions when unable to reproduce (Sternke and Abrahamson 2014).

Gannon, Glover, and Abel discussed the connection between masculinity and infertility. Men experience feelings of inadequacy and questions of identity when they encounter childbearing obstacles (Gannon, Glover, and Abel 2004). Barnes also found that male-factor infertility causes men to feel insecurities about masculinity. There is a need to acknowledge that infertility goes beyond the woman who has otherwise typically been viewed as most responsible for reproduction. This view contributes to the feelings men encounter when the medical diagnosis is theirs (Barnes 2011).

Infertility Support

Domar suggested that psychological services should be a regular part of the fertility journey. Patients should not only seek counselors as a determinant for treatment approval or in times of trouble but more consistently to help people stay enrolled in treatment despite emotional burdens (Domar 2004).

Kahlor and Mackert found that the internet provides easy access to information for a medical condition that can be very costly and is a place where individuals experiencing infertility can communicate with those who have the issue in common. The authors suggested the internet is an outlet to find information free of charge, and online support groups are more accessible than local groups (Kahlor and Mackert 2009).

Conclusion

The research included here shows the role of women within society and family, social acceptance or rejection of medical intervention, and the commercialization and costliness of fertility treatment. Additionally, the lack of government involvement, acknowledgement of lifestyle factors, physician understanding, education, male inclusion, and support are identified.

This dissertation considers all of the factors represented here, and more, collectively to show that many factors shape the infertility experience. The current project differs by using a holistic approach to compare the infertility experience in the two developed but different countries of the Republic of Ireland and the United States. This dissertation will fill the void between the way in which individual factors contribute to the experience by considering how the factors work together to shape the demands of medicalization and subsequent shifts in female identity, including the identification of aspects of the infertility experience that are not included in previous research.

Chapter Three

Medical System Structures

The design of medical systems within societies controls healthcare access and delivery. Reproductive difficulties do not discriminate against individuals who encounter them, but the medical system a person lives in determines fertility treatment access. While developed countries such as Ireland and the United States offer fertility benefits, the presence and level of coverage vary widely. The ability or inability to access medical intervention for infertility contributes to the overall experience for those who need medical services. This chapter explores the medical system structures and fertility benefits within the structures, analyzes the two systems in relation to fertility assistance, and shows how the medical system design in the Republic of Ireland and the United States disrupts the lives of those who seek a medical solution for infertility.

Healthcare in Ireland

The medical system in the Republic of Ireland is divided into two parts. One tier is public healthcare, and the other is private medical coverage (Nolan 2006, 640). The Minister for Health is responsible for the governance of the Irish public healthcare system (Citizens Information-Department of Health).

The Department of Health, under the direction of the Minister for Health, oversees the Health Service Executive (HSE) (Citizens Information-Department of Health). The HSE is responsible for providing and monitoring health services within the public system (HSE-Our Structure). Public benefits provide Irish residents with a basic level of coverage. At the recommendation of a general practitioner (GP), an individual may seek emergency or hospital services without paying the routine €100 fee. If a person seeks urgent medical assistance through a hospital or emergency service without the guidance of a GP, a payment of €100 is required. Additionally, patients may be responsible for some in or outpatient hospital charges (Citizens Information-Charges for Hospital Services). Currently, .86 euro is equal to one U.S. dollar (XE Currency Converter).

The HSE offers public services in two ways. Any single person who has a net income of less than €184 and families who net less than €266,50 per week receive medical cards. Medical cards allow patients to have all designated services covered (HSE-2014 Medical Card and GP Visit Card Income Guidelines), including GP visits, some dental, eye, and ear services, hospital stays, public hospital consultations, maternity services, pediatric care for babies up to six weeks old, and some social work offerings (HSE-Your Guide to Medical Cards).

For those who make more than the maximum allowed to receive a medical card, the HSE issues GP cards. Individuals who have a net income of less than €276 and families making less than €400 per week receive GP cards (HSE-2014 Medical Card and GP Visit Card Income Guidelines). People who do not have a medical card or GP card are required to pay stipulated public rates for GP visits and necessary health services (Citizens Information-Entitlement to Health Services).

GPs, sometimes referred to as family physicians because they care for patients throughout all stages of life, play an important role in Irish society. GPs act as gatekeepers and treat patients until medical conditions resolve or they recommend a referral to a specialist. GPs contract with the HSE to serve public patients and treat private patients on a fee for treatment basis (Murphy et al. 2015, 147).

In addition to public coverage, the HSE provides pharmaceutical benefits. Private health insurance participants receive a public medication benefit that restricts the maximum a single person or family pays to €144 per month (Burke et al. 2016, 238). Pharmaceutical benefits are part of the Drugs Payment Scheme (DPS). DPS benefits are offered to anyone with GP cards or private coverage. Any person or family with a medical card pays only €2,50 per medication with a maximum of €25 per month out of pocket (HSE-Your Guide to the Drugs Payment Scheme; HSE-Medical Card Prescription Charges).

The Health Insurance Authority (HIA) manages and regulates private health insurance (HIA-Our Philosophy). HIA was created at the direction of the Health Insurance Act of 1994, which set forth guidelines for private health insurers (HIA-Health Insurance Regulations). There are four private insurance providers in Ireland. Individuals and families who wish to have more comprehensive insurance coverage may select one of the HIA-approved providers. HIA mandates that private insurance companies must enroll those who seek coverage (open enrollment), cover the person as long as insurance premiums are paid (life cover), and charge only the allowable fee set by the governing body (community rating). This ensures that different people are not charged different prices. The HIA allows insurers to implement pre-existing condition exclusions and waiting periods in permitted situations (Citizens Information-Private Health Insurance).

During the past sixty years in Ireland, public and private healthcare participation has changed. The wealthy no longer comprise the only portion of the population who enroll in private insurance. In 1957, a mere fifteen percent of Irish residents enrolled in private plans, but today, approximately fifty percent of people elect a private policy (Burke et al. 2016, 237-8; Nolan 2006, 635). Enrollees tend to be members of the middle or upper class and have higher levels of education (Nolan 2006, 639).

Aspects of the Republic of Ireland’s healthcare system structure receive criticism. The public and private branches of care are intertwined in several ways. Medical services and physician visits through private benefits occur at public hospitals due to the ease of access for clinicians and the lack of private facilities in some geographic locations (Ibid, 640). For example, physicians who provide services through both the public and private systems can see both public and private patients at the same location, eliminating the need for travel between public and private hospitals. Hospital beds may be designated for public or private use, but patients who need urgent care requiring admission may receive a bed without distinction (Ibid, 644). The Republic of Ireland contains forty-eight public and twenty-one private hospitals (HSE-Accessing Healthcare in Ireland under CBD). “The two-tier hospital system is now widely regarded as problematic from an equity perspective, but there are also serious efficiency issues to be faced because of the incentive structures embedded in this particularly close intertwining of public and private” (Nolan 2006, 648).

Additionally, although physicians at different stages in their careers have received the same level of formal education, some patients prefer to see providers who have more years of hands-on experience. Private physicians tend to have more experience than those providing services publicly (Ibid, 646), which results in some Irish residents enrolling in private plans (Ibid, 639). Younger physicians who are just out of training may choose to work in the public branch due to the demand for physicians to deliver public care and ease of gaining employment. Some medical professionals who are more advanced in their careers transition to private care provision due to the greater autonomy, increased profitability, and schedule flexibility that accompany private practice. Many times, privately insured patients receive the preferred method of care such as shorter wait times and access to nicer facilities. This is due to the increased access and opportunity that accompanies enrollment in private health insurance (Ibid).

Another area of concern is wait times for care. The public system carries long waits for physician appointments, in and out-patient medical services, and hospital admissions. Most waits exceed three months, and some end up being longer than twelve months (Burke et al. 2016, 238; Nolan 2006, 640). Overall, public patients wait longer for care (Nolan 2006, 641). The National Treatment Purchase Fund monitors waitlist times. The expectation is that adults wait no longer than eight months for treatment and no more than twelve months for initial consultations with a specialist or consultant (The National Treatment Purchase Fund).

The Irish medical system structure operates in a way that ensures residents can receive a basic level of care at little or no cost, and those who want more choices in who provides care, where care is delivered, lower medication prices, and more included services may enroll in a private policy that fits their needs. Due to the public guidelines regarding participating physicians and included services, some public patients find a lack of access to desired providers, treatment, and facilities. Treatment is not always delivered within the patient’s desired timeframe. This results in criticism of the mode of healthcare delivery the Republic of Ireland employs.

Fertility Access in the Republic of Ireland

The public and private portions of Ireland’s healthcare system affect infertility treatment access. The HSE’s public services do not include medical treatment for infertility. However, residents pay no more than €144 per month for fertility medications and can receive reimbursement of medical expenses through a tax relief program (HSE-IVF). The allowable tax refund is twenty percent (Citizens Information-Taxation and Medical Expenses).

Private health insurance coverage varies depending on the company. GloHealth allows for a ten percent discount on infertility-related services, but patients must have treatment at Beacon CARE Fertility in Dublin to participate in the discount program (GloHealth). Vhi provides limited benefits to reduce the cost of treatment but requires treatment be delivered at approved locations and allows for a maximum of €1000 for IVF (Vhi). Laya Healthcare offers €1000 toward fertility services (Laya Healthcare-Having a Baby). However, private insurers have fertility treatment waiting periods, and some require fifty-two weeks before fertility benefits become effective (Laya Healthcare-Waiting Periods).

Research shows that private patients consult GPs less than those with public benefits in the Republic of Ireland due to the expense incurred by private patients for GP visits (Murphy et al. 2015, 149). Private insurance may exclude GP visit coverage, require patients pay up to a specified amount before coverage takes effect, or cover only a portion of the visit (Competition and Consumer Protection Commission). However, individuals with private coverage seek GP intervention for fertility-related issues more than public patients because GPs may conduct the initial fertility examination before the patient is referred to a consultant. The disparate use of GPs by public and private patients for fertility concerns may be due to the inability of public patients to afford treatment past the initial diagnosis. This shift in GP usage indicates that private paying patients may not seek medical assistance for a sore throat or back pain, but patients of childbearing age find GP consultation important and worth the expense when unable to have children without intervention.

The landscape of Irish health is in transition. The former Minister for Health, Leo Varadkar, who started the process toward greater fertility coverage, is no longer in charge (Nolan 2006, 638-9), and the recently appointed Minister for Health, Simon Harris, has yet to move the process for fertility benefits forward. Leo Varadkar said, "The ability to conceive a child naturally is a normal human expectation, and a diagnosis of infertility can be a source of emotional distress, physical discomfort and financial hardship" (O’Regan 2016). While the former Minister for Health recognized the challenges of infertility, Ireland has work to do to improve consistent and adequate insurance coverage, treatment access, and healthcare delivery.

The United States Medical System

The United States healthcare system has a somewhat similar structure to that found in the Republic of Ireland. The U.S. government provides public programs such as Medicare, Medicaid, and options for active and retired military (Centers for Medicare and Medicaid Services-Federal Policy Guidance), and those ineligible for public options have private health insurance.

Medicaid is a public service available to individuals and families who have low incomes and meet Medicaid guidelines. Medicaid is funded by a combination of federal and state funding and operated at the state level with states responsible for eligibility determination for residents of the specific state. Medicaid provides free or inexpensive coverage to those meeting criteria (Centers for Medicare and Medicaid Services-Eligibility). As of 2015, Medicaid covered twenty percent of the U.S. population (Leonard 2015). Table 1 gives some examples of income eligibility for Medicaid participation by state.

Table 1. Maximum monthly income for Medicaid eligibility

	Individual	**Family**
California	$1,366	$3,271 for family of five
Mississippi	N/A	$1,950 to $2,727 depends on number and age of children
Montana	$1,317	$3,152 for a family of five
New Jersey	$1,387	$2,829
Ohio	$1,317	$3,153 for a family of five

Sources: California Department of Health Care Services, Mississippi Division of Medicaid, Benefits.gov, NJ FamilyCare, and Ohio Department of Medicaid.

Another form of U.S. publicly funded healthcare is Medicare. Individuals who are sixty-five years or older, and those less than sixty-five with a Medicare eligible disability, may receive Medicare benefits. The benefits reduce or eliminate out-of-pocket charges for those enrolled (Medicare.gov). Data from October 2016 lists Medicare enrollment at fifteen percent of the U.S. population (Centers for Medicare and Medicaid-Medicare Enrollment Dashboard).

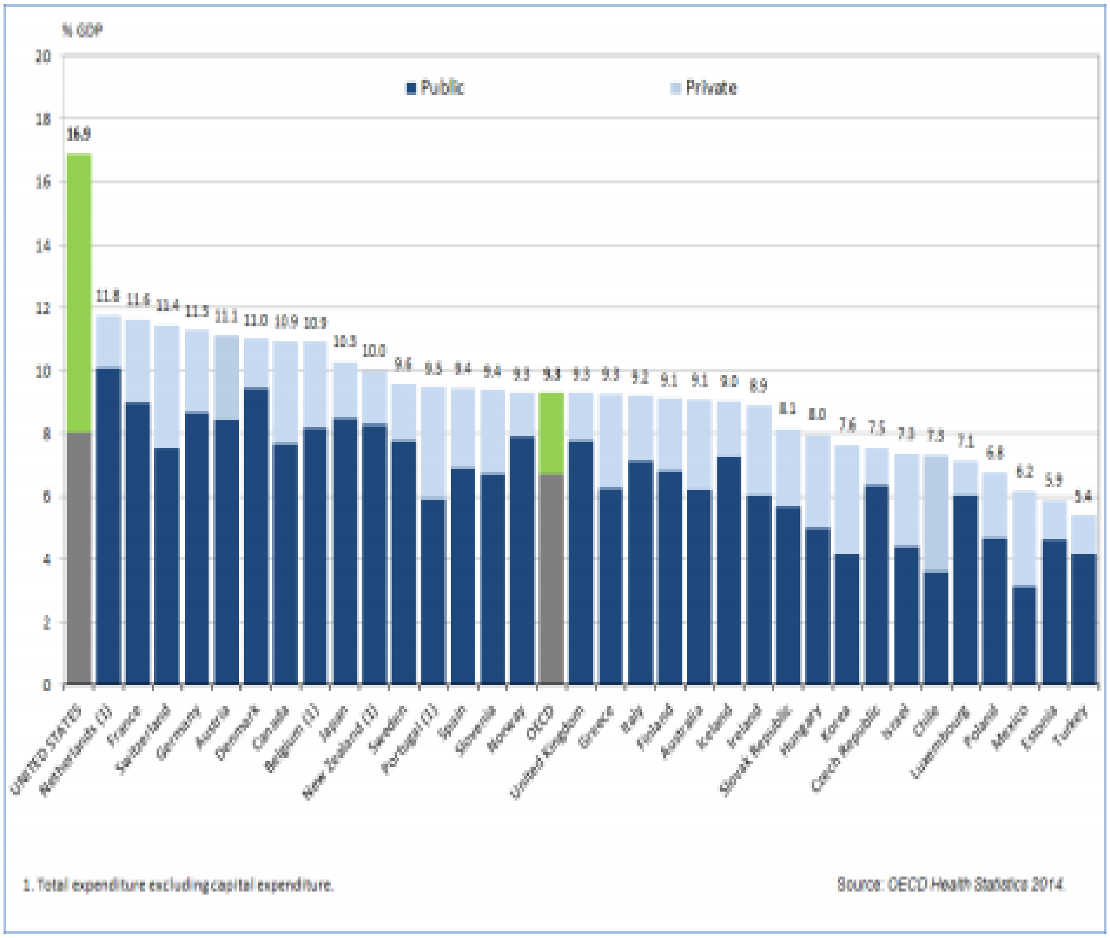
The U.S. Department of Veterans Affairs (VA) and TRICARE provide two types of public funding. Veterans of the United States military may receive healthcare coverage through the VA. VA eligibility requires that enrollees must have served the designated amount of active duty (U.S. Department of Veterans Affairs-Health Benefits). TRICARE is medical coverage provided for active members of the military, spouses, and children (TRICARE). Eligibility must be met to enroll in either of the programs.

One final form of public healthcare coverage in the United States is the Indian Health Service (IHS). The IHS, through the Department of Health and Human Services, provides health coverage to American Indians and Alaska Natives (Indian Health Service-About IHS).

Prescription benefits are provided within each branch of public coverage. The VA gives enrollees medication for free or a small fee (U.S. Department of Veterans Affairs-Prescriptions), TRICARE members receive a medication benefit package (TRICARE), Medicaid members receive medications at rates determined by Medicaid through the specific state (Centers for Medicare and Medicaid Services-Prescription Drugs), the Indian Health Service offers a pharmacy benefit (Indian Health Service-Health Care), and Medicare gives members the option to enroll in prescription programs. The various programs set medication prices within Medicare guidelines (Medicare.gov), but the various Medicare prescription plans tend to be expensive.

There are a number of private health insurance companies in the United States. Due to the creation of the Affordable Care Act (ACA), those interested in private coverage can apply through the governmental website, HealthCare.gov, or search for coverage independently (Healthcare.gov-Need Health Insurance?). As part of enrollment, some companies provide prescription benefits and a number of other services (Healthcare.gov-Getting Prescription Medications). Individuals choose private insurance based on desired benefits and financial ability. The ACA has improved access to coverage for members of the lower class, and the removal of the pre-existing condition clause has improved access for people who would not have been able to find coverage in the past. However, the current state of private coverage in the U.S. creates problems because individuals are forced to purchase insurance coverage or pay a fine, premiums are expensive, deductibles are high, and some reasonably affordable plans do not offer good coverage.

Figure 2 and table 2 show healthcare expenditure and the current life expectancy in the United States compared to other countries.

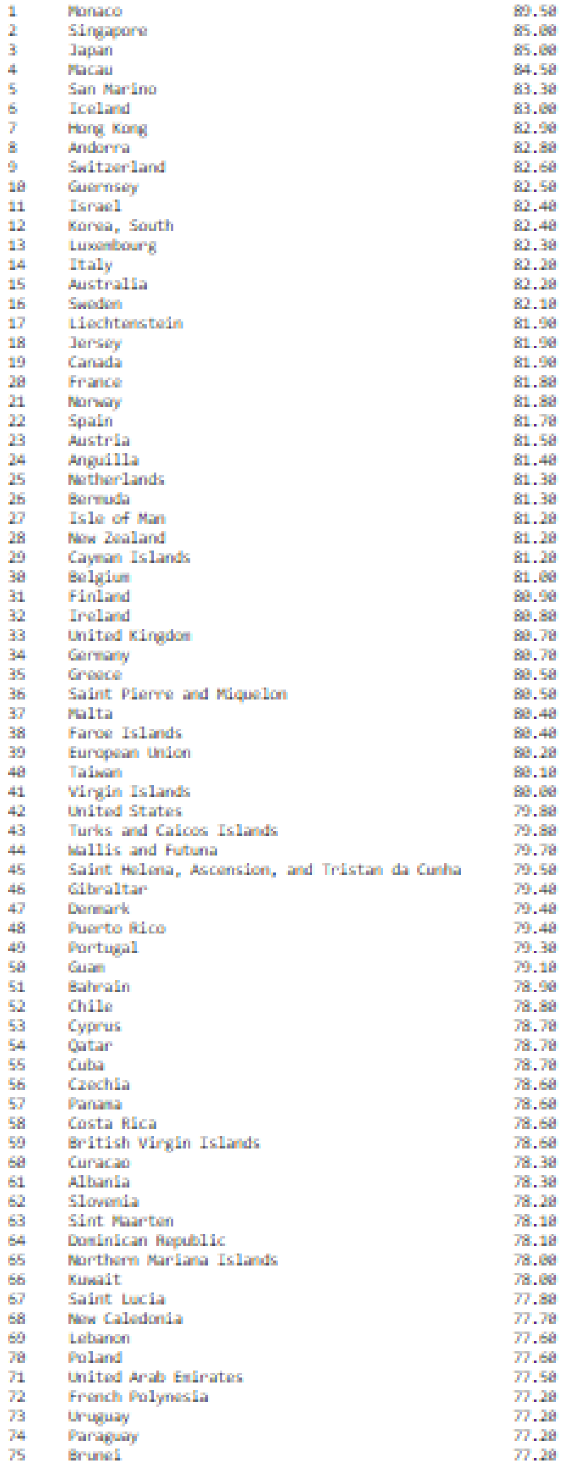


1. Total expenditure excluding capital expenditure.

Source: OECD Health Statistics 2014.

Figure 2. Health Expenditure, Public and Private, as a Share of GDP, OECD Countries, 2012 or Latest Year. Source: OECD Health Statistics 2014.

Table 2. Average life expectancy by country



1	Monaco	89.50
2	Singapore	85.00
3	Japan	85.00
4	Macau	84.50
5	San Marino	83.30
6	Iceland	83.00
7	Hong Kong	82.90
8	Andorra	82.80
9	Switzerland	82.60
10	Guernsey	82.50
11	Israel	82.40
12	Korea, South	82.40
13	Luxembourg	82.30
14	Italy	82.20
15	Australia	82.20
16	Sweden	82.10
17	Liechtenstein	81.90
18	Jersey	81.90
19	Canada	81.90
20	France	81.80
21	Norway	81.80
22	Spain	81.70
23	Austria	81.50
24	Anguilla	81.40
25	Netherlands	81.30
26	Bermuda	81.30
27	Isle of Man	81.20
28	New Zealand	81.20
29	Cayman Islands	81.20
30	Belgium	81.00
31	Finland	80.90
32	Ireland	80.80
33	United Kingdom	80.70
34	Germany	80.70
35	Greece	80.50
36	Saint Pierre and Miquelon	80.50
37	Malta	80.40
38	Faroe Islands	80.40
39	European Union	80.20
40	Taiwan	80.10
41	Virgin Islands	80.00
42	United States	79.80
43	Turks and Caicos Islands	79.80
44	Wallis and Futuna	79.70
45	Saint Helena, Ascension, and Tristan da Cunha	79.50
46	Gibraltar	79.40
47	Denmark	79.40
48	Puerto Rico	79.40
49	Portugal	79.30
50	Guam	79.10
51	Bahrain	78.90
52	Chile	78.80
53	Cyprus	78.70
54	Qatar	78.70
55	Cuba	78.70
56	Czechia	78.60
57	Panama	78.60
58	Costa Rica	78.60
59	British Virgin Islands	78.60
60	Curacao	78.30
61	Albania	78.30
62	Slovenia	78.20
63	Sint Maarten	78.10
64	Dominican Republic	78.10
65	Northern Mariana Islands	78.00
66	Kuwait	78.00
67	Saint Lucia	77.80
68	New Caledonia	77.70
69	Lebanon	77.60
70	Poland	77.60
71	United Arab Emirates	77.50
72	French Polynesia	77.20
73	Uruguay	77.20
74	Paraguay	77.20
75	Brunei	77.20

Source: Central Intelligence Agency.

The U.S. has the highest healthcare expenditure of countries in the Organisation for Economic Co-operation and Development (OECD) but ranks only forty-two for life expectancy on the list of seventy-five countries. These numbers show that the amount of money countries spend on healthcare does not necessarily correlate with people living longer lives. A discrepancy exists between the expensive nature of healthcare and the desired health outcomes, which raises concerns about the effectiveness of the current U.S. medical system.

The U.S. healthcare system draws its own criticisms. When the Affordable Care Act went into effect, there were three aims of the ACA. The first aim was to make health care coverage accessible to more people. Secondly, the ACA was to make healthcare delivery more efficient and of higher quality. Finally, the ACA aimed to improve individual and community health (Sage 2012, 27). “Yet healthcare as currently configured is wasteful and inefficient and costs far more than it is worth” (Sage 2012, 31). At the direction of the current U.S. President, healthcare is in transition. The future is uncertain, but one can hope that future changes will improve healthcare access, coverage, and delivery and reduce U.S. healthcare expenditure.

Fertility Access in the United States

As for fertility benefits, fragmentation exists in the American medical system. Reproductive benefits vary within the public and private spheres. Medicaid gives states governance over fertility benefit provisions. However, no comprehensive coverage exists currently (National Conference of State Legislatures).

Medicare’s infertility provisions differ from Medicaid. Individuals within the childbearing years may be eligible for some medical coverage (Centers for Medicare and Medicaid-Chapter 15). However, Medicare prescription coverage does not include fertility medications (eHealthInsurance Services, Inc.).

The U.S. Department of Veterans Affairs (VA) passed legislation in January 2017 to include assisted reproductive technology benefits if the medical condition relates to a veteran’s service injury. Therefore, if a veteran sustains a service-related injury, the VA provides medical treatment for the condition. Additionally, the veteran’s partner can consult treatment if the veteran’s injury impedes natural reproduction (Federal Register).

TRICARE allows active military and partners to receive fertility intervention by treating medical diagnoses that result in infertility. TRICARE permits medical treatment to correct fertility-related issues but does not pay for artificial reproductive methods (TRICARE).

The IHS is the final form of public coverage. The program includes coverage for prescriptions and prenatal care. However, the program does not cover infertility services (Indian Health Service-Health Care).

Private fertility benefits differ enormously. Legislation regarding infertility exists in fifteen U.S. states, but the level of treatment required within states varies. For example, Arkansas requires in vitro fertilization coverage, Connecticut mandates infertility diagnosis and treatment, New York offers a publicly funded grant program for individuals without financial means to seek medical care, and West Virginia requires HMOs to include fertility benefits (National Conference of State Legislatures).

While some fertility-related assistance is present in the U.S., consistent policies do not exist. Medicaid and the IHS provide no coverage, Medicare, the VA, and TRICARE allow some level of treatment, and private insurance offerings depend on the presence or absence of state mandates. Private insurance coverage for infertility does not cover fertility treatment fully but only reduces the financial burden in many cases. With a small number of states mandating some level of private health insurance coverage for infertility, many states have no legislation to guide private health insurers. These inconsistencies make assistance with childbearing difficult for many and impossible for some.

Analysis

Aspects of the medical systems in the Republic of Ireland and the United States resemble one another, and there are some important differences as well. The design of the healthcare delivery structures in each country affects those who must adhere to and understand the guidelines.

The two systems share a number of similarities. First, both structures are fragmented into public care and private coverage. Within the public and private tiers, the healthcare options and levels of care fracture the systems further. These fragments create complex systems that are difficult for citizens to navigate.

Second, the medical systems in both countries involve varying levels of expense. In order to have a variety of medical treatment options, individuals must participate in comprehensive healthcare plans, which requires financial ability. The added expense that accompanies higher level coverage limits who can access coverage and care.

Third, neither medical system addresses infertility consistently. While the former Irish Minister for Health recognized involuntary childlessness as a life-changing condition, he was unable to push legislation forward before his term ended. The U.S. government fails to acknowledge the gravity of the situation. This failure to recognize that infertility legislation needs to move forward and improved understanding is necessary creates fertility treatment access difficulties. However, some may argue that infertility is not a medical issue that should be treated, and this is a consideration some will raise when discussing the advancement of infertility health policy. Varying views on the nature of infertility determine whether a person embraces the condition as a medical diagnosis affecting one's health or sees involuntary childlessness as a problem that falls beyond their definition of health.

A final similarity involves fertility treatment access beyond medical insurance or public funding. A search of 'number of fertility clinics in Ireland' shows fewer than twenty clinics throughout the Republic of Ireland, with all geographic locations on the east, west, or south coasts within larger cities (see figure 3). Figure 4 shows the distribution of clinics in the United States. These fertility clinic locations show an unequal distribution of fertility clinics in the Republic of Ireland and the United States. Both maps show that clinics are present in urban areas, potentially creating access issues for those who live a long distance from the nearest city. The absence of adequate medical coverage and distance from fertility treatment create financial and geographic access issues for women with infertility.

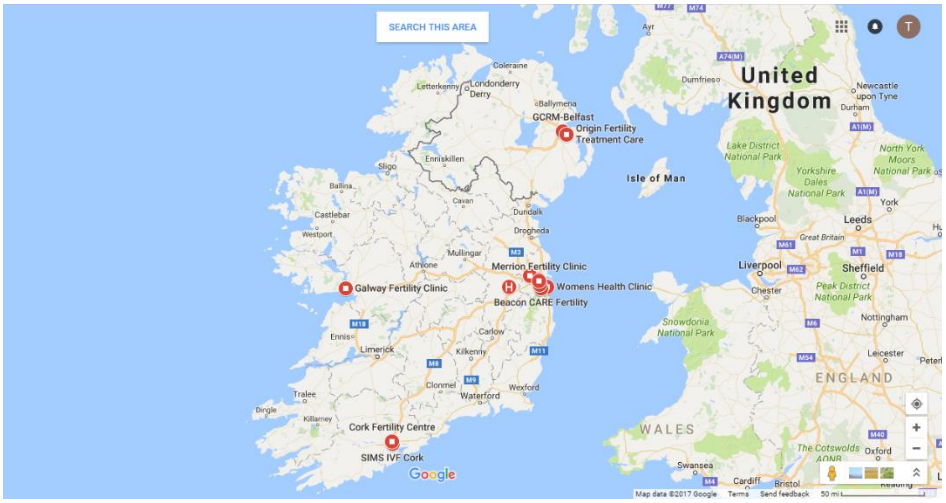
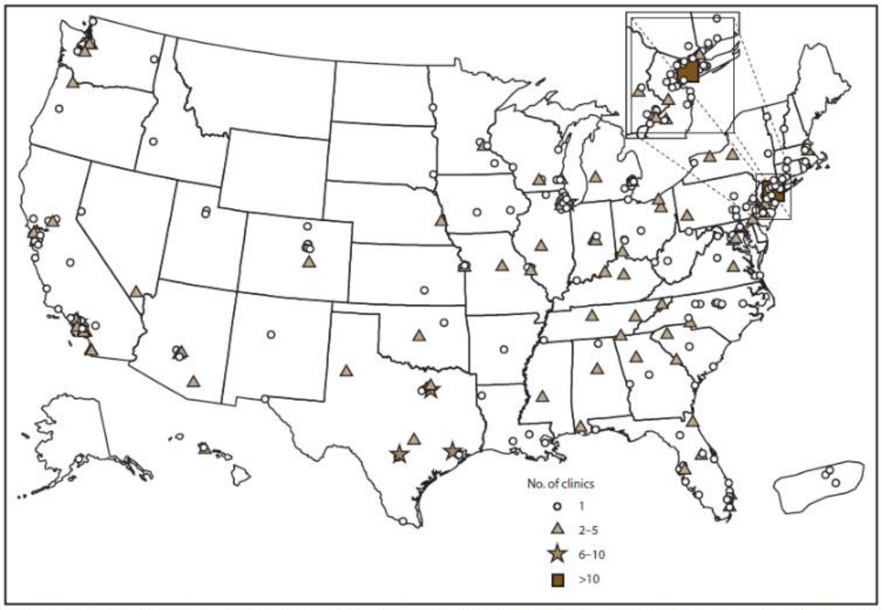


Figure 3. Fertility Clinics in Ireland. Source: Google Maps.



* Number of ART clinics in the United States in 2009: 484; number of ART clinics that submitted data in 2009: 441; number of ART cycles reported in 2009: 146,244 (does not include 12 cycles in which a new treatment procedure was being evaluated); number of live-birth deliveries resulting from ART cycles started in 2009: 45,870; number of infants born as a result of ART cycles performed in 2009: 60,190.

Figure 4. Locations of Clinics Providing Assisted Reproductive Technology (ART) – United States, 2009. Source: Centers for Disease Control and Prevention.

The discussion of access barriers leads to the differences found in the two medical system structures. First, the U.S. and Ireland vary in size greatly. The U.S. population is 325,502,135 (United States Census Bureau), and the population of the Republic of

Ireland is 4,712,590 (Country Meters). The variation in geographic size and population accounts for some of the roadblocks encountered when implementing comprehensive fertility benefits because some locations require more travel than others and the number of resources in both countries is limited. However, size and population variations within the two countries do not address the issue of fertility clinic saturation in urban areas and absence in rural areas.

A second difference between the two countries concerns prescription coverage. Ireland offers the DPS program, which provides women going through fertility treatment with medications that do not exceed €144 per month. This decreases the amount paid for medications greatly. However, prescription benefits for fertility drugs are not guaranteed in the United States. The absence of a pharmacy benefit means women seeking medical treatment for infertility must pay large amounts out of pocket, prohibiting treatment for some. This difference between the two systems demonstrates the value of comprehensive prescription coverage because the ability to get medications for €144 per month for individuals or families who take a number of medications regularly ensures access and affordability.

One final difference between the systems involves coverage consistency. The Irish government regulates public healthcare access for all people using medical or GP cards. However, the U.S. government allows states to set their own public benefit parameters. The presence of one more hierarchical layer in the U.S. creates additional challenges for citizens to navigate.

Medical System Structure Impact on the Infertility Experience

Readers may question why the medical system structures of the Republic of Ireland and the United States are discussed at length in this chapter. To thoroughly understand how a medical system influences infertility, there must be awareness of the complexities within systems. The fragmented structures within both countries makes navigating general medical care difficult, and infertility adds another degree to already complicated systems. Healthcare system design is a maze beginning at the level of governmental regulations and ending at the citizen or consumer. A body of people work to set healthcare policy, but individuals are left to figure out how to navigate the medical system.

The number of challenges created by the absence of comprehensive reproductive benefits, attainable healthcare, geographically accessible facilities, and government acknowledgement of involuntary childlessness as a widespread and life-changing condition contributes to the infertility experience for women. In countries such as Ireland where patients pay €4500 per IVF cycle (Merrion Fertility Clinic-IVF) and the U.S. where IVF costs more than $8100 per cycle, excluding medication fees (RESOLVE-The Costs of Infertility Treatment), medical system structures affect the ability to have a baby greatly, alleviating or contributing to the burdens created by infertility.

Chapter Four

Fertility Treatment Governance, Practices, and Policies

The medical community holds the responsibility for the medicalization of infertility. Without medical discoveries such as fertility medications, in vitro fertilization (IVF), and artificial insemination (AI), the creation of babies for women and men who require assistance would not be possible. Assisted reproductive technologies (ART) create hope in otherwise hopeless situations but affect women's lives substantially in the process.

The medical community, and specifically fertility clinics and medical professionals working in the area of reproduction, determine many aspects of the infertility experience. This control is partially due to the absence of infertility health policy and legislation at state and federal levels. Medical professionals are responsible for guiding the infertility experience for women who consult fertility intervention.

To gain a thorough understanding of medicalized infertility, one must learn how the medical community shapes the experience. This chapter examines the medical community's governance of infertility, medical professionals' perspectives on the experience, and fertility clinic structures in the Republic of Ireland and the United States. The chapter concludes with a fertility clinic analysis and analysis of the medical community's influence on the personal infertility experience.

Medical Community Governance of Infertility

The United States

The American Society for Reproductive Medicine (ASRM) sets standards for the medical treatment of infertility in the United States. ASRM's mission statement reads,

> ASRM is a multidisciplinary organization dedicated to the advancement of the science and practice of reproductive medicine. The Society accomplishes its mission through the pursuit of excellence in education and research and through advocacy on behalf of patients, physicians, and affiliated health care providers. The Society is committed to facilitating and sponsoring educational activities for the lay public and continuing medical education activities for professionals who are engaged in the practice of and research in reproductive medicine. (ASRM)

Operational Guidelines

One of ASRM's responsibilities is operational regulation. The organization sets standards for fertility clinics to follow regarding clinic staffing. The guidelines state that each fertility clinic must employ a medical director, an office administrator/manager, a laboratory director, a genetic counselor/geneticist, a mental health counselor, someone trained in cryopreservation (the freezing of eggs, sperm, and embryos), a urologist, physicians with necessary areas of specialization, nurses, lab support, an ultrasound specialist and an andrologist (male reproductive specialist) (Practice Committee 2014, 682).

In addition to the staff positions mandated, ASRM requires that individuals in each position meet certain criteria. For example, laboratory directors, if not in their director role prior to 1999, must hold a doctorate or medical degree, and all lab directors must possess minimum education, experience, and certification requirements (Ibid, 683).

ASRM requires that fertility clinics use outside laboratories that meet certain specifications. Fertility clinics include labs in house, but some testing involves complicated or expensive technology that cannot be analyzed onsite. In this case, the clinic must contract an outside laboratory that meets ASRM's criteria (Practice Committee 2014, 684).

In an effort to ensure pregnancies are safe for mothers and babies, ASRM sets limitations on the number of embryos clinics are permitted to transfer. This limitation reduces negative outcomes for both patient and child, and the embryo transfer criteria vary depending on age and circumstances. While ASRM issues embryo guidelines, the organization allows medical professionals to make the best choice for a patient based on each unique situation. However, clinics must show necessity before transferring more than the permitted number of embryos, which is one embryo for women who have a good prognosis and are less than thirty-five years old, two to three for women between the ages of thirty-five and thirty-seven depending on diagnosis, two to four embryos for women between the ages of thirty-eight and forty depending on prognosis, and a maximum of five embryos per cycle for women who are between the ages of forty-one and forty-two (Practice Committee 2012, 44-46).

ASRM's ethics committee addresses an important consideration for fertility clinicians. The committee encourages medical professionals to ensure patients are fit to be parents before providing fertility services. While the committee cautions providers against any type of discrimination or bias, ASRM emphasizes the necessity in determining whether a couple will be able to parent adequately and provide a good life for the child through a consultation with a mental health counselor provided by the clinic (Ethics Committee 2013).

Medical Professional Governance

ASRM provides guidelines for clinics and the treatment of infertility, but the American Board of Obstetrics and Gynecology (ABOG) certifies and monitors physicians who are members of the women's health specialty (ABOG). Physicians who treat patients in the fertility clinic setting are trained as reproductive endocrinologists (REs) in addition to practicing obstetrics and gynecology. Additional governance and guidance for REs is provided through the Society for Reproductive Endocrinology and Infertility (SREI). However, SREI requires that REs receive certification through ABOG before seeking membership with SREI. The governing bodies of the American Society for Reproductive Medicine, American Board of Obstetrics and Gynecology, and the Society for Reproductive Endocrinology and Infertility are affiliated with one another (ABOG; SREI).

Patient Protection

An essential part of fertility treatment is the protection of patients. In the United States, the Society for Assisted Reproductive Technology (SART) oversees clinics providing ART. The organization defines ART as services such as in vitro fertilization (IVF) or intracytoplasmic sperm injection (ICSI). IVF involves joining the egg and sperm in a dish in a laboratory, and ICSI requires more manipulation by inserting the sperm directly into the egg through a small syringe (SART, Centers for Disease Control and Prevention-ART, and American Pregnancy Association).

Clinics participate in SART because the organization improves clinic operations and reputability by requiring that participating fertility clinics record and report ART data. SART ensures that medical practices give accurate ART success rates. Currently, ninety percent of U.S. fertility clinics are members. Due to advertising regulations, reporting and practice guidelines, patient protection, and quality monitoring, clinics that do not participate in SART are viewed in lower regard and excluded from health insurance coverage in some situations. Clinics who choose to be members of SART improve reputability to patients due to the number of regulations (SART). Clinics are encouraged but not required to be members.

The need for this reporting by fertility clinics in the United States is evident in the Federal Trade Commission’s (FTC) investigation into fertility clinics’ inaccurate reporting of success rates. In 1990, the FTC found that three clinics violated the Federal Trade Commission Act through advertising inaccurate clinic and procedure success rates. The commission ordered the clinics to create a method of recording, cease false advertising, and keep data for a specified amount of time (Federal Trade Commission).

The Republic of Ireland

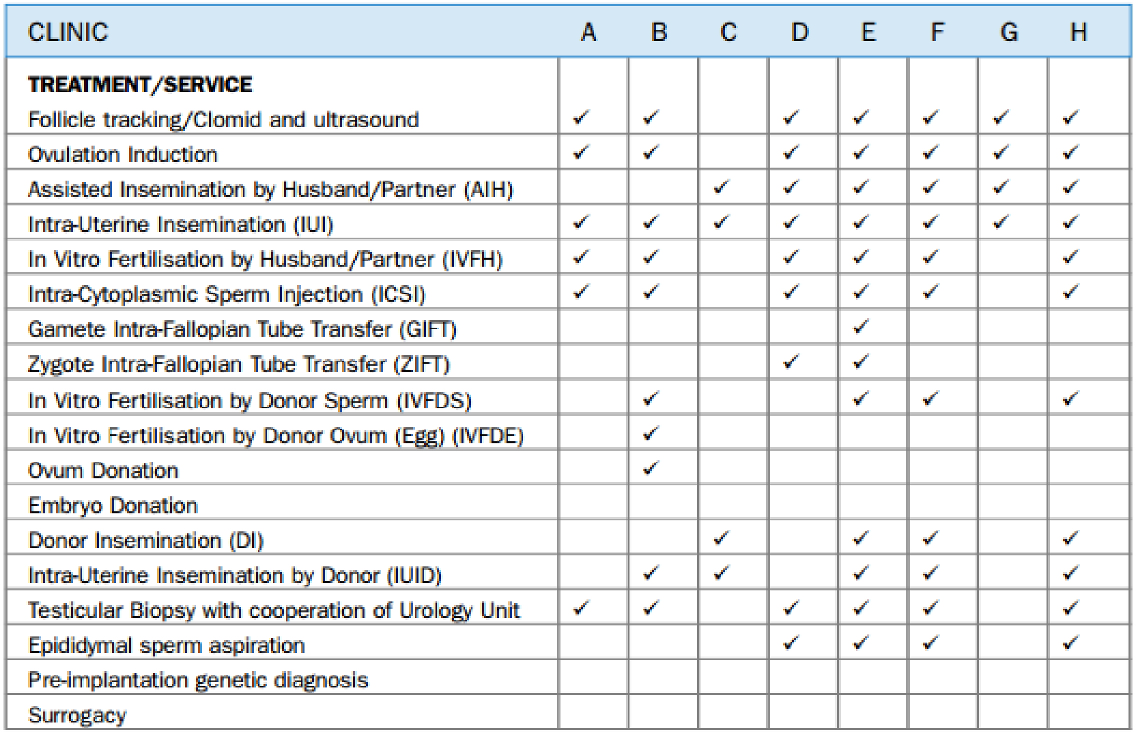
The Minister for Health created the Commission on Assisted Human Reproduction (CAHR) in 2000. The CAHR’s purpose was “to prepare a report on the possible approaches to the regulation of all aspects of assisted human reproduction and the social, ethical, and legal factors to be taken into account in determining public policy in the area" (CAHR 2005, x). Former Minister for Health Micheál Martin recognized the absence of fertility treatment legislation and formed the CAHR to address the gap in legislation (Ibid, 1). Minister Martin set forth two objectives for the committee. They are, "(i) to provide the medical, scientific and legal expertise necessary for a detailed examination of the possible approaches to regulation and (ii) to prepare a report that would serve as the basis for informed public debate before the finalisation of any policy proposals" (Ibid, 1). Governance of fertility treatment in Ireland falls under the CAHR's responsibility, and the Medical Council of Ireland oversees the organization (Citizen's Information-Fertility Treatment).

The CAHR defines assisted human reproduction (AHR) as "procedures that involve the handling of gametes [eggs and sperm] and embryos." The organization's definition includes methods such as IVF and ICSI, and it also considers artificial/assisted insemination (AI) to be a form of AHR (CAHR 2005, x). "This involves the placing of sperm into a woman's vagina, allowing them to negotiate the cervical canal and to reach the fallopian tube so that fertilisation can take place in the normal way" (Ibid, 7).

The CAHR surveyed all of the fertility clinics in Ireland at the time of the report to determine the types of services clinics offered. There were eight in 2002 and nine in 2004, but one clinic did not respond to the survey (Ibid, 21). The service offerings of the clinics follow.

Table 3. Survey of treatments and services provided by respondent AHR clinics in Ireland

Timeframe of survey: November 2004-January 2005.



CLINIC	A	B	C	D	E	F	G	H
TREATMENT/SERVICE								
Follicle tracking/Clomid and ultrasound	✓	✓		✓	✓	✓	✓	✓
Ovulation Induction	✓	✓		✓	✓	✓	✓	✓
Assisted Insemination by Husband/Partner (AIH)			✓	✓	✓	✓	✓	✓
Intra-Uterine Insemination (IUI)	✓	✓	✓	✓	✓	✓	✓	✓
In Vitro Fertilisation by Husband/Partner (IVFH)	✓	✓		✓	✓	✓		✓
Intra-Cytoplasmic Sperm Injection (ICSI)	✓	✓		✓	✓	✓		✓
Gamete Intra-Fallopian Tube Transfer (GIFT)					✓			
Zygote Intra-Fallopian Tube Transfer (ZIFT)				✓	✓			
In Vitro Fertilisation by Donor Sperm (IVFDS)		✓			✓	✓		✓
In Vitro Fertilisation by Donor Ovum (Egg) (IVFDE)		✓						
Ovum Donation		✓						
Embryo Donation								
Donor Insemination (DI)			✓		✓	✓		✓
Intra-Uterine Insemination by Donor (IUID)		✓	✓		✓	✓		✓
Testicular Biopsy with cooperation of Urology Unit	✓	✓		✓	✓	✓		✓
Epididymal sperm aspiration				✓	✓	✓		✓
Pre-implantation genetic diagnosis								
Surrogacy								

Source: CAHR 2005, 22.

The clinic treatments listed in table 3 include the least invasive treatment methods, which involve fertility medication only, and more complex treatments such as IVF and ICSI. The table shows that a wide range of options were offered by fertility clinics in 2005.

Operational Guidelines

The Medical Council of Ireland sets medical regulations, including the prohibition of providing medical services for the sole purpose of monetary gain. These regulations are limited in scope for infertility. Concerning assisted human reproduction, the council mandates that AHR be used only when necessary, that only appropriate clinics and physicians may deliver care, that egg or sperm donation is permissible only when the donation is voluntary and no monetary interests are involved, and that counseling must be part of the treatment process (Medical Council 2009, 20).

Medical Professional Governance

The Medical Council of Ireland regulates medical doctors in the Republic of Ireland. “The Council's purpose is to protect the public by promoting and better ensuring high standards of professional conduct and professional education, training, and competence among doctors” (Medical Council-About Us). The Medical Council of Ireland requires all physicians to register if practicing medicine (Medical Council-Registration).

The Royal College of Physicians of Ireland (RCPI) requires that physicians who want to specialize in obstetrics and gynecology complete necessary training and examinations. Doctors who want to specialize in infertility must complete additional requirements set by RCPI. Upon completion, doctors become members of RCPI (Medical Careers for Ireland).

Patient Protection

The National Clinical Programme for Obstetrics and Gynaecology (NCPOG) began in 2010. The program sets standards for the practice of obstetrics and gynecology and has issued two guidelines closely relating to fertility treatment (RCPI). First, NCPOG recommends methods for the prevention and treatment of ovarian hyperstimulation syndrome (OHSS), which affects the mother and can be life threatening if not treated. The condition can occur in patients who take fertility stimulating medications (OHSS-Diagnosis and Treatment). The second guideline provides recommendations for the diagnosis and treatment of multiple pregnancy. A multiple pregnancy may cause harm to the mother or babies (Management of Multiple Pregnancy).

The CAHR acknowledges the importance of mental health services at all stages of fertility treatment. It suggests counselors should meet with patients at all stages of treatment, including before and after, to assist with emotions involved in the treatment process and outcomes (CAHR 2005, 18).

At the time of its report, the CAHR recognized the importance of assisted reproduction in Ireland and highlighted the need for more thorough regulation of fertility services.

> It is clear that a comprehensive range of high quality AHR services is currently available in Ireland and the Commission fully expects this to continue. The Commission is of the opinion that the Medical Council Guidelines alone are not sufficient to ensure appropriate regulation of these services throughout Ireland. Furthermore, there is currently no mechanism by which service users have access to information on clinic activities and success rates. The Commission wishes to see a more rigorous framework within which AHR services are provided in Ireland. (CAHR 2005, 27)

The medical community’s governance of infertility within the treatment setting encompasses many working parts, and all of these components contribute to the overall experience for those who seek treatment. This section highlights the medical community’s failure to recognize the need for better formal and comprehensive regulation, and the government’s lack of enforcement of or follow up to the CAHR’s 2005 report, hindering fertility treatment progress in the Republic of Ireland.

Medical Professional Perspectives

The topic of medical professional perspectives on the infertility experience lacks comprehensive research, but medical professionals' views play a role in the overall experience for the patients they treat. This section details some perspectives found in the limited literature available and in my own research.

United States

In 2014, I conducted interviews with medical professionals in the United States who specialize in infertility to improve my understanding of medical professionals' views of their patients' experiences (Jenner 2014). Views differ depending on the clinician's level of engagement with patients and the medical professional's willingness to understand. Perceptions vary because some medical professionals understand the complexity of the experience while others minimize infertility as a medical problem that needs to be cured. Some clinicians recognize that the experience and treatment of infertility involve physical, emotional, and financial factors for their patients. Some medical professionals are empathetic toward patients, but others get caught up in the science of fertility treatment and fail to understand that their chosen medical specialty affects patients' lives deeply.

A physician in New England wrote in an article for National Infertility Awareness Week, "But most importantly, I am grateful for the thousands of patients I have treated during my career who have given me the opportunity to help them fulfill their dreams of building a family. Besides seeing my own family grow and thrive, there is no greater joy than changing peoples' lives so profoundly" (RESOLVE New England). This physician understands the nature of infertility and recognizes the impact he has on the women who seek his assistance.

In one of my encounters with a medical professional in 2014, the clinician explained that he feels privileged to treat patients with infertility because women and men who encounter reproductive problems must expose so much of themselves to make medical intervention possible. The medical professional recognized the inexact nature of science and how the inability to have a child naturally creates turmoil for patients. While many of the medical professionals interviewed seem to deliver good care, their level of understanding regarding the infertility experience could improve, making the experience better for patients.

Ireland

During the CAHR's five-year evaluation, it surveyed GPs in Ireland about infertility and found that most determine the origin of involuntary childlessness but refer patients to consultants after the initial diagnosis has been identified (CAHR 2005, 20). GPs deliver the services they are trained to provide but refer patients to consultants when issues of conception or miscarriage are beyond their scope of expertise.

The CAHR, which consists of a range of medical professionals and other professionals, recognizes the burden of infertility for individuals. This is evident in the 2005 report because the committee acknowledged the social and psychological implications, grief, and feelings of being unfulfilled associated with involuntary childlessness.

The committee wrote,

> For those who want to have children, infertility can be an extremely traumatic experience, characterised by feelings of guilt, low self-esteem, depression, and sometimes consequent relationship difficulties and sexual dysfunction. These psychological effects have been compared to those following bereavement. The process of discovery and comprehension involved in the diagnosis and treatment of infertility can be a very isolating period for the individual or couple. There may be social consequences too, as extended families and local communities share bonds through child rearing from which childless individuals and couples feel isolated. They may consequently attempt every possible treatment and continue with a cycle of tests and treatments with attendant psychological and financial difficulties over a prolonged period of time.
>
> Some couples undoubtedly feel strongly about having a biological link to their child whether through genetics or gestation, or both. Some women consider the physical bond achieved through childbearing as an important aspect of having a child, and some men may find it difficult to accept a child to whom they are not genetically related. (CAHR 2005, 9)

The CAHR report shows readers that some medical professionals understand aspects of the infertility experience.

The few examples found in previous research of medical professional perspectives on the experience show that with improved medical professional understanding on a broader scale, patients may develop closer relationships with clinicians, easing some of the infertility-related burdens that women encounter. The way in which medical professionals view their patients’ medical conditions, and the role they play in addressing the conditions, improves or hinders the experience for patients and clinicians.

Fertility Clinic Policies Regarding Treatment Cost and Delivery

Fertility clinics have many freedoms to structure care for involuntary childlessness within the stipulated guidelines set forth in the United States and Ireland.

The lack of healthcare coverage for fertility services within each country and the absence of adequate government regulation contribute to these freedoms, including price setting and financial assistance programs.

United States

In the United States, fertility providers have the ability to set service prices within state and federal guidelines. State and federal guidelines include private insurance mandates and public coverage stipulations. The Center for Fertility and Gynecology has various locations in California. The clinic charges $7,700 for one IVF cycle and $18,000 for a three-cycle package. Patients may also be eligible for discounts or refunds if certain criteria are met. If two IVF cycles do not result in pregnancy, the clinic will provide one free cycle, and if a patient has purchased a three-cycle package with no pregnancy, a refund is issued. Additionally, younger women pay lower amounts for IVF cycles than women who are older (Center for Fertility and Gynecology). Advanced Fertility Center of Chicago charges $8,500 and above for one IVF cycle, and the practice offers bundle packages that start at $18,000 (Advanced Fertility Center of Chicago). These are a few examples of the range in pricing and marketing strategies used to appeal to women.

Financing options for fertility treatment in the U.S. are common. For example, University Reproductive Associates in New Jersey offers two third-party financing options (URANJ). One option is WINFertility. WINFertility participates with a number of fertility clinics in the United States and offers discount programs for clinic visits, services, and treatments (WINFertility). Another common choice is Prosper Healthcare Lending. which finances fertility services for patients of participating clinics (Prosper

Healthcare Lending). Other U.S. fertility clinics partner with a number of financing sources to make treatment possible for individuals without insurance coverage or financial means (Attain Fertility).

The presence of discount programs, refund options, and loan providers for fertility services in the United States shows that medical intervention for infertility has become a profitable business. Some fertility services require the same amount a person may pay for a car or down payment on a house, which requires more than individuals or couples may have in their bank accounts. The prices and policies set forth by fertility clinics in the United States demonstrate that there is a demand for medical intervention, and infertility has become commercialized in the U.S. medical system.

Republic of Ireland

Fertility clinics in Ireland set prices while complying with Medical Council guidelines. Patients are charged for the initial visit, which includes a comprehensive history, bloodwork, ultrasound, semen analysis, and consultation with a physician. The charge for the initial visit is €400 at Merrion Fertility Clinic in Dublin (Merrion Fertility Clinic-MFC First Step Fertility Check) and approximately €550 at ReproMed in Dublin (ReproMed). Beacon Care Fertility in Dublin charges €4500 for one cycle of IVF (Beacon Care Fertility), and the same procedure costs €4400 at Rotunda IVF in Dublin (Rotunda IVF). Clinics charge fees in addition to the fee charged for the IVF cycle for services such as sedation, embryo freezing, and frozen cycle transfer (Ibid). Clinics offer refunds of various amounts depending on the point in the treatment cycle in the event an IVF cycle must be canceled. For patients undergoing one round of IVF in Ireland, the total cost includes the initial examination fee, €4400 to €4500 for the IVF procedure, and additional fees for sedation during procedures, medication, and embryo freezing.

Analysis

Fertility clinics in the Republic of Ireland and the United States share some similarities and differences. The two countries employ similar pricing structures for fertility services. While one may argue that treatment in the U.S. has a higher price tag than that in Ireland, salaries vary between the two countries. The price tag in each country is expensive and can be prohibitive.

The countries differ in financial options. Both countries offer potential refunds, but loan services dedicated to fertility treatment financing are not available in Ireland.

The fertility clinic policies in each of the countries indicate that medical intervention for infertility is now a large, lucrative business. The expensive price of fertility treatments requires that people have money or accept that loans to fund medical assistance will take time to repay when making the decision to undergo fertility intervention.

Clinic Analysis

As part of this dissertation research, I visited four fertility clinics (two in the U.S. and two in Ireland). These four clinics were visited one time each during a two-year period. The purpose of these visits was to understand fertility clinic operations and how the clinic setting contributes to the infertility experience.

First, I visited a clinic in the United States that was nicely decorated, comfortable, and welcoming. The staff was kind and accommodating, and they offered a beverage before sitting down. The physicians' offices were comfortable, and the exam rooms looked like any other exam room. The recovery room was separated by curtains, and clinic staff could be found right outside the recovery area. The clinic, although very nice, seemed money-driven because costs were stated upfront. The procedure room looked outdated due to the equipment looking old and well-used. The room felt somewhat uncomfortable because it lacked any elements to calm patients. The entrance to the office was easy to find, and public transportation was readily accessible. Overall, the clinic was adequate.

The second clinic visited in the United States was easy to locate on arrival but lacked convenient public transportation. The receptionist I interacted with was friendly and told me to take a seat in the waiting room. The waiting room was large, open, and comfortable. One observation I made was that the clinic felt sterile. It lacked decorations, and one was constantly reminded that she was in a medical office. The clinic appeared to be adequate.

The third clinic visited was in Ireland and could not be accessed by public transportation easily. The entrance and clinic were welcoming in appearance. The waiting room was somewhat private and not overly large. The procedure rooms seemed private and mirrored those of most medical offices. The recovery area was separated by curtains. I found the clinic staff to be friendly and engaging. Patients noticeably tried to minimize interactions with one another. This clinic was optimal.

The fourth clinic visited was located in Ireland and was easily accessible by public transportation. The clinic was decorated well, and the staff was friendly. The physicians had nice accommodations to meet with patients. The recovery room was separated by curtains and seemed small. While waiting in the waiting room, I realized that patients avoided eye contact with one another. This clinic was adequate. Additional general observations can be found in table 4.

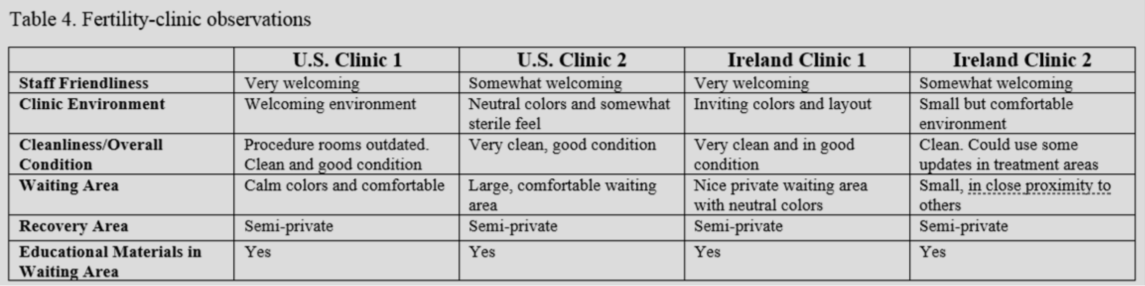


Table 4. Fertility-clinic observations

	U.S. Clinic 1	U.S. Clinic 2	Ireland Clinic 1	Ireland Clinic 2
Staff Friendliness	Very welcoming	Somewhat welcoming	Very welcoming	Somewhat welcoming
Clinic Environment	Welcoming environment	Neutral colors and somewhat sterile feel	Inviting colors and layout	Small but comfortable environment
Cleanliness/Overall Condition	Procedure rooms outdated. Clean and good condition	Very clean, good condition	Very clean and in good condition	Clean. Could use some updates in treatment areas
Waiting Area	Calm colors and comfortable	Large, comfortable waiting area	Nice private waiting area with neutral colors	Small, in close proximity to others
Recovery Area	Semi-private	Semi-private	Semi-private	Semi-private
Educational Materials in Waiting Area	Yes	Yes	Yes	Yes

In my observations, each clinic was easy to locate upon arrival, had friendly staff members, had clean facilities generally, and seemed welcoming. Most clinic setups were quite similar to one another. The offices included reception desks, waiting rooms, private procedure rooms connecting to the laboratory, semi-private recovery rooms, and physician offices for meeting with patients to discuss treatment options and test results. Additionally, some clinics had mental health counselors onsite for patients to consult before treatment begins or when desired.

Two aspects of the observations were of concern. First, some of the clinics display photos of babies. While this may create a sense of hope, I am concerned that the presence of baby pictures might make patients feel uncomfortable or increase their stress levels. However, in other clinics, no materials with babies are displayed, except for clinic promotional materials that may have photos of babies on brochure covers.

Second, the clinics observed all have semi-private recovery rooms. Most rooms accommodate two or more patients. This means patients recover after procedures in an area with a curtain or partial wall for privacy. Sound travels easily from one section of the room to another. Patients and partners lack adequate privacy at a time when they may have received difficult news, or the patient may be experiencing pain after a procedure. While one could argue that all patients need privacy after a procedure, the nature of infertility seems to require a higher level of privacy due to the emotional factors that accompany the experience. If something as simple as private recovery rooms can alleviate some suffering, the modification seems necessary. These two issues are cause for concern and will be discussed further in chapter five.

The clinics in the United States and Ireland differ in two ways. First, wait times for initial appointments are shorter in the United States than in Ireland. Women and men may wait up to one year for an initial consultation in Ireland, whereas patients wait an average of three months or less for an appointment in the U.S.

A second difference is the location of clinics. Some clinics in Ireland are located by and affiliated with maternity hospitals. This means women and men who are trying to have babies encounter people who already have children. The presence of babies creates emotional difficulty for some patients who are trying to conceive. While this design seems to facilitate easy access to testing and is convenient for physicians to treat both kinds of patients at the same location, the close proximity creates concern as well.

While clinic comfort levels varied on my observations, and some possible problems were detected, the four fertility clinics I visited appear to be welcoming, clean, and adequate for the services and treatments offered to patients. However, women who seek assistance at fertility clinics may find their own points of concern, affecting the infertility experience.

Analysis

The construction and delivery of treatment for infertility in the United States and Ireland share a number of similarities.

First, governing bodies regulate clinic operations to protect patients and ensure the care provided is adequate. However, while both countries set operational guidelines, the guidelines are not always mandates. The absence of firm regulation leaves room for error or less than optimal fertility care.

A further concern regarding regulation is whether the groups and individuals responsible for setting guidelines have the necessary knowledge to create infertility care parameters. Some researchers believe there is a need for greater government involvement and regulation of assisted reproductive technology. In Ireland, the Commission on Assisted Human Reproduction (CAHR) is the responsible party, but the Commission lacks medical professional participation and fails to address ART comprehensively. The failure to implement adequate regulations affects those who need medical intervention (Walsh, Ma, and Sills 2011).

Both countries have governing bodies in place to ensure medical professionals have the necessary credentials, expertise, and knowledge. The assurance that clinicians meet these criteria improves patients' confidence and patient safety.

Another similarity in the two systems is the reliance on social services to accompany fertility treatment. Mental health counselors' involvement in patient care creates a way to screen individuals to determine treatment eligibility and provides an outlet for patients to discuss the emotions involved with the infertility experience.

The medical professionals' perspectives section in this chapter shows that some clinicians understand the impact of the treatment process in greater detail than others due to a number of factors. The examples included here show that if clinicians have chosen to be part of this medical specialty dedicated to improving patients' lives through the creation of life, there must be an understanding of the patients they treat. This understanding comes from experience, awareness, and the desire to learn about the infertility experience.

The financial aspect of fertility treatment is an unavoidable topic in both the U.S. and Ireland. Treatment is expensive, and there are no consistent parameters in place to make treatment more financially accessible to patients.

Finally, the fertility clinic environments in both countries share similarities. All clinics observed are suitable for patient care, but some clinics are more accommodating and comfortable than others. One common flaw is the recovery room design. Vulnerable patients should have a place where they can share open dialogue with partners and recover after uncomfortable procedures without worrying if the person next to them can overhear.

Fertility treatment governance, practices, and policies in the United States and Ireland differ in three ways.

First, the level of infertility governance varies. In the U.S., the ASRM reviews care methods and issues reports on a regular basis. However, the last comprehensive examination of fertility treatment in Ireland was conducted in 2005. While Ministers for Health since Minister Martin have attempted to move legislation along, Ireland is left with outdated guidelines from the 2005 report because assisted reproductive technology has advanced, adequate health policy is lacking, and the demand for medical intervention is high.

Second, a significant difference exists in the regulation of fertility treatment reporting in the two countries. Through SART, the U.S. monitors healthcare delivery at ninety percent of fertility clinics. SART ensures that care delivery is accurate and at an adequate level. However, no such framework is present in Ireland. This results in the absence of recordkeeping and data collection to ensure clinics are truly delivering the level of care they promote.

Finally, financial structures differ. Financing options, discount programs, and service bundles in the U.S. increase the marketability of services by increasing accessibility options for the treatment of infertility. However, Ireland has not commercialized infertility in the same way due to the absence of numerous methods of financial assistance. Regardless of the options offered to make fertility treatment financially possible, how to pay the amount charged for assistance with having a baby is a central consideration for the treatment of infertility in many cases.

Conclusion

The medical community has a firm grasp on the provision of medical solutions for infertility. Fertility clinics determine both directly and indirectly whether patients meet the requirements of becoming parents. The level of fertility treatment governance, medical professional perspectives on infertility, and fertility clinic structures shape and contribute to the infertility experience. The degree to which the medical community affects women's lives varies. The way in which infertility has been medicalized in American and Irish societies has created reproductive opportunity but comes with its own burdens for patients. As a result, women who encounter trouble with having a baby are both winners and losers in the medicalization of infertility.

Chapter Five

Public Perceptions

Nearly seventeen percent of couples in Ireland (Mum.ie 2017) and twelve percent of couples in the United States (RESOLVE 2015) who try to have children are infertile. That leaves more than eighty percent of couples in Ireland and the U.S. to form outside opinions of the infertility experience. Opinions that shape and affect the experience for the women who find that they are unable to have children without medical assistance.

Public opinion and perceptions include a number of factors. This chapter is designed to show how public views form over time and how events have led to the current state of the public's perceptions of infertility. This chapter discusses sex education's influence on public opinion formation, fertility understanding, ART acceptance, the media's role in information delivery, and the infertility experience in popular culture. Public views of infertility, and reproduction generally, paint a partial picture of the inability to have children naturally within societies and contribute to the beliefs women form about their own infertility. The information distributed through mass communication has a real and sometimes troublesome impact on women who must navigate through the process of involuntary childlessness.

To gain a better understanding of infertility, there must be improved awareness of fertility first. Education regarding fertility and infertility comes in a variety of forms, and the method of delivery leads to the formation of ideas about reproduction.

Sex Education

Sex education in schools introduces children to topics related to fertility. The first widely used program began in Ireland in 1997 through Relationships and Sexuality Education (RSE) (Mayock, Kitching, and Morgan 2007, 42) and comes in two philosophies: comprehensive and abstinence based programs. Comprehensive programs cover many topics related to reproduction and healthy relationships, while abstinence programs focus on the avoidance of sexual relations. The Department of Education is the governing body that requires sex education in Irish schools today, and the topics covered in many schools fall within the comprehensive philosophy (B4uDecide.ie).

Sex education in the United States began in the 1960s (Planned Parenthood Federation of America 2012, 1). Local and state governments regulate sex education (Hoff et al. 2000, 7), and public schools educate an estimated eighty-nine percent of children on the topic (Ibid, 2) using comprehensive or abstinence programs. Fertility topics include pregnancy, birth, sexually-transmitted diseases, and the importance of contraceptive use (Ibid, 36). The Planned Parenthood Federation of America report includes abortion as a topic of educational inclusion (Planned Parenthood Federation of America 2012, 8). Figure 5 displays the range of topics included in school-based-sex education programs in the U.S., and figure 6 shows states that use the abstinence teaching approach.

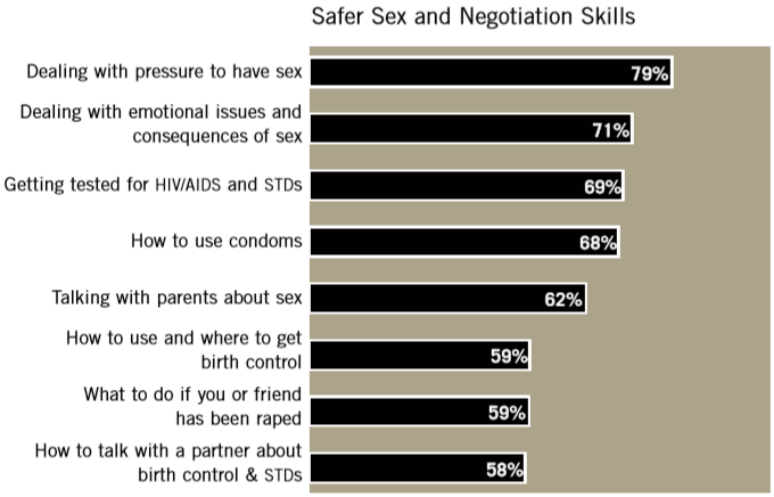
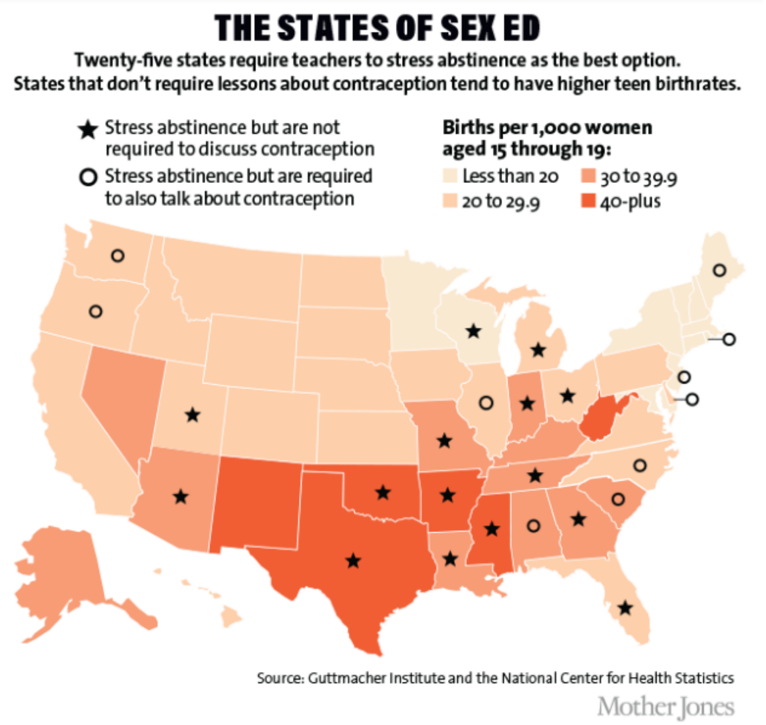


Figure 5. Percent of 7th-12th Grade Students Who Say Their Most Recent Sex Ed Class Covered… Source: Hoff, Tina et al. 2000, 3.



Source: Guttmacher Institute and the National Center for Health Statistics

Figure 6. The States of Sex Ed. Source: Andrews, Becca. 2016.

The data in figures 5 and 6 identify variations in how sex education is delivered in the United States. While schools must teach on the topic, state mandates determine the content of education in the U.S. Sex education teaching methods vary in schools within Ireland as well. In Ireland, although many schools employ RSE, schools differ in how the program is delivered (McGuire 2015). Therefore, depending on the guidelines employed in each location and school, students may receive different levels and types of education.

Some school nurses in the United States receive continuing education hours on the topic of sex education. However, nurses do not teach regularly in school-based programs (Brewin et al. 2014, 35). In a study of sex education in Massachusetts, researchers found that school nurses provide acute care but rarely discuss prevention. This absence of preventative measures is due partially to school administration (Ibid, 37). The authors found that school nurses are valuable assets for educating children and teenagers about sex and reproduction, but the education system structure allows nurses to educate students in informal and sporadic ways only. Instead, teachers of various specialties teach sex education (Ibid, 38).

The study conducted by Brewin et al., and the view that school nurses should be an integral part of sex education, aligns with Irish research. In an examination of crisis pregnancies in Ireland, research suggested the need for better reproductive polices, education, and attention to young people who are members of the lower class (Bourke et al. 2015, 10). School nurse involvement is one possible solution to address the gaps in sex education and improve children’s sexual, reproductive, and relationship awareness. Additionally, some people believe the current status of sex education in Ireland creates fear due to the variation in teaching methods (McGuire 2015). The level of comprehensiveness used to teach sex education in schools results in children either being well informed or misinformed when they emerge from the classroom.

Fertility Understanding and ART Acceptance

Often, exposure to sex education presents children with only the first opportunity to learn about sex and reproduction. Individuals carry the foundational beliefs formed during the school years with them into adulthood, which contributes to the views one holds throughout adulthood.

In a study of fertility awareness among women and men between the ages of eighteen and twenty-nine years old in the United States, researchers found,

> Nearly eight in ten respondents had received sex education, but fertility-related knowledge was poor. For example, only thirty-four percent were aware that a woman's likelihood of conceiving is higher at some times during her menstrual cycle than at others, and fewer than one in ten believed the chance of pregnancy after one act of intercourse without using a contraceptive was ten percent or less. (Polis and Zabin 2012, 33)

This study shows that fertility understanding is lacking or absent in a person's teens and twenties, and young adults require more fertility information to shape their beliefs of sex and reproduction. Improved education in the earlier stages of life is one method to expand the public's fertility awareness. Table 5 shows detailed findings of the study.

Table 5. Percentage of respondents to a national survey of young adults, by selected characteristics, according to gender, United States, 2009

	All	**Males**	**Females**
Knows fertile period	34	43	27
Perceived chance of pregnancy after one act of sex without contraceptive (%)			
0-10	8	7	9
11-24	4	4	5
25-49	9	6	11
50-74	39	37	41
75-100	40	46	35
Perceived chance of pregnancy after one year of sex without contraceptives			
Correctly estimates	35	31	38
Underestimates	19	16	21
Overestimates	46	52	41
Ever visited a doctor for sexual health	60	84	39
Perceived infertility			
Not likely	48	40	54
Slightly likely	36	41	33
Very likely	16	19	13

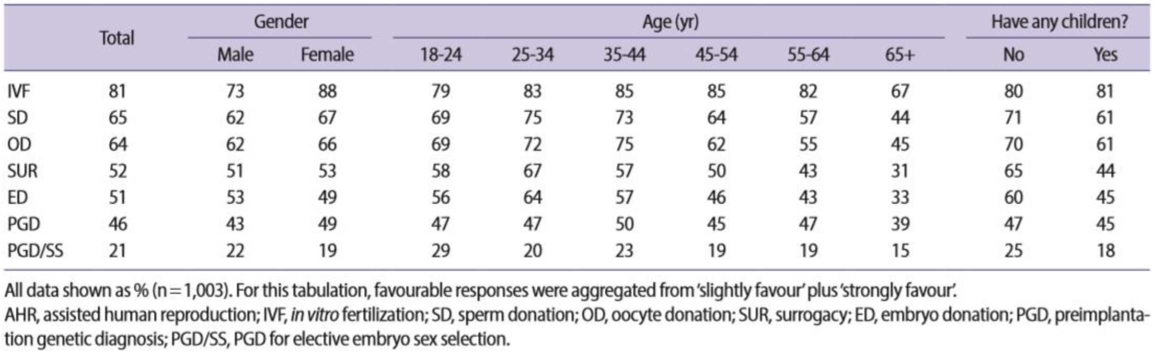
Source: Polis and Zabin 2012, 32.

Some interesting and relevant findings are found in table 5. Study participants were not overly concerned with potential infertility issues, fewer than fifty percent were aware of the fertile window, more men than women had consulted medical professionals for their sexual health, forty percent of participants believed there was a nearly certain chance of pregnancy after one sexual encounter, and fewer than fifty percent correctly estimated the chance of pregnancy after one year of trying. This study suggests that fertility and infertility awareness are lacking in individuals between the ages of eighteen and twenty-nine in the United States.

Research on ART acceptance in the United States revealed that more highly educated and more liberal individuals embrace ART at higher rates (Shreffler, Johnson, and Scheuble 2010, 744), and people who tend to be more religious and align with conservatism question ART methods (Ibid, 743). Personal views contribute to the acceptance or rejection of ART services for the treatment of infertility. Some individuals approve of less invasive procedures, which are those that align more closely with normal and natural reproduction (Ibid, 744).

In Ireland, younger individuals accept the use of assisted reproductive technology at higher rates than those who are older, but Irish people of all ages represented in the table that follows do not view highly the use of PGD/SS, a test used for sex selection.

Table 6. Gender, age, and child status among Irish study participants responding favourably to various AHR treatment types



	Total	Gender		Age (yr)						Have any children?	
		Male	Female	18-24	25-34	35-44	45-54	55-64	65+	No	Yes
IVF	81	73	88	79	83	85	85	82	67	80	81
SD	65	62	67	69	75	73	64	57	44	71	61
OD	64	62	66	69	72	75	62	55	45	70	61
SUR	52	51	53	58	67	57	50	43	31	65	44
ED	51	53	49	56	64	57	46	43	33	60	45
PGD	46	43	49	47	47	50	45	47	39	47	45
PGD/SS	21	22	19	29	20	23	19	19	15	25	18

All data shown as % (n = 1,003). For this tabulation, favourable responses were aggregated from 'slightly favour' plus 'strongly favour'.
AHR, assisted human reproduction; IVF, *in vitro* fertilization; SD, sperm donation; OD, oocyte donation; SUR, surrogacy; ED, embryo donation; PGD, preimplantation genetic diagnosis; PGD/SS, PGD for elective embryo sex selection.

Source: Walsh et al. 2013, 171.

The information in this section identifies the need for improved fertility awareness, especially in the younger years, in both Ireland and the United States. This will enable individuals within the public sphere to gain a more realistic understanding of infertility. Once people become aware of infertility, their personal, political, and religious beliefs shape the views they will embrace regarding the use of medical intervention for fertility assistance.

While one could argue that individuals should not receive financial assistance for fertility treatment if unable to reproduce naturally, the World Health Organization defines infertility as a disease and disability (WHO). These classifications identify infertility as a medical condition that interferes with a person's quality of life. Some people suggest the need for better infertility health policy in the United States and Ireland to address this disease. Helen Browne, co-founder of the National Infertility Support and Information Group in Ireland and former member of the CAHR, believes private health insurance and government provided medical cards should include infertility benefits (Iona Institute for Religion and Society). Marcia Inhorn argued that infertility interferes with an individual's human rights because motherhood is part of being female, and the ability to seek fertility assistance is a reproductive right because people should be able to reproduce, even if medical interventions is needed to do so (Inhorn 2009). As more people become aware that infertility is now classified as a disease and disability, the landscape of fertility understanding and acceptance of medical intervention for involuntary childlessness will continue to change.

The Media

The media are unavoidable. Individuals read newspapers and magazines with breakfast, watch televised news after a long day of work, and listen to the radio on the daily commute. Media outlets contribute to public views, and infertility coverage in the media influences infertility understanding. The media acts as the outlet for public discussion of fertility and infertility (Heffernan 2001, 368).

In an article about the history of infertility in the Irish media, the author explained that fertility clinic advertising was all one would find related to the topic of infertility in newspapers in past years (Ibid, 361). Today, health and science sections of newspapers are the places readers typically find articles about fertility issues, and journalists tend to focus on ART more than other fertility-related topics (Ibid, 360).

In addition to articles about ART, a story about a fashion blogger's inability to get pregnant and the feelings that accompany her involuntary childlessness appeared in an Irish web magazine recently (*Image* 2015), and an article was in the health section of an Irish newspaper earlier this month about the expectations, painful emotions, lack of emotional support, and ways for individuals who are experiencing reproductive problems to prepare for conversations that may include the topic of infertility (McHale 2017).

The media has also played a role in fertility awareness in the United States. The American Society for Reproductive Medicine (ASRM) ran a campaign in 2001 about infertility. The purpose of the campaign was to address infertility prevention as a public health issue in an educational format (Soules 2003, 295-297). Advertisements appeared on buses and the radio in three selected cities: New York, Chicago, and Seattle. After the success of the first year's campaign, ASRM chose the cities of Boston, Houston, San

Francisco, and Washington DC to run the advertisements for a second time (Ibid, 295-297). The actual advertisement follows in figure 7.

SEXUALLY TRANSMITTED INFECTIONS

Sexually transmitted infections are the leading cause of infertility and often have no symptoms.

ADVANCING AGE

While women and their partners must be the ones to decide when (and if) to have children, women in their 20s and 30s are most likely to conceive.

SMOKING

Women and men who smoke have decreased fertility. In fact, studies show that up to 13 percent of female infertility is caused by smoking.

UNHEALTHY BODY WEIGHT

Twelve percent of all infertility cases result from weighing too little or too much.

YOUR DECISIONS NOW CAN IMPACT YOUR ABILITY TO CONCEIVE IN THE FUTURE.

INFERTILITY IS A DISEASE AFFECTING 6.1 MILLION PEOPLE IN THE UNITED STATES.

Figure 7. ASRM Advertisement. Source: Soules 2003, 298.

The ASRM advertisement highlights important infertility factors. STIs, advanced maternal age, smoking, and unhealthy weight have been linked to involuntary childlessness. The ad was meant to assist in the prevention of controllable infertility. However, the ad identifies life choices that can put blame on individuals who have trouble having children on their own for a medical condition that may have no connection to the stated causes in the advertisement. Therefore, the ad contributes to public perceptions of an infertility diagnosis as something that is preventable when that is not always the case. Depending on a person’s age and circumstances, the ad can be interpreted in different ways.

Figure 8. Khloe Kardashian in Redbook. Source: PerezHilton.com.

This *Redbook* cover shows a popular celebrity's struggle in a mainstream U.S. magazine. Khloe Kardashian was vocal about her experience. This cover identifies a common issue for couples experiencing infertility, showing readers that reproductive issues affect relationships.

Figure 9. Tamar in Ebony. Source: Pinterest.com.

This *Ebony* cover highlights another celebrity's fertility struggle and the pain she encountered. It suggests through the use of the word 'miracle' that infertility is not a medical condition that can always be corrected easily. However, the presence of the baby in the photo provides readers with a sense of hope that fertility treatment turns out positively.

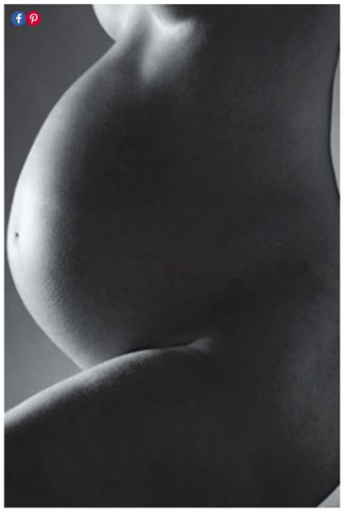


Figure 10. W Magazine Cover. Source: Comita, Jenny 2008.

Figure 8 was used as a cover for *W Magazine*, with a story titled “Pregnant Pause.” The woman who was the focus of the article went through fertility treatment and had a baby. This cover can be viewed as problematic because women do not always have babies when treated for infertility. The use of a pregnant woman to advertise an article about infertility may lead some to believe that doctors can always remedy involuntary childlessness.

This grouping of stories, photos, and advertisements gives the public a glimpse of infertility by highlighting celebrities, fertility-related issues, and infertility prevention, creating improved public awareness of the effects of reproductive difficulty in Ireland and the United States. However, these examples fail to represent with complete accuracy the inability to have children without assistance. The mode of delivery in bringing public attention to infertility also hurts the feelings of those who know the issue intimately.

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Popular Culture

Popular culture has not left the topic of involuntary childlessness unexplored. Before moving into the next two chapters, which explore the disruption of women's lives due to the demands of medical intervention and the changes in identity women experience as a result of fertility treatment, consideration should be given to the various forms of artistic expression within popular culture and how infertility representations influence the public's view of involuntary childlessness in the real world. The following are examples that depict infertility in popular culture

A scene in *Friends* shows Chandler receiving a call from the doctor with fertility results. Monica and Chandler have been trying to conceive and find out that their infertility is both female and male-related. Monica arrives home, Chandler shares the news, and Chandler tries to comfort Monica as she processes the information he has just delivered. Chandler looks as if he needs to be comforted as well (Crane and Kauffman, season 9, episode 21). After the discovery of their fertility issues, the couple goes on to adopt twins (Ibid).

In the seventh season of *Grey's Anatomy*, viewers see Meredith and Derek in a hospital elevator. Meredith's frustration is evident as she tells Derek of her jealousy toward their friend and colleague Callie. A baby shower for Callie's baby causes the jealousy because Meredith and Derek have been trying for a baby, including fertility treatment. Derek embraces Meredith and tells her that he will find a way for her to have a child (Rhimes, season 7, episode 18). Later in the series, the couple adopts a daughter. After more time passes, Meredith goes on to have a healthy biological baby (Ibid).

Robin shares with Barney that she is infertile on the television show *How I Met Your Mother*. Barney and Robin embrace, and viewers witness her sadness. Throughout the series, Robin makes references to her involuntary childlessness (Bays and Thomas, season 9, episode 8). The two go their separate ways. Later in the series, Barney has a child with someone else, but Robin does not become a mother (Ibid). A similar situation to Robin's arises in an episode of *Sex and the City*. The episode includes a scene in which Charlotte runs into her friend Miranda on the sidewalk, and Miranda questions why Charlotte pretended not to see her. Charlotte tells her that she is unable to have children. Miranda seems to dismiss her concerns until Charlotte reemphasizes what she has just discovered from her doctor. A disconnect appears between the two characters because Miranda is pregnant, and Charlotte desperately wants a baby. Charlotte begins walking home, and Miranda follows behind due to the concern for her friend (Starr, season 4, episode 11). Charlotte eventually divorces her first husband due to their different views on pursuing parenthood through fertility treatment, but she remarries and adopts a little girl with her second husband (Ibid).

A television series ran in Ireland last year that followed couples through IVF. The show, *Ireland's IVF Couples*, explored each couple's experience and concluded with each of the couples having children (Murphy 2016).

The movie *Up* explores the topic of infertility through the characters of Carl and Ellie. One day, Ellie and Carl are relaxing on a blanket outside on a sunny but cloudy day. The viewer sees that the two characters make objects out of the clouds, and at one point, Carl and Ellie see clouds that look like babies. Another scene shows Carl and Ellie preparing a nursery for their baby, but a scene later in the sequence takes place at Ellie's doctor’s office. Ellie receives news that she has lost the baby. A final scene shows a depressed and detached Ellie sitting outside alone. Carl watches her from the window and moves outside to comfort her. Carl and Ellie go on with their life together without having children (Docter and Peterson 2009).

Rosie and Marco take viewers on their sad journey in *What to Expect When You’re Expecting*. Rosie gets pregnant unexpectedly and wakes up one night bleeding. The couple leaves for the hospital and finds out from the doctor upon their arrival that Rosie has miscarried. Marco tries to console her, but the loss of the baby affects their relationship because the baby was one of the main reasons they were together. The pain of the loss distances the couple, which is evident after their departure from the hospital. They repair the relationship after the miscarriage, but they do not pursue parenthood (Jones 2012). The series *Brothers and Sisters* explores miscarriage when Rebecca discovers she has spontaneously aborted her baby. The scene is set in a hospital room. Rebecca appears to isolate herself from her husband, Justin, by turning away from him. She tries to isolate herself to numb the pain of the miscarriage. Her devastation and Justin’s desire to help Rebecca are clear during the scene (Baitz, season 4, episode 15, scene 2). Rebecca and Justin do not have children after the miscarriage and end their relationship later in the series (Ibid).

These popular culture examples give viewers a look into the life of someone who is experiencing infertility. In some of these scenes, men are seen as the comforters for their partners, but men experience their own pain and grief. Those watching see sadness, jealousy, isolation, shame, and grief, which are all elements of infertility. Popular culture references merely scrape the surface of the experience but provide a way to educate viewers, connect fiction and non-fiction, and encourage compassion for those who encounter infertility in the real world.

Conclusion

An examination of the public perceptions of infertility shows that various factors contribute to fertility and infertility understanding. Whether the topic is covered in the nightly news, displayed on a magazine cover, or discussed on a morning radio show, each exposure to infertility helps to form the public's understanding and views of involuntary childlessness.

Sex education in schools focuses on safe sex and preventing pregnancy, but wider fertility considerations are left out of the education process. This narrow view of sex education leaves people unaware of possible fertility challenges and perpetuates the idea that pregnancy is achieved easily. While fertility should not be promoted to high school students in a way that encourages pregnancy during the teenage years, a realistic view of what the future may hold is preferable. Otherwise, false hope is created for easily attaining pregnancy, and those beliefs are carried into the later years.

The school years serve as an introduction to creating infertility awareness, but continued discussion must occur into the late teens and twenties to ensure women and men understand that infertility is a medical condition that affects many lives.

The media are an easily accessible form of information, creating a platform for the disbursement of infertility information. However, the media have power, and that power leads to the manipulation of publicized material. While the media can be an excellent resource, one must remember the impact media outlets have on individual opinion formation.

There are various references to involuntary childlessness in popular culture. The examples included show that frustration accompanies the inability to get pregnant and sadness is felt when individuals experience miscarriage. All of these representations only scratch the surface of the infertility experience but provide a vicarious way for outsiders to understand the impact of infertility.

This chapter identifies the many forms of public perceptions that form outside views, contribute to fertility understanding, and shape the experience. Public opinion weighs heavily on the medicalization of infertility and affects the lives of women who encounter reproductive problems. During a time when a basic part of the female role is in question, the way fertility and infertility are portrayed and addressed publicly contributes to the experience by highlighting the expectation of women to become mothers and the inability of some to achieve that goal.

Chapter Six

The Demands of Medicalization: Personal Perspectives

The previous chapters addressed numerous factors that contribute to the medicalized infertility experience, and this chapter shows how the financial, physical, time-related, and emotional demands of the fertility treatment process disrupt women's lives in a variety of ways. The data included here are straight from the participants' narratives. When one begins to classify infertility as a medical condition, the gate opens to the possibility of a medical solution for involuntary childlessness, but the road on the other side of the gate is filled with rough patches, one-way streets, and detours.

The research and analyses in this chapter and chapter seven were conducted using a grounded theory approach. Irish interviewees have been assigned As or Cs, and U.S. participants have been assigned Bs.

Financial Burdens

The first major contributor to the infertility experience and determinant of medical intervention access involves the financial burdens associated with treatment. For many, the financial burdens create an obstacle to treatment. Participant C5 said, "Finance is such a major issue in Ireland to do any of this." Interviewees in the United States shared this view. B8 talked about how finances affected her situation. "This was so heartbreaking because a medical condition was affecting my ability to become a mother and my condition was not being covered by insurance, and the astronomical cost of fertility treatments was too much for me to pay at the time." She continued, "It was kind of disheartening that we couldn’t be parents because of monetary reasons and insurance.” B8 found that “it’s hard because no one wants to go through that [treatment] unless they have to. So, it’s not like you’re making a choice to make it easier on yourself to have a baby. It’s just horrible.” In B1’s case, insurance covered nothing for her. She said, “Our healthcare system is very fragmented. It’s geared toward people who have money.” Every time B1 had artificial insemination, she paid $400. She said, “I will not forget that. So, $400 a month was like our mortgage.” That was in the late 1980s and early 1990s, which was quite a large amount of money at the time. The couple did as much as they could financially but knew that their options were limited due to the amount of money that was required for ongoing treatment. C2 explained that two to three attempts are all a person can take financially and emotionally.

B3 believes it is important to find out how much treatment costs and what insurance covers, but understanding reproductive health policies can be difficult and time consuming for patients. IVF was not an option for B3 and her husband due to the expense. She knows some people take from retirement savings to pay for fertility treatment. When her limited fertility-related insurance coverage stopped, she was very upset. B3 said, “This is our dream and I feel like it’s being limited because of insurance. And, I don’t like the feeling of being held back, and that was holding us back, and you know when you have a dream, you want to do anything you can to succeed at that.”

While conversations with insurers and research into fertility coverage are important, the two do not always lead to improved financial support. B9 said, “I had failed conversations with our medical insurance providers about paying for treatments, which were considered to be like getting a nose job as it was explained. Funny, we thought nose jobs were voluntary or optional." B9 viewed treatment for infertility as necessary because she had no other way of having biological children. B9 did not feel as though the medical community and insurance companies made medical assistance an accessible option for her. She felt her experience with involuntary childlessness was minimized by the comparison to nonessential cosmetic surgery.

B9's perspective gives outsiders a glimpse of how women with medicalized infertility view the need for intervention. While some may believe fertility treatment is nonessential, the participants have a different outlook. The interviewees viewed reproductive assistance as essential because it was the only option they had to create the family they desired.

Before A2 and her husband reached the desired outcome of a baby, they used all the money that they had reserved for treatment. A2 said, "IVF is such a financial headache." The loss of her job a year before did not help the situation. A2 said,

> If you have money, you can do it, and if you don't, you can't. It was huge. We spent over €10,000 over a year in 2011 on two cycles of ICSI. It wiped our savings, and we needed financial help from my parents, and both of those cycles failed. The pressure we were put under to get the money together definitely did not help with the outcome of the cycle.

Seven participants explained that the fertility clinic model has become a high earning business opportunity. A5 said, "It is just a moneymaking racket…with no support system and no care for the patient." B8 said, "Something needs to be done to make it more affordable. Before I went through the infertility process, I never knew how expensive it was."

Overall, financial concerns played a significant role in the infertility experience for many participants. Finances determined whether treatment was an option, how much treatment patients could afford, and at what point treatment was no longer financially feasible. The expensive nature of reproductive assistance and lack of insurance coverage complicated the financial piece of fertility treatment further. In the end, financial resources were a driving force for having a baby through medical means, and the financial burden is one that fertility patients cannot escape.

Physical Burdens

A number of participants explained that treatment creates a physical burden that must be endured due to procedures, medications, exams, and medically-induced hormonal changes. The physical demands of medical intervention are a regular, unavoidable part of fertility treatment.

The treatment process begins with a medical investigation to identify one or more conditions impairing infertility. In Ireland, general practitioners (GPs) are often the first point of contact and control aspects of the process. Due to the medical hierarchy, A2 had to go to the specific fertility clinic her GP recommended. C1's GP was the one to order her to take time off from work when she experienced problems during fertility treatment. C10 experienced delays to an accurate diagnosis due to her GP's lack of concern. During the teenage years, she started to have menstrual pain, but her doctor did not think further investigation was necessary. As the pain persisted into adulthood, C10 continued searching for answers. Finally, another GP at her regular clinic determined the pain was related to her ovaries. C10 said, "why the others missed it, I don't know." The role of gatekeeper through a primary care provider such as a GP in Ireland was mentioned less in

U.S. interviews. U.S. participants chose whom they consulted for medical assistance, and the first point of contact varied among family physicians, internists, and gynecologists.

When asked about the physical demands of the treatment process, participants talked about comfort and responsibility. A2 and C2 mentioned that procedures such as egg retrievals and hysterosalpingograms, an x-ray-guided procedure to check the female reproductive region, can be painful. B1 said that during her hysterosalpingogram,

> They [the medical team] kept asking me if I was in pain. I said I'm uncomfortable. This is uncomfortable. This is different from pain, and they kept saying, 'you're in pain, right?' No, I'm not in pain. I'm uncomfortable, so there was just no understanding… They were not sensitized to people with infertility.

C10 said of the preparations for a cycle, "Toward the end, when they're, the eggs, the follicles get very big, it's sore. The ovaries get really big…and they [doctors] can't just target one ovary. They both have to react." She said of the multiple physical demands required, "We've done everything right. We're eating right. We're taking all the supplements. I'm not drinking or taking caffeine. [I am] sleeping properly, and we're doing everything right, so it didn't work, which it never does." The necessity to undergo uncomfortable procedures on a regular basis and the lifestyle modifications to enable treatment success affect the overall experience.

Regarding patient responsibility, C9 worried that he may have made mistakes in administering his wife's medications at home. C9, despite his fear of needles, did what he needed to do when C8 required injections that she could not administer by herself. C9 felt that the couple had a lot of responsibility. C2 also experienced feelings of great responsibility due to the accuracy with which medication had to be taken at home. She talked about the care she took to organize medications to avoid administration errors. C2 had a dedicated drawer in her bedroom to arrange medications systematically. Painful injections, accurate dosing, and medications taken on time are required components of the physical demands of treatment.

A final physical effect of the treatment process involves changes in sexual intimacy due to treatment requirements. A1 said, “the clinic setting changes a couple’s sex life from enjoyable to predictable.” C10 said, “As far as sex is concerned, it’s only when I’m ovulating. It’s only to make a baby.” For participants, sex became timed and robotic due to the demands of treatment and the precision necessary for conception to occur. The sexual demands affected partners personally and relationally.

The physical burdens of medical intervention demand that women relinquish control of their bodies to allow the medical community to find a solution for infertility. The body is invaded and manipulated routinely in hopes that the physical discomfort encountered will lead to a biological child. These physical demands contribute to and complicate the experience.

Time-Related Burdens

As the previous two sections show, researching reproductive health benefits and undergoing the necessary medical procedures require large amounts of time. Respondents found that life must go on hold when they engaged with fertility assistance. C1 said,

> Our lives were on hold even as a couple. Everything was on hold because you’re preparing for…and you’re saving up money to do another IVF cycle or preparing your body first. Everything was kind of on hold. We couldn’t make plans. No plans to move… I wasn’t going to change jobs because I didn’t want to have to explain myself in another job. So, everything gets put on hold when you’re trying to deal with this. It takes up your whole focus. It really does become your life.

The time that medical intervention requires interferes with women’s work lives. C6 said her employers were understanding in the early stages of treatment but became less accommodating later in the process. They expected her to go to appointments during non-working hours, but the clinic was not open then. She said due to the demands of treatment, “We had to rearrange things with work and with the cottage that we rented.” B2 recalled an occasion when she was much longer than expected at the clinic due to staff miscommunication, and she didn’t have someone to cover her shift. Luckily, the situation got resolved with no work repercussions, but the miscommunication caused added worry for B2. C5 said the process is hard for people who do not have time to take away from work.

Another time-related factor concerns travel. When C1 was unable to achieve motherhood through the resources available within Ireland, she traveled to Prague for assistance because she felt that that was the only option left to have a baby. B3 had to make arrangements at work to leave early or arrive late to make the one-hour drive to the clinic possible on a regular basis. In addition to the large amount of time needed for treatment, travel required time off from work and disrupted the participants’ normal lives. Some participants also found that the ability to travel for leisure ceased. C9 said the treatment process “does pause things quite a bit.”

Some participants talked about another time-related burden. There is constant waiting for appointments, procedures, and clinic phone calls. Once fertility treatment was deemed necessary, participants in Ireland expressed concerns about long waits for the initial visit with a specialist. A3 said she waited nine months for the first visit, and that wait was shorter than usual due to her advanced age. C5 waited five months. These long waits were a source of anxiety for Irish participants. The inability to seek specialized care quickly made interviewees feel as though potential parenthood was being delayed and that they lacked control of the treatment timeline. C9 said, “The two-week wait [for the pregnancy test] is pretty horrific... It seems to go on for like six months.” C6 said, “It [the treatment process] kind of took a while because…you have to do the medication and the injections and all that kind of jazz, so they were overstimulating to get so many eggs.” She continued, “You could be queuing there for God knows how long to get your scan and stuff.” The participants’ discussions of and feelings regarding the never-ending waits align with Boivin and Lancastle’s findings that long waits create additional anxiety, uncertainty, and a general sense of a lack of control (Boivin and Lancastle 2010).

The participants’ concerns about the time-related burdens associated with the treatment process show that work interference, travel demands, and constant waiting are embedded in the experience. Those who find they must travel long distances for medical intervention encounter an additional obstacle. The time-related demands are twofold. Patients must modify their schedules to make treatment possible, but they cannot escape the slow movement of time while waiting for appointments and results.

Emotional Burdens

The many emotions that result from the burdens of the treatment process complicate the experience further. Women experience emotional burdens in a number of ways. Some emotions demanded more from participants than others, but all interfered with the women’s lives.

Clinic Environment and Treatment Delivery

Participants explained that they felt some medical professionals lacked concern for the demands of treatment and the infertility experience. One visit, A2 asked the doctor whether smoking had an effect on pregnancy because her husband smoked, and the doctor said, “I am a smoker and I have four children.” A2 did not want to see the doctor again. She found the comment to be uncalled for and unsympathetic. In A5’s case, she said the doctor told her to give her attempts at pregnancy naturally more time and come back if needed. Her experience was minimized by people at the clinic telling her that a pregnancy would make the couple think nothing of what they had gone through once they were able to have a child successfully. Some interviewees were upset that patients who had received devastating news were just sent to the waiting room with everyone else. A5 said, “Then, they’re sent out…obviously devastated, into a public waiting room. Again, you’re going, seriously, could you kind of consider people here?” She continued, “They [medical professionals] need to start thinking about people a bit.” The women were sensitive to everyone and everything around them due to their infertility, causing all that the women viewed as flaws in the delivery of care to be magnified.

The participants also discovered a lack of treatment personalization during the process, C2 said, “I was disappointed about how basic the approach was. Rather than looking at the individual, the approach seems to be ‘one size fits all.’ In my case, this approach did not work. I believe I only achieved my pregnancies due to my own online investigations.” Many of the women tried to empower themselves through research to find a solution.

The lack of the medical professionals' concern and the inflexibility in the treatment design seemed to minimize the gravity of the women's experience. They felt as though a core piece of being female was missing, but the medical community's actions did not always demonstrate recognition of the challenges of infertility for patients.

The treatment environment is distinctive, and the structure of the environment creates added emotional turmoil for women. C8 said the couple found one particular aspect of the fertility clinic troubling. The room used for retrievals and transfers was divided merely by curtains. Anyone in the room could hear everything anyone else said, including news delivered by the medical team. When C8 was in recovery after a procedure, the couple found the lack of privacy somewhat difficult. C8 said, "When you're going in for your embryo transfer, again, it's in a curtained scenario… So, we could hear everyone's conversations around us."

Other aspects of the clinic setting also caused the participants to be emotional. To add to the level of anxiety for C5, the waiting room was always full when she was there. "The room is packed with couples," she said. At times, C6 and her husband knew other patients at one of the clinics they attended. The clinic setting lacked anonymity. A5 said, "It happened to me about three times that I met people from my industry. I bumped into people. Now, that's a really awkward one because nobody's there for anything but [infertility]." C9 and C8 thought the process of calling names in the waiting room was too revealing. The issues of the clinic environment and proximity contributed to the experience in a negative way.

A3 and C6 said the environment at the maternity hospital, where some clinic procedures were performed, was not good for the situation emotionally. After her laparoscopy, A3 heard babies because they were in close proximity. She kept hearing new life and wanted to have what others had. C6 found the environment was uncomfortable because the women there had babies with them, which made her inability to have children more difficult emotionally. Concerns regarding maternity hospital proximity were unique to the Republic of Ireland because clinics are not structured in the same way in the United States.

The specific diagnosis in itself was a source of anxiety for many interviewees. Some wanted to know the source of infertility, and others did not. A2 would have liked to receive a diagnosis but said a specific cause would not have changed the situation. C2 wanted to know the origin of the issue "because if it was an identified medical condition, then it would result in a focused treatment. It is more difficult to have an 'unexplained' diagnosis." B1 said, "Although I have two wonderful sons, and this makes a lot of the infertility pain go away, I am still so frustrated not to have a diagnosis. Without a diagnosis, all the treatments seem like "voodoo." They may be totally pointless." For some participants, the identification of a cause provided comfort that the correct cure was possible, but others were concerned that a diagnosis would create blame. The interviewees' differing perspectives on the role and impact of a specific diagnosis show that each woman deals with infertility in her own unique way.

The participants' diagnoses included blocked, leaky, or scarred fallopian tubes, immune complications, uterine septums, and thyroid disorders. Additionally, endometriosis, low sperm count or motility, low ovarian reserve, and polycystic ovary syndrome resulted in some participants' infertility. On the other hand, some were unexplained. Some diagnoses could be treated with more ease than others, but all affected interviewees emotionally to some extent.

When women seek medical assistance, they place faith in the medical community to find a cure for infertility. A3 discovered that people must relinquish control and trust the professionals. A2 said, “I know now how important it is to have faith in your consultant. It’s such a difficult process, from a physical, emotional, and financial point of view. So, you have to give it your all, and you need to be able to give over the control of the process to your fertility specialist.” B2 said, “You’re trusting someone else to be giving you the appropriate specimen and to hope they didn’t screw it up or mislabel something.” A3 said sometimes she felt like she couldn’t ask the doctors for the details of what was going on because the physicians determined the course of treatment, and she had little input. C6 said, “When you’re doing IVF, you’re completely powerless. You just have to do everything that you’re being told to do.” C6 said, “They didn’t explain things very well. And, I suppose because it’s the first time going through that kind of a process and you’re relying on all of them…and they’re doctors, so there [are] people in certain professions and you don’t question them. You just kind of go, if that’s what they say, then that’s what we do.” B8 said, “It was something that was out of my control, and I didn’t have the backing to help make this happen.” Participants relinquished control in an effort to have a child, but the emotional burdens that resulted made the process more difficult.

The lack of control contributed to many interviewees feeling uncertain. A3 encountered complete ups and downs. She felt like she was holding her breath the whole time. She was told to relax but felt stressed. “You try everything and anything.” A2 explained that the hardest part was “the not knowing” how the process was going to turn out. She continued, “The innocence is gone.” Bad things do happen. “It’s not like anything else you’ll go through. You just can’t explain it.”

Pregnancy Loss

Another emotionally burdensome aspect of infertility involves miscarriage. Many participants experienced one or more spontaneous abortions before or during treatment. C1 had five miscarriages and found the process to be hard. She wishes a better medical investigation had been done before she experienced a number of miscarriages. C4 worries how many other women go through the situation because doctors do not complete thorough investigations initially. B4 had three miscarriages and was fearful when she got pregnant again. She said, “I was waiting and waiting for… I was just waiting to lose the baby. I was waiting to miscarry, waiting for a stillbirth.” The participants were affected deeply by the loss of their children, and they felt the medical community could have prevented some of the heartache encountered by being more proactive before and during the treatment process.

B8 experienced similar emotions with her second pregnancy because her first pregnancy led to the premature birth of her baby at twenty-three weeks. After a bit more than a week in the NICU and a poor prognosis for her baby, B8 made the decision to withdraw life support. The loss of her first child created fear during her second pregnancy, but she was relieved when it ended with the birth of a healthy baby.

The high rate of miscarriage highlights an important consideration. While the women felt as though their physicians were not as concerned with the history of spontaneous abortion as they should have been, one must remember that miscarriage is fairly common. There is a 13.5 percent chance that any given pregnancy will end in spontaneous abortion, and that rate is higher for women of older age (Nybo Andersen et al. 2000).

Despite the realities of the high rate of miscarriage, the interviewees were in an emotionally-charged state and wanted the medical community to be more sensitive to their past and current medical statuses. For the participants who experienced miscarriages, the loss of their babies before their pregnancies came to term complicated the experience by creating additional feelings during a time that was already difficult. The inability to carry a baby to term made the women feel as though they could not control the outcome of pregnancy.

Isolation, Guilt, Blame, Shame, and Grief

Some participants stated that infertility created a sense of isolation. This isolation resulted from the need to protect one's self and the demands of the experience. A5 said of the isolation she felt, "I suppose it's just an understanding of what a lonely path it is and it really is. Nobody, no friends, no family, nobody can give you what you need. The baby isn't there, and it's just a big black hole."

Guilt, blame, and shame are closely related and interwoven into the infertility experience. B3 felt guilty because she wanted badly to give her husband children because he is so good with kids. B2 thought she may be to blame for her infertility. She said, "They stress prevention, so then you start preventing, and through that, have I done something because I've been preventing? Is it because of taking medication to not [get pregnant] for so many years? You sit and wonder, did I do something by doing the prevention?" B2's feelings connect to the negative response to the ASRM campaign that was discussed in chapter five. The advertisement suggested that there are life choices that cause infertility and it raised questions of personal blame. B2 felt as though her previous choices may have contributed to her reproductive problems, causing her to blame herself. A2 and C1 encountered feelings of shame because they were unable to have children without help. The feelings of blame, shame, and guilt relate to the view that reproduction is fundamental for females. When women cannot get pregnant on their own, they try to reason their way through the experience.

Interviewees experienced grief as a result of infertility. A1 said, "My womb knows it's broken. It's too traumatized." A3 said, "You have to redefine your life… Infertility is like an ongoing daily grief." She had thoughts of what a person should be doing with children. "I have nowhere to put this nurturing, caring, love that I have, and I really don't know what to do with that." C1 explained, "It's grief but it's a specific grief." She had a "feeling like you're left behind" and was fearful having children may not happen. B1 said,

> [I] learned a lot about loss. There was grieving involved in that. You think life is [going to] be exactly as you plan it and there are some people who have life go exactly as they plan it. And, I was angry at those people because for me, life did not go exactly as I planned it. In fact, it was very far from how I planned it.

B3 said, "When you go through the testing and everything, you put your body through so much, and that alone was emotional just because month after month it's like a loss that you're experiencing." B4 was not going to tell husband about her last pregnancy because she expected to miscarry. She said, "I think it was kind of like trying to normalize a heartbreaking time.” Participants encountered grief in a number of ways because they were constantly wanting a baby but not receiving what they tried so hard for. C1 went from getting pregnant naturally to not getting pregnant after the treatment process began. C1 grieved for her babies and the uncertain future. “But, we were also grieving. Grieving the loss of the babies that we did lose. Or, potentially grieving the loss of a future that we hoped to have that we don’t know if we’re [going to] have anymore.” Thoughts entered her mind about moving away, becoming a dog groomer, and having animals. She felt like she would always have the burden if she could not become a mother. Therefore, life would need to change. C1 said, “You just feel like you’re sitting there watching the game play out and you’re just not part of it.” Grief accompanied negative results, miscarriages, financial hurdles, and detours in treatment.

Desperation

One of the most striking findings of this research is the participants’ feelings of desperation to find a solution for their infertility. The interviews revealed that the level of desperation rises as the treatment process wears on and options are exhausted. C10 talked about her desperation, and while she cannot imagine her life without her partner, motherhood is also essential to the life she planned. She said, “I want them both,” but if she had to choose between the two, a baby would be the choice she would make at this point in her life. B1 said, “You’ll do anything if you want to get pregnant. You’ll do whatever it takes.” She continued, “People will stop at nothing to have that baby.” C9 said of his wife, “You want it so bad for the other person… When I prayed for it…I’d think, ‘Please let this happen. I can’t see her go through this again.’” He continued, “You really want it for yourself, but you want it doubly for the other person; triply almost for the other person." C6 said, "By all means, give it everything. Absolutely do whatever you need to do so at least you can look back in your life and say, 'Well, I know I did everything I could, and it was out of my hands then,' but at least you tried." C2 said she would have done anything for treatment to work. "I would have danced naked in the moon." She continued, "As a woman, I felt like I couldn't do what I'm here to do, and that was a horrible feeling." She could not control the treatment outcome. C1 said, "It was something I really wanted. I really, really wanted a child and wanted that to be part of me and my husband's path and life together… I couldn't comprehend not having a family or not having a child." The participants were desperate to find a cure for involuntary childlessness, and the women made the sacrifices necessary due to their high level of desperation.

The desire for children created feelings of jealousy for interviewees because they saw others have the children that they so desperately wanted. B1 said she remembers that her teenage neighbor became pregnant at the same time she was undergoing treatment, and she thought how unfair for her neighbor to be able to have a child so easily. B2 said, "It seems so natural and so easy for people, [but] it's actually crazy to me that some people so easily do become pregnant… That leads to frustration too." In an effort to avoid feeling jealous, interviewees found ways to avoid situations that spurred feelings of jealousy toward others. Some found that being in the presence of children was difficult. Three of the women talked about avoiding uncomfortable situations such as parties, celebrating holidays, and events to protect themselves from unwanted pain.

Due to the number of emotions that are part of the experience including this desperation, the women who were part of this research employed a number of methods to cope with infertility, including counseling, reflexology, acupuncture, and relying on faith. Some interviewees went to counseling on their own, and others chose to include their partners. A3's faith helped her to get through the process. Prayer helped A2 during the experience in addition to her family's support. Her priest was also very helpful and supportive despite the Catholic Church's views on fertility intervention. B4 said that she had faith and was prayed for. One member of her church community told her that she was sure that she would have a child. "I had no other choice but to rely on my faith in God and just trust his plan." The coping methods used were important in navigating the experience, treatment, and demands.

As a result of infertility and medical intervention, many of the participants found inner strength during the infertility experience. A4 gave herself strength "because no one can understand what you are going through." Other participants also found that they became stronger people during and after their encounters with involuntary childlessness. B8 said,

> I learned how strong I can be, and I didn't realize that I have this in me because when you first start going to the fertility doctor, having them tell you, 'well you can't do this procedure unless you pay $10,000,' it was kind of like a slap in the face. You kind of feel like this is all my fault because I can't have this baby on my own.

She continued, "I think I came out a better person." She found that the process made her more compassionate, and she started making fewer assumptions about others and the struggles they may be going through.

Another example of this sense of desperation involves a number of participants changing clinics during the treatment process due to a variety of factors. B3 said she had to switch physicians during the process because when she miscarried, the doctor did not acknowledge the gravity of her loss. Most felt that the clinics tried to be considerate of their feelings to some extent. In all, twelve participants chose to change clinics. Their decisions to seek assistance elsewhere resulted from a lack of comfort with staff or the clinic environment, the absence of desired outcomes, the need for change after an extended period of unsuccessful treatment, or the hope that another clinic might be able to find the desired solution. B8 said, “The first experience almost was more like it was all about the insurance and the money, and this is how much [the procedure] costs [and] not so much of them taking an interest in kind of the mental aspect of what I’m going through, and that was disheartening.” She did not come to that realization until she sought care at the second clinic, where they seemed more concerned about the experience. A2 said, “The first piece of advice I would give anyone is to see how you feel about your consultant, and if you’re not happy, then go somewhere else.” Clearly, the participants felt as though something was lacking that required them to change clinics. This finding shows that women with infertility do everything they can to find a solution, even if it adds to the number of burdens they encounter, and women require human-centered care to ease some of the burdens associated with medicalized infertility.

This sense of desperation to become mothers and find a cure for infertility leads to the other emotions discussed here. The decision to pursue treatment carries some level of desperation, but when that level increased as the process consumed more of life, the women found that the strong desire to overcome infertility and the lengths to which they would go affected how they felt, interacted with others, and lived their lives. At some point in the journey, the women's desperation meant they would stop at nothing to fulfill the desire, but that driving force also meant that life would not go on in the same way. In many ways, desperation acts as the overriding theme that connects the numerous emotional burdens infertile women encounter, and it is responsible largely for the extent to which those who want to have children will go to achieve that goal.

The emotional burdens of infertility result from the methods of treatment delivery, the clinic environment, a history of miscarriage, isolation, guilt, blame, shame, grief, and a sense of desperation. The emotional burdens are intertwined with every aspect of the treatment process. The unavoidable nature of the emotional impact of infertility disrupts women's lives, which suggests that the medical community must acknowledge the demands associated with the medicalization of infertility, and it must begin delivering more person-focused, compassionate care to ease some of the emotional burdens.

Effects on Relationships

One of the realities of the infertility experience is that relationships are affected. Some participants experienced difficulties with their partners. The effects of A4's infertility resulted in questions whether her marriage would survive. B8 said,

> We were told by many people, nurses in the NICU, and at the fertility doctor's that sometimes when they go through all these fertility treatments and then something horrific happens that it could break up a marriage because you're blaming one another… You just don't really know what to do.

B8’s relationship with her husband strengthened, but that was not the case for some other participants. C1 said tearfully, “It [infertility] was taking me away from him.” For most, infertility either deepens the connection or creates separation between partners.

The majority of participants found that the relationships with their partners strengthened during the experience. C2 said, “It’s physically demanding, it’s mentally demanding, it’s emotionally demanding, and it’s financially demanding, so I don’t know how you do it without both of you jumping in together.” B3 discovered “how much love you have for another person” B4 said, “There was no one else I could have had at that time that would have kept me sane.”

Interviewees shared the importance of being open with partners. B3 wants others to know “don’t close yourself in. Speak with your spouse… Our journey was from 2009 to 2016. The fertility journey is not quick. It’s very strenuous on a woman’s body with all the procedures, but we’re strong.” They stayed strong and found out that everything reproductively must be just right. “God created it pretty amazing.”

Support from partners was significant for many women who went through the experience. Nine participants discussed the ways their partners showed concern and support during treatment. C9 felt divided because he saw his wife hurting but he also knew that if she could not continue treatment, it ended there. He thought, “I hope she can go through it again because if she doesn’t, we have to call it.” B6 said it was hard to see his wife go through the experience. “Your whole sexuality’s out on the table literally.” People were wonderful, but the process “was a very negative process for me,” B6 said. B8 knew she wanted and needed her husband to be with her to get through it. She said, “He was so supportive of knowing that it was me that was having the issues and not him, but he had gone through testing." C10 said, "He's very understanding, and he hates to see me upset, and he hates to see me in pain, and I hate to see him hate me upset." She knew she could rely on him for anything she needed. C8's husband gave her a meaningful gift while going through fertility treatment. The inscription reads, "When it rains, look for rainbows; when it's dark, look for stars." She found that to be so appropriate.

Partners acted as encouragers for the participants, but on the other hand, partners also reinforced the importance of having children. While the women wanted others to help them through the process, their partners' encouragement to keep fighting created added pressure to continue treatment.

Both expectations and experiences differed for women and men. C4 said, "it does feel like everything is on the woman. You're the one injecting yourself. All that kind of stuff and there's very little he can do." B7's husband encountered his own difficulty. "My husband was very stressed. It meant everything to him to have kids." B2's husband encountered some frustration during the experience. "He just wanted it to be natural." He knew the baby would be his but wanted it to be through the normal process. He was upset by the inability to conceive without assistance.

The toll on relationships reaches beyond couples. The experience caused relationships with family members to be strained. One specific area of concern involves tension between sisters. B1's one sister got pregnant with her second child and complained about it taking six months. B1 thought, "You're pregnant and I'm not …" and was frustrated that her sister complained about the length of time it took her to get pregnant without considering that B1 was unable to get pregnant at all. She said, "My [other] sister had also experienced this, so we had a commonality, and at that point, we could talk a whole lot more, and I felt like we understood each other." A1 felt like her story was forgotten when babies became part of her family. She said, "They've kind of forgotten our story because they're so absorbed in their own lives now."

In addition to familial tension, infertility affects friendships. A1 lost five of her friends through the experience. The six had been friends for years, but when infertility became an issue, "they didn't know how to be friends with me" because they could not relate to the situation. A1's friends made her feel like an outsider when she was the only one in the group without children. She found that mothers seem absorbed and do not know how to be with those who are not mothers. The loss of friendship changed her life. She resorted to telling stories about other kids "just so I can be involved in the conversation." She has cried as she has witnessed children getting on the bus on the first day of school. In all, twelve participants experienced some level of friendship involvement. Some friendships were affected temporarily and the difficulties resolved, some friendships were redefined, and others ended due to infertility.

Relationships with others played a significant role in the lives of the interviewees. Relationships strengthened, weakened, changed, and terminated as a result of the burdens women encountered when undergoing treatment. In the end, human connection was paramount for those who became paralyzed by the inability to have children naturally. Everything in their lives was in flux, and the people around the participants had the ability to ease some of the burdens just by being a source of support.

Conclusion

The demands of undergoing treatment are multifaceted and life altering. C1 said, “The emotional toll of IVF…it’s huge. The drugs, the regime, the trying to manage a cycle, and carry on with your life, be at work, and manage time off.”

First, women and men must recognize that infertility can be a medical problem. They must allow the medical community to take control of the body for the purpose of reproduction. Individuals must have the money and time demanded by treatment. There must be levels of physical and emotional strength high enough to commit to the burdens of medical intervention. Patients must recognize that relationships will be affected, even relationships with partners, and the damage may be irreparable. The list of demands is long and exhausting for those who must take the fertility treatment route. The demands of treatment are accepted by women in an effort to become mothers, but the burdens embedded in medicalization create a significant disruption in women’s lives.

A positive difference between the two countries exists in the U.S. and involves the length of time patients are required to wait for treatment. In Ireland, patients may wait months to a year for the initial appointment with a reproductive specialist, but the length of wait in the United States is a fraction of that time. This positive attribute of the American medical system enables treatment to begin sooner, allows a medical diagnosis to be identified without a lengthy wait, minimizes the emotional burdens experienced when waiting for infertility to be addressed by a medical professional, maximizes the amount of treatment one can receive if of advanced age, and potentially decreases the level of desperation people experience when unable to have children naturally.

The burdens created by the medicalization of infertility made some participants question whether they would seek treatment again, but many said they would do it again. A1 said, “I think I still would as I wouldn’t be the me that I now am and we wouldn’t be the couple we are without it.” A2 would also seek treatment again and has. “In fact, he’s [her son] so worth it that we did it again, and I’m now almost seven weeks pregnant with number two!” C2 said, “I would have done anything to have a baby so would do whatever it takes!” B8 concluded, “As invasive and emotionally draining it is, at the end of the day you have a chance to be a parent and that is so special and worth all of it.”

Not everyone holds a positive view, however. B1, who had one child naturally after treatment and another through adoption, said, “I remember the infertility treatment time as the worst time of my life, and we didn’t get pregnant during the infertility treatment process.” B1 would not undergo the treatment process again because she is scarred by the experience.

The ability to classify infertility as a medical issue and seek assistance in the Republic of Ireland and the United States is significant. No amount of difficulty accompanying medical intervention would deem the medicalization of involuntary childlessness unnecessary. Both countries have advanced reproductive technology, adequate fertility clinics, and fair amounts of reproductive specialists, but there are many improvements each country can employ to improve the medicalization of infertility for those who must undergo fertility treatment.

When women seek medical intervention to remedy the absence of desired children, they must expose the most personal aspects of themselves in an effort to become biological mothers. The nature of the condition requires that the medical community must think beyond merely correcting a medical problem and consider how the burdens of infertility and the treatment process affect the patients they care for. To improve the treatment experience, the medical community should deliver care that incorporates the needs of the whole patient, they must communicate more effectively with patients, and they need to be more compassionate toward the women who need medical assistance. These are the first steps in making the medicalization of infertility more human-centered and less burdensome for the patients who must rely on the medical community and will be discussed further later in the coming chapters of this dissertation.

Chapter Seven

The Effects of Medicalization on Women’s Identity

The previous chapters of this dissertation explore the shaping of infertility through medicalization, and the purpose of this chapter is to show how women’s identities change before, during, and after the fertility treatment process. The definition of identity that is used in this dissertation is the “condition or character as to who a person or what a thing is; the qualities, beliefs, etc., that distinguish or identify a person or thing” (Dictionary.com). Identity involves both characteristics that set an individual apart from others and those that align with a social group (Buckingham 2008, 1). The role of medicalization is an important one for women who are unable to have children naturally, but medical intervention comes with its own burdens as described in the preceding chapter. The process of seeking assistance for infertility changes the identities of the women it affects. The medicalization of infertility causes women to lose pieces of themselves during a time when they already feel as though they are not whole without children.

The transition between viewing reproduction as an easy part of the female condition and the discovery of infertility marks the first major shift in identity. The desire to become mothers and the inability to achieve motherhood through natural means highlights an inadequacy in the female identity. A second shift occurs when women begin to recognize infertility as a medical condition, and a third shift occurs after fertility treatment concludes.

Loftus and Namaste explored infertility and identity and found that women attempt to embody the potential identity of mother, which contributes to the actual identity of infertile. A woman may struggle to achieve the identity of biological mother, but she cannot assume that identity due to her reproductive limitations, which characterize her actual identity (Loftus and Namaste 2011). These competing identities interfere with a woman's life and her idea of self in a number of ways, including her interactions with others, job interference, changes in relationships, and intrapersonal turmoil. The participants' narratives in this dissertation also show this making of a new identity through the experience of involuntary childlessness and the medicalization of infertility. The women included here represent those who intended to get pregnant, were unable to do so on their own, and sought medical intervention.

Identity Before Infertility

For many, childbearing is part of the female identity. Motherhood and fatherhood are desirable and expected in the Republic of Ireland and the United States. A1 said, "Your life isn't legitimate in this country [Ireland] if you don't have children and … that comes across in everything." She learned "how biased we are towards family … Two people isn't a family. You know, one person and a cat isn't a family. This notion that family includes small people. We would love to have dogs viewed as family in this country." Women learn at an early age about the importance of reproduction and expect to be fertile. A3 said, "Your body is like you're made to have kids. Made to carry children. Every month when you get your period, there's a constant reminder that this is what your function is." Marcia Inhorn discussed the expectation of women to become mothers across cultures and the ways in which that expectation is targeted by the medical community in her review of ethnographic research conducted globally and wrote,

> … their most essential characteristic is seen as their ability to reproduce, to give birth, to mother their children, to reproduce the generations… The medical and public health fields devoted to women's health - namely, obstetrics and gynecology and maternal and child health - literally target women as reproducers or potential reproducers. (Inhorn 2006, 350)

The Infertility Experience Before Medicalization

Some of the participants said that the inability to have children raised questions of fulfilling the female role. A5 said, “You do feel that am I a whole woman sort of thing … Why can’t I get pregnant? This is part of being a woman.” A1’s awareness of her reproductive difficulty and inability to fulfill the expected role was heightened by a number of her friends having children.

The interviewees expressed their strong desire to have children. The women knew they wanted children before they discovered infertility, and the desire did not decrease when they encountered reproductive difficulty. C10 said, “All my life, it’s been babies, babies, babies and having to wait this long is just killing me.”

Despite their desire to have children and the expectation to be able to get pregnant easily, the participants discovered that an unwanted reality awaited them. C10 said she knows now

> how much is working against you… It’s been my dream since a little girl. I thought I was doing all the right things, but this happened anyways. And I always thought when I’d see women who had no children or who had IVF, those poor women, thank God I’m not like that and here we are anyways… I’m one of those women.

This discovery of infertility marked the first major change in identity. The women no longer viewed achieving motherhood as simple, and they became aware of their own biological limitations.

Recognizing Infertility as a Medical Condition

When women recognize the inability to have children naturally as a medical problem, a second shift occurs. Fertility treatment is the vehicle to move women from the actual identity of infertile to the desired outcome of biological mother. Women and couples recognize involuntary childlessness as a treatable condition when they enter the realm of medicalized infertility. Some participants viewed their reproductive difficulty as medical early in the process or before seeking medical intervention for the first time. A1 said, “as our infertility arose directly from a major medical emergency that happened to me, my ectopic pregnancy rupture, I was referred to our fertility clinic by my surgeon, who continued to see me after my discharge from hospital.” A1 viewed her inability to get pregnant as a medical condition from the outset. A2 identified her infertility as medical when she started considering the need for IVF. B1 said, “I don’t know if there was a precise time when I felt the infertility was one-hundred percent medical. I think I always felt that there may have been multiple causes. Because we still don’t know why we were infertile, there is still no clear answer to this.” The exact point in time at which participants began viewing involuntary childlessness as a medical condition varied, and some were unable to identify a moment when their infertility gained a medical connection.

Participants discussed the medical nature of their involuntary childlessness. C6 said, “If you found out you had cancer, you’re [going to] do something about it.” C6 recognizes the two issues are very different, but if a person wants children and is unable to get pregnant naturally, seeking help is the next step. Others also thought medical intervention would be the solution. At some point in the journey, participants began viewing their infertility as a condition treatable within the medical domain. A1 said, “Be honest about how much you want children,” and if children are part of the plan but childbearing is a problem, take the appropriate steps. A1 wants others to

> go and do it, and check it, and ask questions, and take the risk that you’re going to get bad news. Pussyfooting around or procrastinating doesn’t bring any solace. You’re either going to get pregnant by yourself or you need help, so the worst that can happen is you go…ask the question and [then] it happens by itself.

When the women in the study encountered reproductive problems, they found medical treatment to be the most acceptable method of addressing infertility. Biological parenthood was the desired outcome, and non-biological options were viewed by participants as a backup plan. A1 explained that the idea of family is rigid because more value is placed on having biological children than on adoption. Gayle Letherby, a professor of sociology and feminist studies, found in her research that the field of medicine plays a role in helping women achieve the societal expectation of becoming biological mothers and reinforces the importance of having biological children. She wrote, “the power and status accorded to medical science encourages us to seek biological (and medical) solutions to social problems” (Letherby 2002, 286).

For women and men who consult fertility assistance, the decision to have children is no longer entirely their own. Fertility clinics decide whether patients are fit to become parents. C5 said of her pursuit of childbearing through medical intervention, “This is a very wanted child. It is a very planned child. It just doesn’t come out of luck. This is a very wanted child and therefore shouldn’t every wanted child be encouraged.” B1 said, “The process of having to prove that you’re good enough to be a parent is humiliating.” B1 said no one asked her neighbor who became pregnant easily if she was fit to be a parent. For those who must depend on others to assist with reproduction, the apparent lack of control over their own choices is problematic.

The identity continued to shift when participants experienced a moment of sudden recognition when a diagnosis was identified. A3’s laparoscopy identified endometriosis. When she woke up after the procedure in pain, she knew something was wrong. She said, “I’m on a journey now and it’s not going to be easy.” C10 said,

> I was just so surprised. I had been assured up until then [the time of her procedure] that it wasn’t going to be a fertility issue. I could still have my babies. It could still be on the cards for us. I was very excited to get married. I was very excited to have children.

She continued, “You know that feeling I don’t really feel like a grown up, I still feel like a thirteen-year-old girl? I lost that feeling when they said I wouldn’t be able to have kids. I felt very adult in that moment.” A1 said of her realization,

> The irony for me is I suppose that my infertility came from enormous loss of life, which to me makes it more like, this sounds a bit crude, but I kind of compare it to somebody who loses something in a car accident… If you lose your sight in a car accident, it’s an actual traumatic loss. Except in my case, what I think is weird about it is that it didn’t appear like that at the time… The OB would have consistently been reassuring that ‘you have everything. You have everything. It all works. You’ll be grand.’ It appeared for a long, long time that I didn’t lose anything at all…technically, or emotionally, or physically, or philosophically or anything; so, it’s only obviously with time that I would now kind of in hindsight or go back and say that’s the moment that I lost my ability to control my own fertility. [That’s] when I lost my right to have expectations as to what I can have rather than lose something tangible like your womb or your eyes.

A1's fertility expectations changed the evening she experienced her ectopic pregnancy and found out that she would require reproductive assistance. The interviewees experienced their moments of sudden recognition at various times. For some, the gravity of the infertile state became apparent after a procedure was performed or a diagnosis was delivered, and for others, the sudden realization occurred for no identifiable reason.

The inability to control their own fertility and their feeling as though motherhood was essential to enter adulthood fully are two aspects of the new identity. For some, these aspects became evident during the participants' moment of sudden discovery, and they serve as two important examples of infertility's impact on the women's changing identities.

In the beginning, all participants were hopeful that treatment would be the answer, but the level of hope decreased for some interviewees over time. C6 was so hopeful early on that she started purchasing baby items. She was very surprised at the negative pregnancy test result because she had so much hope. Now, she knows that the likelihood of having a successful cycle on the first try is low. Often, it takes more than one try.

As the women became less hopeful, they recognized that the medical community has a tendency to create false hope. A1 said,

> As the science and medical interventions are impressive, it gives a false confidence as to what is possible. We have come to realize that you can have totally unexplained IVF failure where the medical advice is simply to do exactly what you did again in the hope of a different outcome – a form of madness really!

A4 said medical professionals offer options based on what a person can pay for. The clinic tried to make her situation seem better by saying she did not need to have many preliminary tests, and the clinic kept offering services to increase her chances. She said, "I felt like they were lying to me sometimes." A4 wanted more transparency with her clinicians. A5 said the medical staff always talked about the baby she would have, encouraging hope when hope is not guaranteed. C10 said,

> Everyone just wants to cheer you up and say it will happen, but I found that very difficult. Saying it will happen doesn't mean it will. It's not as if I didn't get the car I wanted and now I have to get a different car. I cannot physically conceive a child, and I think until you're in a situation where you are thinking about or trying to have your own baby do you realize the loss. I mean, I was grieving.

As treatment wore on and options were exhausted, the women's identities and attitudes continued to shift. Their levels of hope decreased, and they felt as though the medical community contributed to the experience negatively by creating false hope. Achieving the desired identity of mother looked bleak at moments, making the shortcomings of the treatment process more evident. C7 said, "You kind of do have to get yourself mentally right for whatever happens… You're kind of a bit naïve initially…because you're so reliant on everyone else."

Throughout treatment, participants found that their views of the medical community changed, which connects to the demands discussed in chapter six. C2 shared, "My view on the effectiveness of the intervention has changed. I believe the fact that this is a profit-making business for the majority of practitioners has disadvantaged the treatment process." B1 said,

> I felt as though the medical community was inept, lacked knowledge, and also lacked caring. I was going through deep emotional pain, and there was absolutely no one who acknowledged this. We felt all alone. We also felt taken advantage of by the medical system. I came to think infertility was basically a money-making scam.

Regardless of whether participants would seek medical assistance again, many were grateful for medical intervention, however. C2 wrote, "Living in a city meant that I had easy access to all the relevant services: gynecologist, private hospital for scans, investigations, etc.” B7 said, “It provided us with a plan to maximize our ability to have children. I think the ability to seek help reduced our anxiety. It helped us feel like we were doing all we could do to have a family.”

With each step of the treatment process, the women tried to reason their way through the experience. Their views and expectations shifted as they became more accustomed to medical intervention. The changes in perspective were the result of treatment demands and ongoing heartache. The classification of infertility as a medical problem caused a significant change in identity that continued to shift when the women’s fertility expectations changed during the treatment process, they experienced a moment of sudden recognition at some point in the journey regarding the reality of the situation, their levels of hope in treatment decreased as the process wore on without achieving the desired result, and the participants coped by finding meaning in each part of the medical journey. These important factors that resulted from undergoing medical treatment for infertility influenced the larger changes in the women’s identities.

Identity After Treatment

The participants had all reached temporary or final ends to their infertility journeys at the time of interview. Some had the children they desired with fertility assistance, and others went on to have children naturally once treatment concluded. For those who were unable to have a baby, some found ways of moving on with life and others have been unable to move past the inability to have children. Some participants have not closed the door entirely to the possibility that they may become mothers.

Whether they have or have not moved past infertility, they will never have the same identities they had before discovering that the path to motherhood would not be as easy as anticipated, which represents a third and multifaceted shift in identity.

Those who have not been able to have children biologically have found that treatment does not always end happily. A3 said, "… [Y]ou feel the one little isolated failure over here. It works for everyone else but not you." A3 has had difficulty accepting life without children. At one point, she thought that her life ending may have been better than the pain she experienced as a result of her infertility. She said, "Nothing in my life has ever affected me as deeply and on an ongoing basis as this has." C10 said,

> There's no experience to prepare you for this. There's no point of reference. There's just no rulebook or guidebook… I don't feel like we should be ashamed of it…We didn't choose it. It just happened to be the way things are and we've done what we can to have our family.

A1 said,

> I now also realize that when you take the step towards achieving a pregnancy through treatment, it is very difficult to go back and to a large extent the infertility world, including the medical industry, keep pushing you along to a point where stepping out or off without success, is tough to do. I say, if you have been fighting a war for years, where you are prevented from seeing sunshine and beauty around you as you need to be prepared to fight, it is very difficult to get down from the warhorse and appreciate the flowers and the rivers and enjoy the sun. The constant battle changes you and if you don't have a child at the end, what are you left with?

C6 said, "It's totally made me reevaluate my priorities and my life… Now, it's like if I have to work as a waitress or in a bookshop or whatever, it doesn't really matter as long as you're able to pay your bills and have your little family. That's what life's about." Some participants know the unwanted outcome of treatment personally. They continue to view motherhood favorably despite the inability to have children, and they have not accepted that this is where their journeys have ended. The desire to have children, the absence of a medical solution, and the nonacceptance of their status characterize this new identity.

Some of the women have reconciled themselves to their childlessness and have found ways to enjoy life. The women who have not achieved motherhood but have accepted the reality experienced a third but different shift in identity. A1 said,

> We have begun our childfree life – leaving treatment behind by choice not by circumstances, as we don't want our lives to be defined by whether or not we achieve a successful cycle and have a baby. We feel that if we wait until circumstances tell us to stop – money, age, medical advice – it might be harder to find a life without children that we love.

For the participants who went on to have children with medical intervention or became pregnant naturally after treatment concluded, the outlook on the experience differs from those who were unable to have babies. B7 said,

> Parenthood seems like this natural progression where you have this child and it's a baby… It's a nice picture. No one prepares you for when the story does not happen that way. Things are not [going to] work out necessarily the way you want them to when you want them to.

She wants others to realize that it may not be the way a person wants. She could see her own sad ending. C1 will always remember the embryos that did not survive. C8 said the failures they experienced feel like losses because each attempt at pregnancy involved parts of each of them.

B2 explained, "It's a wonderful process if it works, and I know that sometimes it doesn't, but I hope that there truly is a God's plan for those that are unable to successfully have that special child in their life." B5 now sees the complexities of reproduction clearly. “How miraculous it [pregnancy] really is that it ever happens on its own naturally.” The process requires that so much must go right. C2 said,

> You’re probably never in your life more vulnerable than [when] you are dealing with infertility. You’ve got two people and a marriage… It’s core to your entire human being to reproduce. Whether or not you know it or you don’t, there is something internal that has this push, and you are extremely vulnerable.

A2 explained that the medical result of a child does not wash away the negative aspects of the experience. She said, “Many of my close family and friends were easily having babies, and we were still left waiting. It wasn’t just a matter of deciding to have a baby for us; it was a heartbreaking, expensive, painful process that took us seven years.”

Two other interviewees went on to have both biological children and children through adoption. Of her changing perspective, B1 said, “I think my attitude toward life changed in that it [life generally] became a lot less predictable, so that was a gamechanger; a life changer just knowing that,” B1’s statement demonstrates the feelings that accompany these shifts in identity.

The final type of this third shift in identity is one of attaining motherhood through medical or natural means. While the participants who went on to have children experienced their own heartache throughout the infertility experience, they eventually achieved the desired goal. They now embody the actual identity of mother.

Despite the strong desire to have biological children, a number of participants were open to non-biological options, but they saw the process as more difficult due to the knowledge they had of adoption. A1 said, “adoption is more hopeless” than fertility treatment in the quest for children due to the difficult structure of the process. A1 said, “You can’t apply and you can’t go through that process if you’re still looking for treatment because of your file, and your social worker talks to your doctor, and so you kind of technically have to stop one." She continued, "The adoption process is just so unhopeful ironically. So, as hopeless as I might have historically felt about IVF given our journeys being on paper so positive and yet it doesn't produce the results, actually, the adoption world is more hopeless at this moment in time."

The women's views of the lives they planned changed at the conclusion of treatment. Whether they had children or have found ways of living life without children, aspects of their lives have changed indefinitely. The attainment of motherhood in the end did not eliminate the negative aspects of the treatment process. The identities held changed from living a life that was predictable and controllable to one of relying on the medical community, devastation, and the need to find new meaning in life after treatment concluded.

Conclusion

Girls begin forming their identities around the importance of motherhood from an early age. Baby dolls and dollhouses are part of childhood for many little girls. Becoming mothers is viewed as one of the steps in the normal life trajectory. Girls learn that having children is biologically simple, and unprotected sex should be avoided in an effort to prevent unwanted pregnancy.

For women who experience infertility, the inability to reproduce goes against everything women are conditioned to believe and accept. Achieving pregnancy is not easy for them, and trading in the childhood doll for a real baby requires more than regular intercourse with a partner for some women. The absence of pregnancy delivers a hard blow to those who want nothing more than to become mothers.

The societal and familial expectations of women to have children determine the identities women embody. In an attempt to fulfill the expected role, women consult medical intervention because society deems biological motherhood as the preferred solution and non-biological options as a less desirable alternative. However, the idea that pregnancy is achieved and carried out easily inspires a false sense of hope in treatment, disappointing those who find that childbearing with medical assistance is not as simple as advertised. External pressure to reproduce and the expected way in which women should have children affected the participants' personal sense of identity. Recognizing a need to reshape societal expectations, A1 said,

> I feel very strongly that the world needs to start talking about life without children. I think that Ireland doesn't understand family without children, it doesn't understand women without motherhood, and it doesn't understand how a person or couple can be fulfilled without parenting. I think we need to embrace childfree as we have embraced gay marriage as a different way to live life. If we do that, then I think maybe future couples might feel that they have a choice from the very beginning to love the life they have and not almost kill themselves trying to pursue the life they are used to seeing everyone around them with.

The process of seeking treatment for infertility carries with it a long list of demands. In addition to the burdens embedded within medical intervention, the reproductive flaw in the female identity is on full display. The need for fertility assistance prompts women to question whether they are fulfilling the female role. Due to the societal, familial, spousal, and personal pressures to reproduce, women seek the potential identity of mother with desperation, while being tormented by the inadequacies within the actual identity.

Childbearing begins as a private matter between partners and becomes a medical endeavor that requires a number of moving parts. A fundamental and expected piece of the female identity transitions to a matter that others control, causing women to question themselves.

The discussion of changing identities is an important contribution of this dissertation. There are three main identity shifts that occur as a result of infertility and seeking medical assistance for involuntary childlessness, with numerous smaller accompanying shifts. The first identifiable change involves a woman's discovery of her fertility limitations, the second is classifying infertility as a medical problem, and the third is learning how to continue on once treatment concludes. The societal expectation to become mothers, personal feelings of inadequacy when unable to achieve pregnancy naturally, and the lack of control of fertility due to biological limitations and the medical community's control are additional factors that contribute to the ongoing changes in identity during and after the treatment process. The changes in identity that women experience are in response to medicalization, and the end result of treatment leaves a permanent imprint on women's identities. These personal changes that result from the medicalization of infertility necessitate improved medical community awareness of the impact of infertility on the female identity to create a treatment environment that addresses the issues that accompany undergoing reproductive assistance.

When women with infertility embark on the journey to motherhood, they do not expect the barriers that will be encountered on the road to achieving a desire that is at the core of being female. The journey is a lonely one with lots of bumps along the way, and the desire to embody the identity of biological mother leads women to do anything within their power to change their identity from one that is unwanted to one that is wanted above all else. At the end of the journey, aspects of the identity possessed prior to the discovery of reproductive problems can be difficult to recognize. Women no longer hold all of the pieces of themselves that they did prior to treatment because they have handed their bodies over to outside control and they view reproduction differently than before discovering infertility. With the expectation that motherhood will be achieved naturally with ease, women who want children build their lives around that desire. When medical intervention becomes necessary, women begin to view that expectation differently, and those who find that medicalization is not always the solution, discover that childbearing is not as easy as many believe. People who want children and have children get the identity they want, but those who cannot, never embody the identity they desire.

Chapter Eight

Conclusion

Infertility, like other medical conditions, affects lives without invitation. The inability to have children naturally creates suffering for those who include motherhood as part of their life trajectory because reproduction is a natural, culturally promoted, and desired part of human existence for many.

The medical community plays a key role in shaping the infertility experience in the developed countries of Ireland and the United States, which eases or worsens the burden for women who require medical intervention to become biological mothers. The way in which involuntary childlessness is shaped, viewed, judged, and stigmatized within societies contributes to the pain encountered when one is unable to have children naturally. The medical community controls many aspects of an experience that is personal and life altering.

This research shows that the societal expectations of women to bear children as part of the female role make those who must seek assistance for infertility feel inadequate or abnormal. These expectations pressure individuals to adhere to the requirements set forth by cultures, religions, and families.

When unable to have children, one must seek medical intervention if she desires to remedy the situation, creating the need for fertility services and a profitable business model. The absence of comprehensive health policy and insurance, lack of government acknowledgement and regulation, and current medical system structure leave the medical community and those involved in the provision of fertility services in control of the medicalized infertility experience. The lack of consistency creates added hardship for women who are infertile because layers of complexity make the medical system difficult to navigate. The difficulties in navigating the system, desire to have clinicians better understand the experience, financial burdens of fertility treatment, level of clinic comfort, and commercialization of infertility further complicate the experience for those who go through it.

Reproductive awareness begins when teens are exposed to sex education during the school years, but adequate fertility education is lacking in Ireland and in many areas of the United States. Previous researchers have highlighted some of the issues with inconsistent teaching methods, and some of the women and men interviewed identified the need for better fertility focused education. The absence of adequate fertility understanding in a person's teens and twenties leads to unhappiness when individuals realize that achieving pregnancy is not as easy for some as they were taught to believe, and life choices can influence one's ability to have children. Fertility awareness and understanding help to form the acceptance or rejection of assisted reproductive technology within societies. Therefore, improved understanding is necessary for the accurate formation of beliefs about infertility and reproductive assistance.

The media are a powerful tool for the dissemination of information, education, and belief formation. Media outlets are able to disburse information widely and easily, making access to infertility-related media coverage easy for the public. However, people must remember that the media have agendas, and the information available does not represent infertility comprehensively. Oftentimes, readers, viewers, and listeners are exposed to celebrities who have encountered infertility, which fails to represent individuals who have financial barriers to fertility treatment. The media shed light on the issue but only act as the first layer of discovery. Better coverage of infertility-related topics in the media will continue to build understanding.

Popular culture is another vehicle for the delivery of infertility and fertility-related information. Popular culture references expose the topic to a large number of people in an informal and enjoyable way. While the infertility experience in literature, film, and television shows may only scratch the surface, highlighting the topic on a large stage improves understanding and helps those going through the experience to find that they are not completely alone.

The interview portion of this dissertation affirms the information presented in previous chapters. Personal accounts show readers that there are many demands of the fertility treatment process. In an effort to have a biological child through medical intervention, women must endure physical changes, medical procedures, emotional turmoil, expensive treatment methods, life interference, and ongoing heartache. The burdens created by medicalization are unavoidable, and women tolerate the demands with the hope that treatment will resolve with a baby.

Additionally, comfortability with clinics and medical professionals is important for women who seek medical intervention because the process requires patients to develop trust, bare their bodies and sexuality, spend large amounts of money and time for treatment, and delay other aspects of life to commit to treatment. The medical community plays a central role in the infertility experience for those who consult fertility assistance.

Infertility represents an inadequacy at the core of the female role. Women begin the treatment process with the hope that they will become mothers. When treatment is first undertaken, women are hopeful that treatment will be the solution. As time goes on, women are willing to do more and more to accomplish the goal and transition from the actual to the potential identity. The treatment process requires continuous shifts in identity due to the landscape of medical intervention. In the end, the female identity changes regardless of whether treatment results in a baby due to the burdens embedded in the treatment process and the new perspective gained throughout the experience. Medicalization causes permanent changes in identity, forcing women to figure out how to navigate life after treatment concludes.

The major shifts in identity that women experience as a result of infertility include the transition from viewing conception and pregnancy as easily achievable to being more difficult than anticipated when reproductive problems are identified. Second, women's identities change when they begin to view their infertility as a medical problem because they must rely on the medical community and let go of personal control of their fertility. Third, the female identity changes once treatment concludes. The third shift in identity is either one of the acceptance of childlessness, the inability to accept that treatment was unsuccessful, or the attainment of motherhood and desired identity while not forgetting all that had to be endured to have a biological child. The changes in the way women see themselves before, during, and after the treatment process are an unavoidable part of the medicalization of infertility.

Participants from both the Republic of Ireland and the U.S. expressed concern about the commercialization that accompanies infertility, absence of government involvement, inadequate delivery of sex education, need for improved fertility understanding, and demands of treatment. Additionally, they experienced shifts in identity, relationship interference, improved relationships between partners in some cases, the discovery of strength and resilience during the process, uncertainty that is part of infertility, and a lack of control associated with involuntary childlessness. These similarities show that there are common elements of the infertility experience in Ireland and the United States.

Infertility is an experience unlike any other. Involuntary childlessness puts life on hold when women cannot have children naturally because having children is a fundamental part of many societal and religious traditions. The absence of children when motherhood is a central goal interferes with many aspects of life, including the identity one holds. Through improved understanding of the medicalized infertility experience, all members of society can make contributions to improve the experience for those who find they must face the undesired state.

Recommendations for the Medical Community

The infertility experience puts life on hold for patients in many ways. This research identifies the need for a number of medical community improvements.

First, medical professionals must improve their understanding of the impact of involuntary childlessness on the patients they serve. As chapter three shows, the medical systems in both countries are complex and difficult to understand, but medical professionals do not always recognize that medical system inconsistencies affect patients more than anyone else involved. Women encounter added burdens due to the fertility clinic design and medical system structure that can be alleviated by increased awareness and consistency within the medical community.

One example to improve physicians' understanding is to incorporate into medical training a new educational opportunity for doctors specializing in obstetrics and gynecology. Physicians practicing in obstetrics and gynecology often play a role in the early stages of infertility, and those who choose this medical specialty need to be introduced to the realities of infertility early in their medical careers. This can be achieved by holding a narrative session in the reproductive endocrinology portion of OB/GYN training. For the session, each medical resident receives two patient charts to review prior to the session and must write their reactions to each. One patient has had a child through fertility treatment, and the other has not been able to have a child with medical assistance. After reviewing the two charts and writing their reactions, the residents listen to the two patients tell their stories of infertility in which the patients have received guiding questions beforehand. Each patient is given thirty minutes to share. At the conclusion of both narratives, the residents have an opportunity to ask questions. Both participants are made fully aware of the process ahead of time, and the selection of participants requires that each is in a place emotionally that permits them to tell their stories. A mental health counselor is available before, during, and after the session as a precaution. After questions have been answered, the residents are asked to write about their reactions to the session to determine how the thought process changes before and after hearing the stories. This teaching approach, based on Rita Charon's work in narrative medicine, particularly her use of Parallel Charts (Charon 2006), gives physicians a glimpse of the burdens their patients encounter in order to understand the struggles of the patients they treat and before choosing to continue on with medical training in a reproductive medicine fellowship. This example differs from Charon's use of Parallel Charts because her model has medical trainees and physicians write narratives about medical cases and share their written work with colleagues. In this teaching opportunity, the patients introduce more to the medical case or chart by sharing their own stories, and medical residents write and share about their pre-and post-patient storytelling encounters with their colleagues. While the first session is important to inform physicians of the patient experience, ongoing teaching in this area is necessary to reinforce the importance of listening to and learning from patients' stories. For doctors who choose reproductive endocrinology, narrative sessions and learning opportunities must continue throughout the fellowship years. This early exposure to infertility is important to ensure that physicians are equipped to deliver optimal care. The approach exposes physicians to a necessary but often unrecognized part of treating patients with reproductive problems and builds collegial relationships in the process. An improved focus on the whole person instead of the medical problem presented is one way to provide more compassionate treatment, and it can begin with humanities-based teaching opportunities such as the one explained here.

Second, improved inclusion of and communication with patients regarding the details of treatment is essential in the area of reproductive medicine. The women felt as though they had lost control, and some of that control can be given back to women if those caring for them make women feel as though they are active members of the treatment process. This requires that doctors take adequate time to explain the details of treatment and ensure that patients feel as though they are active participants in and contributors to the fertility treatment process. Physicians must make sure that their patients receive the education needed. This is part of making women active participants in the healthcare delivery process and is necessary to make sure that the women who seek treatment are fully informed about the process. As discussed in chapter four, the medical community controls the treatment process, but empowering patients is an important step that fertility clinics need to take.

Third, many participants expressed their concerns about the treatment environment. One solution to make the treatment setting more patient friendly and focused is to make recovery rooms private. Women feel vulnerable and exposed when going through fertility treatment and providing a private recovery area ensures patients and partners have privacy. This will increase comfortability and the focus on patient-centered care.

A final recommendation that can assist in reshaping the medicalized infertility experience involves improved counseling service offerings at fertility clinics. Mental health counseling is not a consistent part of the clinic environment, but as the CAHR report identified, counseling at all stages of treatment is important. While some women underwent treatment at clinics that offered counseling for those who were interested, others sought care with providers who did not make mental health services readily available. The burdens of the treatment process and identity changes that result from medicalization require guidance throughout the treatment process. Some women may not be interested in the services, but for those who want to make therapy a part of the process, social workers and counselors can provide continuous support to assist patients with navigating the burdens, emotions, and personal changes connected to the medicalization of infertility.

The medical community can improve the treatment process for all involved by understanding that reproductive medicine is more than a medical specialty. The specialty not only manipulates science in amazing ways but deeply affects the lives of those who need assistance in creating a family. For the women who encounter infertility, they experience not only a medical problem that needs to be corrected but also a medical problem that results in changes that affect many aspects of their lives.

Recommendations for Future Research

This dissertation is the first attempt at research of this kind in the field of medical humanities. Future research should focus on interdisciplinary cross-cultural analyses of the medicalization of infertility in other cultures, including developing countries, to determine the commonalities and differences involved in the construction of medicalized infertility. These cultural differences and similarities provide a lens through which the treatment process and the effects of medicalization can be evaluated and improved to make the infertility experience better for women.

Additionally, medical humanities research in the area of reproductive medicine should continue in an effort to create a medical specialty that is optimal for the medical professionals who choose to work in it and for the patients who must consult medical assistance. Medical humanities research is necessary to improve the medical professional/patient relationship and the healthcare experience for all.

Appendix

Personal Perspectives

The narratives included here were written to assist me with the writing process. The personal perspectives included in this dissertation have been amended and expanded on, which makes some of the text included in the body of the work and this appendix vary. The narratives have been included here to give readers a more complete look at each participant's story.

Ireland

A1

A1 found out soon after marrying her husband that she was pregnant. One night, she collapsed in extreme pain in her friend's house and went to the emergency department. She had lost a lot of blood and the doctor determined A1 was experiencing an ectopic pregnancy. The medical professionals found that the position of the embryo was not typical because the location was almost in a safe area. The doctors tried to preserve her ability to have children, despite knowing A1's life was at risk. After the operation to remove the implanted embryo, she recuperated for one week in the intensive care unit. The night of the incident, A1 went to a maternity hospital because it was close by, but had she been at her own home, the results may have been different. She may have lost the ability to get pregnant. The maternity dedicated hospital enabled gynecologic evaluation, which enabled the preservation of her fertility. Medical providers at a general hospital would not have been able to intervene in the same way. A1 said,

> The irony for me is I suppose that my infertility came from enormous loss of life, which to me makes it more like, this sounds a bit crude, but I kind of compare it to somebody who loses something in a car accident… If you lose your sight in a car accident, it's an actual traumatic loss. Except in my case, what I think is weird about it is that it didn't appear like that at the time… The OB would have consistently been reassuring that 'you have everything. You have everything. It all works. You'll be grand.' It appeared for a long, long time that I didn't lose anything at all…technically, or emotionally, or physically, or philosophically or anything; so, it's only obviously with time that I would now kind of in hindsight or go back and say that's the moment that I lost my ability to control my own fertility. [That's] when I lost my right to have expectations as to what I can have rather than lose something tangible like your womb or your eyes.

Her fertility expectations changed that evening.

Three to four months later, and three months into her marriage, A1 tried to conceive again. A1's husband was scared of her getting pregnant again because of what she had been through just a few months ago. Upon further consultation, doctors found that one tube was scarred and one did not function. Her physician advised her to seek a fertility consultant's opinion. The initial consolation took place a bit more than one year later. At first A1 thought, "there's nothing wrong with us. We just have transportation issues. Please just do whatever you need to do to circumvent the problem."

They began IVF soon after seeking fertility assistance. The first round resulted in five embryos surviving until day five, which is ideal in the world of infertility and IVF. The retrieval and survival of five embryos resulted in three cycles of IVF. One ended in a chemical pregnancy, or very early miscarriage. The doctor checked A1's uterine lining when the three cycles concluded with no pregnancy. Bloodwork sent to Chicago revealed a "high immune system." A1 said, "My womb knows it's broken. It's too traumatized."

At that point, she focused on her thesis because she was sick of treatment and needed some time off. When A1 returned for more treatment, the doctor prescribed more medications, and the egg collection during another round of IVF resulted in two embryos. That cycle of IVF ended with no pregnancy. A1 found she was exhausted from the medications and steroids. In another attempt in March of 2014, she again did not get pregnant.

A1 and her husband started to think about adoption, but Ireland does not permit anyone to begin the adoption process if under fertility care. She and her husband decided "adoption is more hopeless" than fertility treatment. A1 mentioned a recent referendum that determined the mother has rights over her children. That means, children may be removed from unfit mothers, but those children will be held in foster care in hopes they may return to the biological mothers someday. Mothers' rights over children's rights lead to a lack of adoptable children.

A1 said people do not talk about other options. People avoid talking about children who are not biological children. A1 realizes that lots of people do not get pregnant but they don't choose other options either. They do not feel as though they can seek other options. Adoption, although difficult, usually turns out well. A counselor once told her, "There are people in the world who want to own their own children, and there are people who want to parent children." According to the social worker, A1 is the latter. The couple thought of fostering as a last route. A1 is no longer scared of not having children because she knows there are options, and she and her husband are open to those options. She felt paralyzed in the past but no longer feels that way. "This fear that I had of never wasn't a never."

A1 talked about the lack of fertility treatment coverage in Ireland. "The state keeps closing doors." She finds that thinking of alternative ways to have children does not work with the current structure of the system. The idea of family is rigid. The idea of treatment is more acceptable than other options. Seeing pregnancy advertisements that are government funded is common but nothing exists for infertility. The structure of the system makes her upset because the cause of her infertility is medical but yet she received no coverage.

“The few unfortunate souls who can’t have children” are underrepresented and almost forgotten. Soap operas do not talk about childlessness. The country does not talk about not having children. “Your life isn’t legitimate in this country if you don’t have children and how subtle that comes across in everything.” She has learned “how biased we are towards family… Two people isn’t a family. You know, one person and a cat isn’t a family. This notion that family includes small people.” “We would love to have dogs viewed as family in this country.”

When asked about her views of medical professionals, A1 said they were all very good. The doctors took the appropriate actions to save her fertility, and they kept reassuring her that she could have children. Her consultant wanted her to be able to have children and gave her a referral to another clinic when needed. She felt her husband was included in the process as well but the demands of treatment change a couple’s sex life from enjoyable to predictable.

Although the families were concerned for A1 and her safety due to her history, there were familial hardships. The families found out about the couple’s fertility issues naturally. A1’s sister’s pregnancy created tension, and she felt she could not be open with her sister because her sister could not relate to the situation. Additional tension existed because A1 got married first, but her sister had two babies before she and her husband had any. The couple feels like their story has been forgotten now that babies are in the family.

In addition to familial tension, infertility affected friendships. A1 lost five of her friends through the experience. The six had been friends for years, but when infertility became an issue, “they didn’t know how to be friends with me” because they could not relate to the situation. A1’s friends made her feel like an outsider when she was the only one in the group without children. She found that mothers seem absorbed and do not know how to be with those who are not mothers. The loss of friendship changed her life. She resorted to telling stories about other kids “just so I can be involved in the conversation.” She has cried as she witnessed children getting on the bus on the first day of school.

A1 cannot let go of her losses, but she has found ways to enjoy life through travel. Her personality has strengthened her. She always looks for solutions and does not dwell on the past. Looking at the future gives A1 hope. She and her husband are open to what the future may bring, and she is grateful she has been able to be open with him throughout the experience because infertility is quite isolating. She said, “You just keep going.” They have gained knowledge by watching others for the past five years. This experience has “reaffirmed the value of compassion.”

She wants others to “go and do it and check it.” People need to realize what they want and decide whether their career or having children is the main priority. “Be honest about how much you want children.”

A4

After two years of trying, A4 went to the doctor. The cause of her infertility was unexplained. There was a possibility that her immune system contributed to her infertility. Eventually, she became pregnant, but four years after her son’s birth, she has not been able to get pregnant again. IUI did not work, so she began IVF. Nine eggs were retrieved, but she did not get pregnant. A second round of IVF did not result in A4 becoming pregnant. She was told she did not have a problem, but still, she could not get pregnant.

A4 said medical professionals offer options based on what a person can pay for. The clinic tried to make her situation sound better by saying she did not need to have many tests. The clinic kept offering services to increase her chances. “I felt like they were lying to me sometimes.” A4 wanted more transparency with clinicians.

A4 found that fertility treatment is very expensive in Ireland. Prescription coverage is the only good thing. She had to pay for everything in full because she did not have medical coverage for fertility services.

She did not share anything with others but held everything to herself. A4 didn’t want added pressure, so she remained quiet about the experience. Sharing with her mother would have made the situation more difficult. She found people were judgmental of her weight gain induced by the medications.

At the beginning of treatment, her husband did two tests. He came to important appointments with her, but she had to ask him to participate the second time around. She made it known that she wanted him there. Now, the couple is experiencing relationship problems and considering separation. Infertility is a large factor in the couple’s relationship difficulties.

Through the experience, she gave herself strength “because no one can understand what you are going through.” She knows “not to expect too much from life.” People minimized her experience because she already had a son naturally. People always acted as though they knew what she needed, but what she needed was the brother her son kept asking for.

A4 shared her story because she wants to feel better and she encourages others experiencing infertility “to be strong.”

C6

The conversation began with a discussion of the current state of healthcare in Ireland. C6 said Ireland is one of two countries in the United Kingdom to provide no funding for infertility.

C6 and her husband were married for one year, and despite trying to conceive, nothing happened. They married first to keep with religious tradition. Historically, if a child was conceived before marriage, s/he was taken away. Members of the previous generations hold onto that.

After one year of trying, C6 was referred to a fertility clinic after her GP’s initial evaluation. She was thirty-two at the time. The consultant ordered more testing and gave her an injection to make sure ovulation was happening properly. Upon further evaluation, the clinician found endometriosis. C6 and her husband were advised to try again naturally for a year, but the couple felt that was too long to wait.

In January 2013, the couple changed clinics. The consultant recommended IVF due to low egg reserve. The cycle was tough because the clinician could access only one ovary for retrieval. Due to complications, C6 was not ready for the transfer, so the embryos had to be frozen. The treatment process was long and required the couple to change work schedules and reschedule their vacation.

The couple decided to go through a less invasive natural process at a different clinic, when the previous method did not work. The treatment required tracking the body. C6 realized that work related stress was interfering with her monthly cycle. The doctor was more present with this type of treatment. C6 and her husband tried the natural treatment method for more than a year. A specialist then found a septum that interfered with her uterus. C6 was surprised that it took so long to find the septum. The discovery in December 2014 provided hope. In August 2015, after no pregnancy, the couple stopped intervention.

C6 talked about her views of the medical community. The business nature of one of the clinics was clear, and their interaction with the doctor was limited. C6 said they always had to pay right away. “They didn’t explain things very well.” An additional difficulty was the clinic’s proximity to a maternity hospital. C6 found it was uncomfortable because women would have babies with them, which made their fertility issues more difficult. At times, the couple knew patients at one of the clinics.

C6 found friendships were hard with some. Some people just did not grasp what was going on. She did not always want to be in the presence of children. There were times she wanted to be with friends without children present. She felt like friends did not try to accommodate her in the situation she was going through. C6 didn’t feel as though friends really heard her because they were so occupied with their children on outings. Her friends disappointed her when they did not care for her. She had a feeling that she could not share fully because others would be bothered. “You go through life, and relationships change regardless of fertility issues or not.” She recognizes that friendships change and people grow.

Other people did not want to know the details of what was going on. Many doors were closed and topics were off the table in old Ireland and generations past. She said, “no one talks about it here.”

Her perspective has changed through this. C6 was so hopeful early on that she started purchasing baby items. C6 was very surprised at the negative result because she had so much hope. Now, she knows a cycle is not a one-time thing. It takes more than one try.

“If you found out you had cancer, you’re [going to] do something about it.” She recognizes the two issues are very different, but if you want children, seeking help is the next step. Her employers were understanding in the beginning but shifted throughout the experience. They expected her to go to appointments during non-working hours, but the clinic was closed then. She decided a job is temporary in a sense but family is permanent. Children will be there.

Infertility is “a tough process.” She encourages others to be happy with each other and be comfortable with each other.” C6 said, “Give it everything but know that your relationship will be alright if things don’t go according to your plan. Know that you tried but it was beyond your control. A lot of men find it very difficult to open up and talk about their feelings and this process and what it’s doing to them. When you get that negative test, it’s not just you that’s getting that negative test. It’s them as well… It’s geared all around the woman and people forget about the man in the process.”

Know that the process may be long. It may not be one try. “You have to be realistic.” Don’t feel pressured to go right into IVF even if the doctor is saying so. Research the topic. In her case, the septum made a difference and affected her outcomes. She recommends having fertility checked early on to know what the status is.

The topic lacks education. She read a book about reproduction and was told to ask questions if necessary as her form of education in school. People were taught that within the Catholic Church, talking about sex and reproduction were thought of as a sin. The emphasis is on prevention and “not embracing your femininity.”

The experience made them a stronger couple. “I think sometimes he knows me better than I know myself.” They relied on one another and two friends who were incredibly supportive. The couple has begun thinking about treatment again. Their outlook has changed now and they feel better prepared. They are waiting to pursue treatment in the spring of this year. The couple has looked at various options for treatment this time. They will seek treatment at a new clinic. They are excited to try again and have heard good things about the clinic they have chosen.

C7

When C7 and his wife, C6, consulted medical intervention, the GP sent them off as soon as testing was done. The pair started fertility treatment, and they were frustrated that clinicians took so long to identify the septum. C7 and C6 had hope once that was diagnosed.

As for interactions with the medical community, he didn’t have a good feeling in the first clinic. C7 just did not feel like the clinic meshed with them. Due to fertility clinics being businesses, it was evident that money is important. “It is a conveyor belt.” They were advised to have additional testing for the embryos to ensure the optimal ones were transferred, but that added to the cost. To him, treatment seems commercial. In the beginning, they were not told that it would be a series of treatments. C7 and C6 wanted to be more informed about the process from the medical community. He said to be sure to demand to be part of the treatment process. C7 wishes they would have discovered that the ovary was hiding before they went in for the retrieval. The inaccessible ovary diminished their chances greatly. Sometimes, medical professionals are good at what they do but lack the ability for good patient interaction. The clinic used previously was always busy, and C7 is hopeful for treatment at the next clinic.

C7 said tension was evident due to the unsteady nature of infertility. The couple only shared basic information with family because that is all the family wanted to know due to generational differences. He questions whether friends were true friends if they could not understand the situation. Friends tended to minimize issues. People would then apologize once they knew what was going on. He said, “You start to take things very personally because you think the whole world is getting pregnant purposely just to piss you off, but it’s the natural way of life.”

C7 said that it is okay to share because you do not know if others are going through the same situation. Some may just need validation. He believes infertility needs to be “more of an educational thing.” Government involvement would bring the topic to the table for discussion. Infertility is framed as a negative condition. He concluded with, "Don't take each other for granted." The couple has gained concern for one another in a new way. "Everyone's in this race to be what society tells us is what you should reach for," but many more things matter than what society says.

C10

C10 knew for a long time that she wanted a baby. That was part of her plan, and her husband supported her strong desire to become a biological mother. The discovery of reproductive problems was not part of her plan. She said, "All my life, it's been babies, babies, babies and having to wait this long is just killing me."

C10 began having painful menstrual cycles and back pain in her early teen years. Doctor after doctor did not seem concerned that she experienced horrible pain during that time of the month until a GP, who was filling in for her regular GP, said the pain she had was ovary related. Upon further investigation, C10 was diagnosed with ovarian cysts and endometriosis. She said, "why the others missed it, I don't know." The result of the laparoscopy was one functional ovary and the other ovary could not be repaired. C10 said,

> I was just so surprised. I had been assured up until then that it wasn't going to be a fertility issue. I could still have my babies. It could still be on the cards for us. I was very excited to get married. I was very excited to have children.

After the procedure, she was told to try getting pregnant naturally for another six months, but C10 did not want to waste any more time.

In December of 2016, C10 underwent her first cycle of IUI, which did not result in a pregnancy. She decided to take a break from fertility assistance after that and was planning to restart treatment sometime this year. After the termination of treatment, C10 and her husband continued to live a healthy lifestyle to maximize the chances of pregnancy. She continues to watch her diet, avoid sugar, and make sure that she does not have caffeine. Her husband wears boxers and tries to remember to carry his phone in his back pockets to avoid any interference with his reproductive region.

During the treatment process, the clinic and staff met her expectations. The staff was open with her and shared details of the process with her. The only negative part of treatment was when she was anesthetized by an anesthesiologist who was unfriendly. Some of C10's relationships changed as a result of her infertility because others don't "understand fully." Some friends were supportive while others could not grasp what she was going through. Some of her friends even had their own fertility checked due to her experience. Her mother wanted to become a grandmother badly, which added to the pressure to have a child. C10 said,

> Everyone just wants to cheer you up and say it will happen, but I found that very difficult. Saying it will happen doesn't mean it will. It's not as if I didn't get the car I wanted and now I have to get a different car. I cannot physically conceive a child, and I think until you're in a situation where you are thinking about or trying to have your own baby do you realize the loss. I mean, I was grieving.

Her husband was her source of strength. "He's very understanding, and he hates to see me upset, and he hates to see me in pain, and I hate to see him hate me upset." He supported her but also would have been supportive if she decided not to pursue treatment. She is the decision maker when it comes to addressing infertility. C10's husband calmed her when she needed to be, and she knows how important being surrounded by a good support system is now.

The inability to have children has changed her life. She said she is "unable to have fun as I did before." Sex is for the purpose of procreation and not for pleasure. C10 is trying to make sex enjoyable again. She is hopeful that she will have a baby, but she now understands that there is no guarantee that she will be given the opportunity to become a mother. C10 said, “I don’t want to be childless,” and she will return to treatment to achieve her goal because becoming a mother is her priority. If treatment does not work, she and her husband will begin pursuing the adoption process because it takes so much time to adopt in Ireland.

She was so surprised when she discovered reproductive problems and thinks the topic needs to be talked about because conception is not as easy to achieve as many believe. She said fertility is not as they teach in school. C10 said there is not a lot of time to wait, and those who want children need to know the realities of becoming a mother. The inability to have children should not cause shame. She said,

> There’s no experience to prepare you for this. There’s no point of reference. There’s just no rulebook or guidebook… I don’t feel like we should be ashamed of it…We didn’t choose it. It just happened to be the way things are and we’ve done what we can to have our family.

She said she knows now

> how much is working against you… It’s been my dream since a little girl. I thought I was doing all the right things, but this happened anyways. And I always thought when I’d see women who had no children or who had IVF, those poor women, thank God I’m not like that and here we are anyways… I’m one of those women.

A3

A3 met her husband at thirty-three and married at thirty-six. The couple tried right away to get pregnant for six to eight months. A medical evaluation uncovered diagnoses of underactive thyroid and a low sperm count. A3’s and her husband’s diagnoses led to a nine month wait for a fertility clinic consultation. That long wait was even expedited since they were a bit older. A laparoscopy identified endometriosis. When she woke up from the procedure in pain, she knew something was wrong. “I’m on a journey now and it’s not going to be easy.”

The couple began on the IVF journey. Ten eggs were collected for the first round of IVF. Unfortunately, an infection was detected, and the cycle was canceled. Next, they tried ICSI. Seventeen eggs were retrieved and nine fertilized. This attempt did not result in a pregnancy.

The doctor helped A3 remain hopeful. She experienced both positives and negatives with her doctors. One time, her husband should have been taking an antibiotic, but the staff missed it, and she was already preparing for the cycle. That time, they had to rush to make the cycle work. Her husband felt left out by the medical community. Everything was sent in her name, but financial correspondence was addressed to her husband. A3’s husband also felt embarrassed when giving a semen sample because the clinic did not handle it in a private manner and made him feel exposed. He was sent to a regular public bathroom for collection. Despite her husband’s desire to be part of the process, everything was focused on her. As for the nurses, “I found a lot of them sometimes through trying to be nice and helpful gave a lot of false hope.” She continued, “… You feel the one little isolated failure over here. It works for everyone else but not you.” A3 thought the doctors “are far removed.” One time her husband saw the doctor and embryologist in a negative conversation about them. A3 said sometimes she felt like she couldn’t ask everything that was going on from the doctors because the doctors determine what and when everything will be.

The environment at the hospital was not good for the situation. After her laparoscopy, she heard babies because they were in close proximity. A3 kept hearing new life and wanted to have what others had.

Relationships have been hard. A3 found that people in life say the wrong things at times, and they don't understand the pain Christmas can bring. The couple's loss of a baby right around Christmas makes the holiday difficult. She removes herself from situations when she cannot be around kids. "It hurts too much." She found that family does not always understand and has had friendships ruined through the process. Discussions of children tend to dominate conversation, and she feels friends have no concern for her situation. Of her loss of friendships, she said, "but you have to get through it because you're struggling with a bigger grief." She told her boss, but others at work did not know. She had to endure whatever was going on for long working hours. "People tried to be compassionate but said the wrong things. "People say the most bizarre and intimate things to you."

She believes she and her husband are strong people but found that the experience required lots of resilience. She said you give up everything: money, body, emotions. People must relinquish control and trust the professionals. The couple found strength within their relationship, knew they wanted the best for the other, and would protect each other. They never really knew what was causing their infertility. There was no blame.

The couple was not opposed to adoption but had trouble with thinking of surrogacy. The couple found surrogacy and the use of a donor hard to consider. A3 wanted the child to be her husband's. He wanted the same. She had trouble thinking of another woman's eggs with her husband's sperm. Her husband did not like the idea of another man's sperm with her eggs. They were told they might be too old for adoption, and she knew few children are given up for adoption in Ireland.

A3 is sad that others can have children so easily. When she sees her nephew, she thinks about the children she could have that would be the same age. A3 limits attendance at parties and events when menstruating every month because of her emotions. She avoids a particular store where lots of children are at her time of the month. She recalls buying for her nephew one time, and she started crying. A3 threw the clothes down and went to cry in the bathroom for maybe thirty minutes.

A3's faith helped her. She used meditation and prayer, and she found that her husband, mother, and sister helped her. One friend offered eggs, who had no kids of her own. She was completely surprised by the offer. People in general were difficult, gossiped, and had no true concern.

During the experience, A3 encountered complete ups and downs. She felt like she was holding her breath the whole time. She was told to relax but felt stressed. "You try everything and anything." It was constant waiting for appointments with little support and invasive procedures. She wondered how much heartache she could handle. Round after round of IVF meant being poked. A3 felt drained physically and emotionally. She recalls when she saw the embryos and thought how wonderful, but then A3 realized it didn't work. "I could still see the two of them on the screen." She had lost something so important in the toilet. Despite following a strict regimen and being healthy, she was given less than a one percent chance of having a child because the embryos "fragmented and died."

“You have to redefine your life.” “Infertility is like an ongoing daily grief.” There are thoughts of what a person should be doing with children. “I have nowhere to put this nurturing, caring, love that I have, and I really don’t know what to do with that.” She kept wondering why it didn’t happen. Could they have done something wrong? She wanted every part of parenthood. At one point, she had a feeling that if her life would have ended then, it would not have been terrible because she was in so much pain. A3 cried for hours with her husband after that. Any advice she had found she would try, including eating organic pineapple. She would have done whatever if they knew a baby was at the end. She could not sleep and was depressed at times. A3 remembers crying on the floor of her apartment because she was so troubled. “Nothing in my life has ever affected me as deeply and on an ongoing basis as this has.”

Her husband did not experience the process in the same way. A3 said infertility causes a divide between partners. Her husband saw her suffering and that hurt him. A3’s husband felt like he had to be the support through it all. Counseling was helpful for both of them.

She is a different person now. A3 felt more positive in the past. She has no advice for others because she knows how hard it is, but she is hopeful others will find ways to navigate the journey. She tries to find positive aspects of the experience but has so much trouble. A3 said those going through infertility should try not to blame and keep open with their partners. Be considerate. Avoid situations when feeling uneasy or unprepared.

She shared her thoughts on outside views of the experience and believes people do not understand. She said others should be careful about showing their children’s pictures or photos of ultrasound scans because those images affect others who may encounter infertility.

“It is too late for me,” but she wants to help others. If she can just help one, she wants to. A3 is happy that this is being addressed in Ireland but said money is not spent on research for women at the level it should be.

She concluded, “Every aspect of your life changes” when going through treatment, but others can get pregnant at home with their husbands. A3 finds it hard that she and her husband spent fifteen to 16,000 euro for their infertility. She recalled a visit to the hospital pharmacy, which was located at the maternity hospital, and being surrounded by pregnant women there for scans as she passed by. That upset her and made her wonder why she couldn’t get pregnant. “Will I ever get to sit here with a bump?” A3 said, “Your body is like you’re made to have kids. Made to carry children. Every month when you get your period, there’s a constant reminder that this is what your function is.” She feels like she will not accept this even as an old woman. “I think your future is haunted by it.” She will have no kids to carry her legacy. She and her husband’s story stops with them instead of children carrying it on.

A2

A2 got married in 2006, and after trying to get pregnant for two years, went to the doctor. She was 28-years old at the time. The GP seemed unconcerned. Her bloodwork was fine, and the semen analysis was just slightly abnormal. A2 tried medication with no result. Finally, a laparoscopy showed “you have wavy tubes.” At that point, she was prescribed Clomid for three more months. The doctor determined later that she had low ovarian reserve and her husband had low sperm motility, when the medication did not result in a pregnancy. When the couple consulted a fertility specialist and moved to IVF, A2 was terrified at the egg collection. The egg collection was horrible. Before pregnancy occurred, A2 and her husband had used all the money they had reserved for treatment. “IVF is such a financial headache.” The loss of her job a year before did not help the situation. “If you have money, you can do it, and if you don’t, you can’t.”

One visit, she asked the doctor whether smoking had an effect on pregnancy because her husband smoked, and the doctor said, “I am a smoker and I have four children.” A2 did not want to see the doctor again. She found the comment to be uncalled for and unsympathetic. She was angry. A2 tried counseling, acupuncture, and an alternative practitioner of shamanism. She started losing hope that it would work, but then her husband said maybe they should try again. She said it was “such a big thing to even think about trying again.”

The couple began treatment at a different clinic because they wanted to be comfortable with the doctor. A2 liked the new consultant. He said she had a twenty-one percent chance of pregnancy. The doctor said they would try, and if it didn’t work, they would try something else. The couple began a cycle for the third time, but it was the first at the new clinic. A2 was prescribed more medication that time around. Finally, she was pregnant.

A2 and her husband thought trying to conceive should be private, and it was not their own because they required medical intervention.

As for her interactions with the medical community, she was only able to be referred to a specified clinic determined by her GP in the beginning. A2 thought her GP was very open to options and supportive.

She said her family gave her strength through the experience, and her husband was great. Prayer helped her through in addition to her family's support. Her priest was also very helpful and supportive despite the Catholic Church's views on fertility intervention. A2's husband did not share about the experience with others but did eventually when she was ten weeks pregnant.

She said of her experience, "Unless you've gone through it you don't understand." One friend tried for six months and got pregnant, but she said she understood what A2 was going through. People on the outside do not understand. Through the process, she found that she couldn't be around women who were pregnant. "Nobody understood what I was going through." She experienced that lack of understanding for six years and wishes people would understand that pregnancy is not always easy.

A2 explained that the hardest part is "the not knowing." She continued, "The innocence is gone." Bad things do happen. "It's not like anything else you'll go through. You just can't explain it."

When asked if she would seek treatment again, A2 said she would and has. "In fact, he's [her son] so worth it that we did it again, and I'm now almost seven weeks pregnant with number two!"

A5

Eighteen months after coming off the pill, A5 wondered why she was not getting pregnant. She went to her GP and started tracking menses and ovulation for a few months. When pregnancy still did not happen, she found out that she had one blocked fallopian tube. A5 went to a specialist to have the tube cleared and found out she had endometriosis. She returned a year later to figure out her options. The consultant recommended IVF, but A5 wanted to try IUI first. Three IUI cycles did not work. She moved on to have three ICSI cycles. Some eggs fertilized but she did not get pregnant. The doctor told her to give it time and come back if needed. The experience was minimized by the clinic telling her that a pregnancy would make the couple think nothing of what they had gone through. The consultant recommended one more round but told A5 that the chances of pregnancy were low. The couple stopped treatment at that point.

The clinic staff did well at their actual job description but failed to provide adequate follow up after cycles did not result in pregnancy. There were no support services other than counseling at the beginning of treatment. She found it was awkward to meet patients you know in the clinic. Patients with devastating news were just sent to the waiting room with everyone else. “They need to start thinking about people a bit.” A5’s outlook on the clinic setting is negative due to her results. “It’s a money-making racket” and not patient focused. She believes the clinic’s reduced rate for purchasing multiple cycles is to improve statistics. She feels the medical professionals perpetuated false hope. They always talked about the baby she would have. “They’re a business.” She told the clinic she needed to think about their options but never heard from the clinic after she said that and found it to be a “disappointing service.” She said she would never go back.

A5 said it’s a burden to have to pay for treatment in Ireland unlike the National Health Service in the UK, but she found ways to have treatment covered. She had coverage for services related but only those that were not actual fertility treatments. A5 thinks the government needs to address the issue, but politicians tend to avoid the topic.

A5 found support in various forms. Her sister tried to help by suggesting a fertility show where clinics and new procedures were displayed. Her friends were all pregnant and having babies. They tried to support her but couldn’t grasp what she was going through. The best support she received was from her reflexologist. The appointments were a fraction of fertility clinic prices, and she was an active part of treatment unlike her experience at the fertility clinic. The reflexologist gave her more follow up than the clinic. She also went to an alternative practitioner and counseling.

A5 found others judged her. She handled that by mentioning her situation first. “Every month I had to deliver the bad news.” She could not stop thinking about it.

Pregnancy occurred naturally within six months after treatment ended. She started realizing her period was late in the car one day. A week later, she took a test and it was positive. A5 believes it was a combination of things.

“It still baffles me how teenage pregnancy occurs.” The number of pregnancies is crazy. Her understanding of reproduction has improved through the process. No one could give her what she wanted, but everyone else can move on. She found it to be a continuous pressure. “There needs to be education” because infertility affects a lot of people, but young people are not educated. Schools should address the issue and educate on available options. She believes people need to help individuals through the journey because the road is lonely and isolating. The inability to have children raises questions of fulfilling the female role. A5 says until it is discussed, nothing will change.

C1

C1 began trying to get pregnant in June 2011 and had her first miscarriage in July 2011. At first, she just thought it was bad luck but experienced another miscarriage in October. C1 went to her GP in January 2012 and received a referral to a fertility clinic. She had another miscarriage in May 2012, but her doctor advised her to try more. C1 was upset at that point. She wanted the doctor to say more than that, but the doctor did not seem concerned. He didn't consider looking at something else. He thought providing the patient with care and attention was more important than aggressive treatment. C1 felt she did not have control over her body or situation and sought out communication with an online community familiar with the experience.

C1 saw a second consultant and had more testing. The second consultant found a septum that came through the center of her uterus and removed it. She began taking a stronger blood thinner than the aspirin she had been prescribed previously and had another miscarriage. She was sent to a consultant who specialized in a certain type of testing. The issue seemed to be hers for the first two years. Then, her husband became more involved in treatment. The doctor concluded that the embryos were abnormal due to her husband's sperm. IVF was recommended to select ideal sperm. She found treatment in "Ireland is just so expensive," and some clinics are not as advanced.

C1 went to Prague in May 2013. The consultant recommended chromosomal testing to check embryos. Three eggs were collected on the first IVF cycle, resulting in one embryo. Testing confirmed the embryo was not viable. C1 felt devastated after that because she thought IVF would work. She felt very hopeful before beginning the cycle. A second round began three months later. This time, there were three embryos. One was normal and implanted in December 2013. A blood test on St. Stephen’s Day revealed she was not pregnant. C1 was very hopeful that IVF would be the solution because she was getting pregnant on her own before but was unable to sustain the pregnancy. Eventually, she took time away from work because the experience was overwhelming. C1 had hope and looked for solutions after each miscarriage, but after IVF did not conclude with a pregnancy, she could not be hopeful.

The couple struggled in 2013. They felt out of sync with each other. Her husband saw her going through one sad time after another and didn’t want to see her hurt. “It was taking me away from him.” She also had difficulty separating what was going on with work and thought it was hard to act as though all was alright. The couple decided to take a break from treatment.

When treatment resumed, the egg collection concluded with three viable embryos. The doctor transferred two, and she miscarried once again. C1 started to think it might not work, and she did not experience that thought before. She could not let herself think that motherhood might not happen. C1 said, “The emotional toll of IVF…it’s huge. The drugs, the regime, the trying to manage a cycle, and carry on with your life, be in work, and manage time off.” She saw a consultant locally. He sent results to Prague. C1, and when necessary, her husband traveled to Prague, which was undetermined in advance due to the vulnerability of each cycle. C1 would go back home after a collection and wait until test results were reported. The process was emotionally and financially draining.

After she did not get pregnant with IVF, she decided to take a more natural route, where she monitored her body and intercourse. The doctor focused on diet, different tests, and ovulation medications. She tracked ovulation, and the treatment suggested when to have sex to become pregnant. C1 tried this approach for five months. The consultant checked her follicles once per month, and despite being more holistic, the treatment still seemed very medical. The sexual spontaneity was gone.

C1 went from getting pregnant to not getting pregnant. That change created stress, and she started to think and talk about the future. She knew she would want to change careers if she could not have a child. She lived in a constant stage of grief due to the situation and environment. C1 grieved for her babies and the uncertain future. “But, we were also grieving. Grieving the loss of the babies that we did lose. Or, potentially grieving the loss of a future that we hoped to have that we don’t know if we’re [going to] have anymore.” She saw parenthood as a part of life with her husband. Thoughts entered her mind about moving away, becoming a dog groomer, and having animals. She felt like she would always have the burden if she could not become a mother. Therefore, life would need to change.

The couple tried another consultant, and C1 had her immune system evaluated. The doctor identified a high immune response that attacks progesterone. She began taking HCG, steroids, and intralipids to help sustain pregnancy. Her initial visit with the new consultant occurred in January 2015. The tests went to the U.S. and took a month for results. This time, the testing included her husband. The testing required medication to build the endometrial lining, which was much like the preparation for an IVF cycle. C1 took ovulation stimulation drugs and timed sex. While prepping for that, her period was late. The acupuncturist told her to take a pregnancy test, but she didn’t think she could be pregnant. C1 took a test a week later and found out she was pregnant. The consultant had her take lots of medications to sustain pregnancy until week twelve. She was very nervous about what might happen. Cramping at six weeks frightened her. To protect the pregnancy, she took more time off work. The GP gave her time off until week twelve. She became more hopeful after week twelve and had her baby in February 2016.

C1’s experiences with medical professionals differed throughout the process. In total, she saw seven consultants. They varied from conventional to more out of the box. Some were kind and considerate. Most had some level of compassion. She always felt like she was a number. They understood her infertility experience to a degree, but she always knew she was allowed only a certain amount of time.

C1 found strength in an online community of women. Through the experience, she met two supportive people online. “You can literally pour your heart out” because it is private. She went to counseling also, and her husband went with her for relationship counseling. She decided that men cannot grasp the situation in the same way because they don’t have it happen to their bodies and are not required to take medications.

The experience isolated her from friends. She felt left out and avoided some events. C1 lost one friend because she could not understand the situation. She could no longer be in her group of seven friends because they were all mothers. In time, the friends reconnected and realized what C1 had been through. She has repaired her other friendship somewhat. Some friendships strengthened because of the situation. She said it seems like a person may get to watch the game but does not know if she will get to be in the game.

She told her employer what she thought they needed to know so they would not start to wonder what was going on. One supervisor knew the details of her situation more than others.

Today, C1 focuses on the importance of self-care and is mindful of her needs. She knows when she needs alone time. She is a bit anxious about life and worries about her son. She is more aware or sensitive to potential danger because she is scared that what she has could be taken. She and her husband give their son so much love because they had to go through so much to get him.

"It is a grieving process." Whether she was not getting pregnant or miscarrying. "You just don't feel that you have any control over your life or your body." Shame and stigma accompany it. "I'd like it to be more talked about." She continued, "It's grief but it's a specific grief." You have a "feeling like you're left behind" and are fearful it may not happen. "I just felt like it was failing me," and she started to resent her body.

She said one must figure out how to change life to cope. "Everything was on hold." Treatment was her first priority. "It really does become your life."

She wants people to better understand the experience. For those who encounter infertility, "It's one of the most difficult things you're ever [going to] go through, and you can't do it alone." Try to understand what is going on and have some level of control. "Arm yourself with information.

C2

C2 and her husband married in 2008. Concerns about pregnancy began in 2009. The GP referred her to a gynecologist. Blood tests were fine, but a dye test showed a blocked tube. C2 received a referral to a fertility clinic, where the consultant determined that her FSH level was high. She was perimenopausal. She took the news moderately well because her sister had been diagnosed with premature menopause as well. C2's other sister had fertility trouble too.

She began her first IVF cycle in January 2010. The clinic transferred the cycle to IUI because only one follicle had developed. Three rounds of IVF later, and C2 was not pregnant. Her eggs always looked good. She was advised about donor eggs but asked to have a laparoscopy first. The doctor mentioned that she might have seen something. C2 had a procedure to seal one tube up, and she became pregnant two months later. She experienced the absence of menstruation for one year due to nursing and found she was pregnant again. The reason for infertility had to be her tube. Now, she has a boy and a girl.

C2 found support through the internet and her drive to make a pregnancy happen. If someone would not have mentioned a leaky tube online, she would have never pushed to have a more thorough investigation. "There's not a shred of doubt in my mind that if I had not been proactive, I wouldn't have gotten pregnant." She acknowledges that there are so many unknowns.

C2 recalled her interactions with medical professionals. The GP and gynecologist were fine. The fertility clinic nurses were positive but the doctors were very to the point. She said,

> You’re probably never in your life more vulnerable than you are dealing with infertility. You’ve got two people and a marriage… It’s core to your entire human being to reproduce. Whether or not you know it or you don’t, there is something internal that has this push, and you are extremely vulnerable, and I feel they can’t be nice enough to you.

Some medical professionals seemed disengaged. The level of empathy was not what it should be for the situation. She discovered patients in the clinic avoiding eye contact, but the proximity of the clinic was helpful because treatment requires so many visits. Due to the close proximity, treatment interfered with work minimally.

C2’s immediate family knew about the fertility issues, but her husband’s family did not. They shared with her husband’s family after the process because they did not want to have too much concern and involvement. No one asked either. She thinks people would have assumed something was wrong without being told. In her mother’s time, you came back from the honeymoon pregnant, so others would have made assumptions.

The couple supported one another. There was no blame but only support. Her husband focused on the scientific component and success rates. He was the encourager when she needed it. They each paid half of all expenses. They were never out of sync. Both checked medications in the beginning, but then she took over. The medication process seemed long because she had to poke her tummy for months. The trigger shot right before the retrieval was scary, so C2’s husband helped with that. The experience requires involvement from both partners. “It’s physically demanding, it’s mentally demanding, it’s emotionally demanding, and it’s financially demanding, so I don’t know how you do it without both of you jumping in together.”

The couple had help from their family. While the couple had friends going through infertility, they found the interactions were difficult because different friends were at different points in the process. The friends did not experience happiness and sadness at the same times.

C2 said she felt that she could not discuss her infertility because the experience is so painful and private. Friends who haven't been through it do not understand how those with infertility feel. Life and interactions are different after kids. C2 felt a natural separation between those with and without children.

Her expectations were not high because of her diagnosis. No matter how many eggs the clinic retrieved, she was always happy. "I thought I'd won the lottery when I heard I had three mature fertilized eggs and was just euphoric with joy." She even thought maybe she would have twins because she was so hopeful. There were shifts between happiness and worry. There was worry about whether they would grow. Then, when they were inserted, she felt great again, but that turned to worry a day or two later. The concern continued when she didn't feel any noticeable changes a week in. She would have done anything for treatment to work. "I would have danced naked in the moon." She continued, "As a woman, I felt like I couldn't do what I'm here to do, and that was a horrible feeling." Men also experience that feeling.

C2 thinks the experience is so widespread but not addressed. The private nature is unfair. Lots of people want children but do not have the financial means. Two to three attempts are all a person can take financially and emotionally. The clinic statistics are not accurate because people cannot always pursue treatment until they have a baby. She said the language used makes a person feel worse about the situation. "You're thirty-five and a geriatric mother. I should have had a cane."

During her pregnancy, she kept a reminder in her wallet that said, “Most pregnancies are successful” and looked at it maybe ten times every day. The morning sickness at seven to eight weeks reassured her that it was okay. A scan at nine weeks launched her into a period of enjoyment. When the morning sickness stopped, kicks started at fourteen to fifteen weeks. C2 experienced no problems with either baby and said her issue was to get pregnant. She found she was sad after pregnancy because she liked the feeling. During pregnancy, she was a mama, but the baby was with her and she could carry on. C2 was excited about the other side but knew it would be work.

Through the experience, she discovered what is important and what matters. She discovered resilience, inner strength, and hope. The journey may have made her a more empathetic person. C2 is grateful and feels she has become a better, more developed person. The unpleasantness of the experience made her even more grateful.

C4

C4 and her husband tried for a year to conceive with no result. She went to the doctor, was prescribed thyroid medications, and lost weight. Then, she got pregnant but lost the baby. C4 and her husband took a three month break and then tried for another three months, which resulted in another pregnancy. She miscarried her second baby. C4 had a medical investigation due to having two spontaneous abortions. At that point, she was diagnosed with a blood clotting issue and experienced a third miscarriage. The couple tried for six more months but nothing happened. More testing determined that her AMH level, an indicator of egg reserve, was low. She saw a fertility specialist in July and began her first cycle in September. C4 got pregnant through one cycle of IVF.

During C4’s treatment, the consultant was to the point and aware of his success with fertility intervention. C4 saw the physician once but then worked with the rest of the staff. She was told to forgo IUI because if it did not work, she would be upset that she did not go directly to IVF. During the round of IVF, four eggs were collected and three matured. She said, “Oh my god, I just want these back in me before anything happens in the next two days.” Two embryos were in good condition on day five. The two were transferred and she became pregnant with twins.

The path to pregnancy was not easy. She never thought anything was wrong because she was able to get pregnant. During the cycle, she hoped each day that the embryos were okay. Initially, the doctor wanted to transfer two embryos but “the people who were dealing with me at the end were kind of almost surprised that I was getting two back in. I don’t know. It was strange as if the message hadn’t got through to them or something. There was a little disconnect there.” The embryologist supported the doctor’s recommendation and agreed on two.

C4’s husband was supportive and involved throughout the experience, but “it does feel like everything is on the woman. You’re the one injecting yourself. All that kind of stuff and there’s very little he can do.” She shared details of the process with family. Her mother was not as supportive as she anticipated. C4 thought her mother would understand because she also waited until later to have children. One friend could not grasp what C4 was going through, which affected the friendship. She had a counselor from the time of her miscarriages, who continued to help through IVF

C4 now knows what to expect the next time. She found the process to be hard and wishes more thorough testing would have been done before she experienced three miscarriages. She worries how many other women go through the situation because doctors do not complete thorough investigations initially. C4 thinks AMH levels should be checked on a more routine basis, and clinicians should not wait to conduct the test so far into the process. Additionally, counseling should be more readily accessible and advertised to patients.

C4 suggests women should seek medical help sooner even though they are told to try to get pregnant for a year first. “Time’s not necessarily on your side even if you’re younger than thirty-five.” She advises women to trust their own instincts and consult resources.

C5

C5 knew years ago that she wanted a family. She wanted children to be part of the equation regardless of her relationship status. C5 knew the adoption process in Ireland is difficult. Fostering could not happen because she would be an only parent and needs to work. C5 would not be home enough to qualify for foster care. She recognizes that she may have waited a long time but desired to try the biological route first.

When she sought fertility assistance, C5 was diagnosed with infertility issues that would have prohibited a natural pregnancy. She was diagnosed with polycystic ovary syndrome (PCOS). She advocated for herself and thinks she may have consulted care sooner because of her unique situation. C5 said treatment takes times, and testing takes time. She waited to start treatment for five months after testing, procedures, and counseling. For people who do not have time to take away from work, the process is hard.

The wait between the retrieval and transfer was horrible. C5 awaited morning calls from the embryologist. Then, she transitioned from receiving daily clinic updates to waiting for the pregnancy test after the embryo insertion. C5 always watched for her period to come to determine if she was pregnant. She found women become much more aware of the menstrual cycle when going through infertility. Undergoing more cycles of IVF creates a more realistic view. A frozen cycle requires the woman to prepare as normal for IVF, but she will not know if the embryos are alive and ready for transfer until that morning. If the embryos do not survive the defrosting process, the cycle is canceled. C5 found that the call during a frozen cycle was the hardest. To add to the level of anxiety, the clinic waiting room was always full when she was there. “The room is packed with couples.”

She worried about finances running out before she could get pregnant. Due to her friends’ great kindness, C5 was able to afford a round of IVF all because she told her story. A letter came saying the friends wanted to help. The first cycle did not work, but she was able to afford another round of IVF because of their generosity. She views the first IVF cycles as an experiment to determine appropriate treatment. “Finance is such a major issue in Ireland to do any of this.” She may have only been able to afford one cycle, but now she has her son because of kindness.

C5’s labor was difficult, and she experienced depression after her son’s birth. Her parents helped her with the new baby, but she did much of the work alone. Now, she feels more prepared for her second child.

C5 feared that she could not have children. She had “fear that it was never going to happen. That I was going to have to actually walk away from that chapter in my life.” She feared others’ judgment once pregnant.

Many of her friends have experienced infertility. That has brought them all closer together. C5’s father had a hard time with her decision. He worried that the community would wonder and question what had happened. At first, there was lots of chatter, but what she thought would be negative gossip turned out to be good. People approached her and told her that they wish they would have taken the path she had chosen. C5 acted as a voice for women who would want to do the same thing. In time, her father embraced the situation and has a close relationship with his grandchild.

After the birth of her son, a nurse followed up with C5 by visiting her home. The close following created more anxiety. The public health nurse assesses everything. Her visits are quite spontaneous, and the nurse will follow C5’s son until the age of two. Public health nurses have great power and can have children put into foster care if living situations are inadequate.

She knows now that she is strong because she has chosen to be a single mother. She is a determined person. C5 is sensitive to her needs for alone time and has an excellent sitter for when she needs an hour or two away.

“It is definitely not easy to get pregnant… Information isn’t widely out there… I think a lot of women are absolutely oblivious to fertility and infertility issues.” She teaches sex education to children and she makes sure she talks to them about fertility in their 20s. “We need to start educating our teenagers about fertility and fertility issues and talking about things like PCOS, and talking about things like endometriosis, and even things like fibroids… This is stuff we need to talk about."

C5 is a more empathetic person now. "My priorities changed." She modified her lifestyle to fit her desire for motherhood and is excited to see her children understand their special story. "This is a very wanted child. It is a very planned child. It just doesn't come out of luck. This is a very wanted child and therefore shouldn't every wanted child be encouraged."

C8

C8 and her husband got married and took time to travel before they began trying to conceive at the age of thirty. They discovered pregnancy was not happening on their own. At first, doctors made them feel as though they were not overly concerned, but nothing happened when they continued trying. The couple was advised to try IUI and had no result with two cycles of treatment. When they moved to IVF, three low grade embryos were retrieved. Two were transferred. The couple went for a second round of IVF, but no embryos survived for transfer. The doctor said continuing IVF would only be a good idea if donor eggs were used. C8 said, "The whole world came crashing down" between the call that the embryos had not survived and the next appointment.

C8 and her husband consulted a second clinic at age thirty-three. They felt as if they had started all over again and were frustrated at the fact that science is inexact. C8 began taking the supplement DHEA and used immunotherapy. The next round of treatment improved.

C8 talked about the constant waiting and clinic phone calls. She said the wait is better than the phone calls. The first call is the most difficult because that is when the embryologist tells patients the status of the embryos. The call was terrible. “You’re constantly thinking about numbers.”

One round, only two embryos continued growing after starting with double digits. The clinic defrosted one additional embryo from a previous cycle, but only the two survived. That cycle did not end in pregnancy, but they felt hopeful after that because the embryos made it to day five. The last cycle was very difficult. The process was delayed due to abnormal hormone levels and the discovery of a cyst. Finally, seven months of delays later, the transfer was completed and C8 became pregnant.

C8 talked about her experience with the medical community. She said one of the consultants was not very patient oriented. The second clinic was upfront about recommendations due to their history. The couple found one particular aspect of the fertility clinic troubling. The room used for retrievals and transfers was divided merely by curtains. Anyone in the room could hear everything anyone else said, including news delivered by the embryologist. When C8 was in recovery after a procedure, the couple found the lack of privacy somewhat difficult.

C8 and her husband have gotten closer with their family. She was very open with her family. She remembers one situation after a round of IVF at the second clinic. A faint positive result turned negative by the next morning. C8 shared the news with her sister the evening it happened, who then shared the story with their mother instead of allowing C8 to discuss the event with her mother. In the beginning, she expected to become closer to her sister but found that did not happen.

C8 and her husband believe they have a better relationship now. They were always worried about getting distanced from one another, so they focused on staying close to one another. They were on the same page throughout the experience and did not have a time when they had difficulty with one another. They thought that being on the same page helped. C8 recalled one particularly difficult time when she had an ectopic pregnancy from an IVF round and then miscarried. Her husband was very focused on her at that time. She was quite depressed for a while, and he gave her strength even though he was devastated as well. She wanted him to be able to grieve. “There’s a certain amount of exclusion of the man other than he has one job to do. He needs to come in on that one particular day.” The pair grew closer through each stage of the process. They found more resilience along the way. C8’s husband gave her a meaningful gift while experiencing infertility. The inscription reads, “When it rains, look for rainbows; when it’s dark, look for stars.” She found that to be so appropriate.

C8 feels as though she aged through the process. “It is almost like your life is on hold to a certain extent until you know the final outcome.” She talked about an occasion when she was at the bank. The banker was quite inquisitive about the need for a cash withdrawal and asked what the money was for. When she explained, the banker said he was going through the same thing. That interaction helped her see how widespread infertility is.

She believes that success changes the outlook. If a cycle fails, people have pity, and there is a tendency to be less open. Sometimes, there are feelings of jealousy toward those who have kids. She avoids the subject if she knows someone has gotten married and has yet to have children because she worries about how her response will be received.

C8 recognizes that “every IVF story is different, and you can never compare your own to somebody else’s.” Everyone’s approaches are different. She would have found a way to move on. Although she felt that something had to be wrong with her, she did not blame herself, and her husband never blamed her. The failures they experienced feel like losses because each attempt at pregnancy involved parts of each of them.

C9

C9 and C8 were told that they had time to conceive. The doctor initially said to relax and then said it would be unlikely to have children. The perspective changed so quickly about what they should do. Financially, they could pursue multiple attempts at IUI and IVF, but they feel bad for those who do not have the financial means.

C9 talked about the medical experience. When a round ended with a negative result, the doctor gave them no hope to try again. The second consultant was straight forward but knew the power of what he said. He had empathy for his patients. The second clinic was more accommodating. The first clinic only focused on science. “You felt very powerless. You didn’t feel you had any control. Whereas at the second clinic, you felt really part of it. You felt you were trying your best as well.”

C9 elaborated on the recovery room. Five to six women were in recovery together with dividing curtains. Everything was audible to others. That horrified them. “It’s such a private thing, and I think because it’s run so much by I suppose big companies here, they’re pushing as many clients through as they possibly can because they’re making money.” He said the clinic pushed add on services. Additionally, C9 and C8 thought the process of calling names in the waiting room was too revealing. There was a visible transformation in care when the second clinic began to grow and staff changed. The quality changed over time. The staff began making errors in medication and cycle dates. He said although they tried to forget about money, it still matters in the process. C9 thinks that because people are in such dire need, clinics will never have trouble recruiting. He emphasized the need to make sure people mesh with the clinic and feel comfortable. Asking questions and raising concerns are important. “It was like a whole new experience really when we had people who were listening properly.”

He explained some of his views on the treatment process. “You would do anything to distract yourself” when waiting for calls from the clinic. “The two-week wait is pretty horrific as well. It seems to go on for like six months.” He worried that they may have made mistakes in his wife’s medications that they were responsible for administering at home. C9, despite his fear of needles, did what he needed to do when C8 needed an injection. He felt they had a lot of responsibility. As for how the clinic treated him throughout the process, “I never felt completely excluded.” He felt the importance to involve himself in the treatment.

C9 discovered that lots of their friends were also going through infertility. He is amazed at how many people are affected by this. He talked a bit more about interactions with others and said comments others made were hurtful. One time a comment was made about concern for whether he might leave his wife due to the issue. People don’t understand that the words they say can be devastating.

C9 and C8 hid the situation from his family in the beginning. They did not know for years. Then, the couple had a sense of guilt and worried what his family was thinking. They explained what was going on. His mother was not open about discussing IVF but accepting. The family has a sense of gratitude for the baby because they have tried so hard for the life that has been created.

C9 wanted a child so much for his wife. He wanted it too but twice as much for her. He was worried that one of them would have been the cause and is grateful that they were both involved. C9 was concerned that identifying a cause would affect their relationship somehow. They found strength in one another and their friends. They were determined. C9 felt divided because he saw her hurting but he also knew that if she could not do it again, it ended there. He thought, “I hope she can go through it again because if she doesn’t, we have to call it.”

Infertility affected their lives in a number of ways. Their love for travel stopped. Finances took over. “It’s there in the back of your mind all the time, and if it’s not there, the saving up for it is there and the putting money aside and all that.” Infertility “does pause things quite a bit.” He feels like part of life was stolen during that time. “I think it’s only recently the relief has really kicked in because again you’re still not sure…but you get safer and safer along the pregnancy.” The feeling of extreme concern was present until his wife reached the twenty-eighth week of pregnancy. They always wondered what might go wrong. C9 said his wife’s pregnancy has changed his outlook on the experience. “It’s like somebody has washed away six years of awfulness.” The time is not gone, but there is relief.

The United States

B1

B1 began trying to conceive at the age of twenty-nine. After she did not get pregnant for some time, the doctor sent her to a specialist. Eventually, she had a total of nine rounds of artificial insemination. “I was not thrilled” about the initial evaluation. She felt the doctor did not fully understand. The clinicians were not sensitive to the experience. The doctor B1 consulted “did not inspire trust.” Different medical residents conducted each artificial insemination, which added to the stress of treatment. “You never knew who was [going to] be doing the insemination. I never really trusted these residents. You know like you’re putting this stuff into me and how do I know it’s really my husband’s.” B1’s and her husband’s work schedules did not permit them to go to treatment together. He would go for his part, which was embarrassing, and she went on her own to do her part. Insurance did not pay for any of the procedures. After the experience with the clinic, she knew she could not go through treatment again. She remembers that her teenage neighbor became pregnant at the same time she was undergoing treatment and she thought how unfair for her neighbor to be able to have a child so easily.

B1 said there is lots of insensitivity about infertility. Others thought she was focusing on her career and not trying for a family. Instead, she was. Older men would ask unwanted and inappropriate questions about starting a family. A man asked one time if she was a “modern woman.” Her friends already had kids. The church community was not always understanding. She did not have a community who had gone through the experience.

B1 did not discuss her infertility with her parents, but her sisters knew. One sister got pregnant with her second child and complained about it taking six months. “You’re pregnant and I’m not… As far as friends, I don’t think I shared enough.” B1’s mother supported her quietly. She had a friend at work at the time who was also going through the experience but with more medication. She felt fortunate to be in a working community where three of her five coworkers had infertility. The common experience created job flexibility and understanding.

B1 eventually became pregnant naturally and had a safe pregnancy. She was thirty-four at the time. She worried that something would go wrong and thinks the infertility experience created that concern. She remembers being told a percentage of pregnancies end in miscarriage. After her first son was born, she got pregnant again but lost the baby at five weeks. After that, B1 and her husband went on to adopt a second child.

She said adoption is difficult too. Both fertility treatment and the adoption process are invasive. It’s “not the way you want to deal with sexuality… I can’t even relate it to sexuality. It’s not sexual… [B]aring your body and with adoption you’re baring your soul.” Life is invaded. No one asked her neighbor if she was fit to be a parent. “Both processes are very humbling.” Tons of documents and money are involved in both processes. “I don’t know how people who don’t have an education do it.” Once her adopted child was in the home, the couple was followed rather intensely for six months. The social worker explained she was there only to help the new parents succeed with the child, but B1 found the time to be very stressful. The actual adoption took a year.

B1’s husband felt done after their first son was born. “He likes to kid around and say that his sperm got so upset after he found out the cost of adoption that they got to work.” He worried because she was upset about the process. There was friction in the relationship, but he was supportive. Their relationship has changed. “You have to “rediscover each other.” Her husband was content with just her but she wanted a baby.

B1 said there are positive and negative aspects of experiencing infertility in the United States. “We do something about it.” She thinks about her family members before her who could not have children and just accepted childlessness at that time. She addressed the burdens of seeking medical assistance in the U.S. and the fact that fertility treatment is commercialized. Insurance covered nothing for her. “Our healthcare system is very fragmented. It’s geared toward people who have money.” Every time she had artificial insemination, she paid $400, and that was some years ago. The couple did as much as they could financially. Overall, she said she would not seek assistance now, even if insurance covered treatment.

She “learned a lot about loss. There was grieving involved in that. You think life is [going to] be exactly as you plan it and there are some people who have life go exactly as they plan it. And, I was angry at those people. Because for me, life did not go exactly as I planned it. In fact, it was very far from how I planned it.”

B2

B2 was in her early twenties and married for two years when she decided to stop taking birth control. After one year of attempts at pregnancy, she began to worry. She saw her physician and there was no diagnosable reason she could not get pregnant other than she was pre-pre-menopausal. She tried another year with no pregnancy and finally received a referral to a fertility specialist. The specialist thought the cause was most likely diabetes related or vascular. Her fallopian tubes were evaluated, and no abnormalities were found. The doctor recommended IUI. The second cycle of IUI resulted in pregnancy. Her pregnancy went well. However, nearly three years have passed, and she has not been able to conceive once again. She and her husband are in the planning stages of going for fertility treatment again.

During her experience, B2's fertility specialist was great and "easy to talk to." The consulting gynecologist was more direct and distant, but that worked for her because she works in healthcare. She did find some aspects of treatment difficult. "You're trusting someone else to be giving you the appropriate specimen and to hope they didn't screw it up or mislabel something." There was concern whether things would be alright since they did not do things the normal way, and she and her husband worried that they were interfering with the natural process.

The first time B2 sought treatment, some of her medications were covered. This time will be more expensive and different. She said it's a lot of money to commit. She started switching shifts at work to enable treatment and spent a lot of time driving or going for appointments. "You have to be able to move your schedule around" because the process is time consuming. She recalls an occasion when she was much longer than expected at the clinic due to a staff miscommunication and didn't have someone to cover, but she was able to get back to work quickly when the mistake was discovered.

B2's family has been supportive. Her mother was nervous for her daughter due to her diabetes, and her husband was completely agreeable to treatment. His family only knew basic details of the situation. B2 shared different amounts with different people.

Her husband encountered some frustration though the experience. “He just wanted it to be natural.” He knew the baby would be his but wanted it to be through the normal process. He was upset by the inability to conceive without assistance. The picture turned out differently than anticipated. They were not fully themselves through the process, but they leaned on one another because it was hard. Her husband supported her decision for treatment and endured the process.

Before the experience with infertility, B2 always knew she wanted children and started worrying that she would not have that. The doctor gave her hope because he was optimistic. If she could not conceive, adoption would have been an option. She tried to stay positive and did not worry about what might or might not occur. She learned patience and the importance of eating well.

She cautions others not to take for granted the ability for childbearing. “It seems so natural and so easy for people,” but “it’s actually crazy to me that some people so easily do become pregnant… That leads to frustration too.” She knows how easy the process is for some. “They stress prevention, so then you start preventing, and through that, have I done something because I’ve been preventing? Is it because of taking medication to not for so many years? You sit and wonder, did I do something by doing the prevention?” Pregnancy didn’t happen for her like people said it would.

B2 said when a person tries to get pregnant, so many other people are getting pregnant. Finding someone to share with is important. “Surrounding yourself with people that have positive thoughts and can have the understanding…of what you’re going through is helpful.”

“It’s a wonderful process if it works, and I know that sometimes it doesn’t, but I hope that there truly is a God’s plan for those that are unable to successfully have that special child in their life.”

B3

B3 got married in 2009. She never knew she would have trouble with pregnancy but wondered. She knew “we wanted to have a big family.” The couple tried to conceive, but tests were negative time after time. The gynecologist prescribed fertility medications for a year before she was sent for a consultation with a fertility specialist. She and her husband were “both tested; I got the brunt of it.” She started with injections. The doctor determined she had a hormone imbalance. “When you go through the testing, and everything you put your body through so much, and that alone was emotional just because month after month it’s like a loss that you’re experiencing.” After a round of IUI, she had her first pregnancy in 2011, but the doctor discovered there was no heartbeat. She continued with an additional three to four rounds of IUI before getting pregnant with twins. Another round of IUI concluded with her becoming pregnant with a boy. The twins and baby boy did not survive. The number of years it took to get to that point was so disappointing.

B3 said, “It’s kind of like God led us down a path.” They began fostering two children: a boy and a girl, whom they have today. The kids relieved some of the stress by the house being full. “We basically put it in God’s hands.” Two months after the foster children began living with the couple, she became pregnant naturally. Their baby girl is ten months old.

She and her husband’s health insurance covered treatment before their son but did not cover after, so they had to pay for that pregnancy. Each cycle of IUI costs $350. “That stuff adds up quick.” Insurance also covered a large portion of the medication. She said how important it is to find out how much treatment costs and what insurance covers. IVF was not an option for B3 and her husband, and she knows some people take out retirement money to fund fertility treatment. When the insurance stopped, she was very upset. “This is our dream and I feel like it’s being limited because of insurance. And I don’t like the feeling of being held back, and that was holding us back, and you know when you have a dream, you want to do anything you can to succeed at that.”

Their employers and coworkers supported both of them. They were able to go to work late during treatment, which could be as much as three times a week. On mornings she needed to go to the clinic for blood tests, B3 left home at 5:45 a.m. Treatment required an hour drive in each direction. Her employer allowed her to leave work early or go in late.

The family tried to understand but found the situation hard to comprehend. Overall, B3 believes relationships improved through the process on both sides of the family.

Their interactions with the medical community were good. They became close because B3 and her husband were with them so much. B3 got close with one nurse who seemed to have been working in that capacity for a long time, and she felt the doctors took the time needed with her.

B3 worried “that we would never have a child” and learned to be patient. “That was a tough one to learn.” She discovered fertility requires time and less fun. Once treatment was stopped, stress was relieved. “We could refocus on our relationship. We just came out stronger than ever before.” The couple started doing what they liked to do again.

As she looks back, she realizes “that I’m not a quitter,” and “I’ve learned that we have an amazing marriage through all of this.” B3 discovered “how much love you have for another person” and the importance of good friendships. She feels like there was a purpose in each pregnancy.

B3 wants others to know “don’t close yourself in. Speak with your spouse.” “Our journey was from 2009 to 2016. The fertility journey is not quick. It’s very strenuous on a woman’s body with all the procedures, but we’re strong.” They stayed strong and found out that everything reproductively must be just right. “God created it pretty amazing.”

B4

B4 was diagnosed with polycystic ovary syndrome at the age of sixteen. The doctor mentioned conception may be hard but B4 was not concerned. Since that time, she took birth control. She experienced pain a few months before marriage and was diagnosed with a cyst. The cyst was removed. Then, the doctor said she had a boggy uterus and endometriosis. The physician told her she “had the uterus of an old woman.” B4 and her husband were encouraged to try conceiving soon, but they had just gotten married.

They waited three months, and tried to get pregnant for a couple of months. B4 became pregnant for the first time on November 11, 2011 and miscarried one week later. She was pregnant again in January 2012 but miscarried. In June 2012, B4 experienced another miscarriage. She was not going to tell husband about the last pregnancy because she expected to miscarry, but he found the test in the trash can. “I think it was kind of like trying to normalize a heartbreaking time.” After that, B4 did not get pregnant.

She started taking Clomid in 2013, and the couple became foster parents at the same time. The doctor determined that she was not ovulating. The couple decided to stop trying at that point because there were foster children in the house. “We had kind of given up.” The decision was difficult.

B4 and her husband encountered another difficult time when they had no children to foster. They were lonely and started drinking. She said that period of time was horrible.

One day at work, she felt nauseous, and one of her coworkers commented that she might be pregnant. She decided to test two days later, and the test was positive. B4 was more concerned than excited when she saw the result because she thought she would miscarry again. She and her husband had a trip planned that could not be changed and she felt would be disrupted. The test indicated that she was five weeks pregnant, which was further along than she thought. The couple left on their trip after she shared the news with her mother, who was more hopeful than she was initially. When she went in for her visit after returning from the trip, her blood test results were high, indicating she was progressing well in her pregnancy. She felt “a lot of things that are different this time,” but she was filled with worry. “I was waiting and waiting for… I was just waiting to lose the baby. I was waiting to miscarry, waiting for a stillbirth.”

B4 talked about some of her involvement with doctors. She had to switch physicians during the process because when she miscarried, the doctor did not acknowledge the gravity of her loss. The second physician was not particularly friendly, but she trusted his abilities. The first physician was unkind and did not understand what she was going through. B4 was not looking for friendship with her providers but wanted to be confident in the care they provided.

She tried to take control of her situation prior to that pregnancy. “There was no more inaction.” Her attention changed direction when the couple pressed forward to adopt twins. The adoption has since been finalized and she gave birth to a healthy baby girl.

During the experience, B4 was friends with another couple going through a similar situation. “It’s like you’re part of a club you never asked to be in.” There is a common understanding with those who have gone through infertility.

Other friendships were more difficult. She avoided a friend’s baby due to the pain it created for her so close to her miscarriages. The friendship has found balance since, but B4 said the relationship has changed from what it was before she began experiencing infertility. The level of closeness within the friendship has changed. Although they have a good time together, there is tension, and she doesn’t know if there is full forgiveness. She realizes how it is to judge others through the changes she experienced with that friendship.

Once she told people her story, others opened up to her. “So many women don’t know that others have experienced the same exact thing.” She can create relationships when she shares her story.

She has faith and was prayed for. One member of her church community told her that she was sure that she would have a child. “I had no other choice but to rely on my faith in God and just trust his plan." Friends had told B4 and her husband that the situation either improves or destroys relationships. "There was no one else I could have had at that time that would have kept me sane." Her husband was supportive and was conscious of her needs.

B4 was fearful through the process. She had anxiety daily and worried "maybe I'm not meant be pregnant. Maybe I was never meant to be pregnant." She questioned whether she was fit to be a mother because she had always been concerned about all that could wrong. She wanted to give her husband children badly because he is such a good person with children. They work in volunteer capacities with children in need. That is a big part of their life.

B4 has learned that "life does not always go as planned." "A good support system is imperative." She no longer worries too much about the small things or those that are out of her control.

People on the outside do not grasp the pain of the experience. B4 wants people to be understanding on both sides. Families and those who go through infertility need to try to understand one another. If someone doesn't want to come to a party, understand that there may be something going on. Also, understand that those who haven't gone through it may not be able to grasp the depth of the situation.

B5

B5 got married in 2012. She had IUI after IUI and eventually moved to IVF. More embryos were collected than expected. The couple decided one IVF attempt would be all they could do, which meant three rounds due to the number of embryos that would be left over from their first cycle. In total, the couple tried to get pregnant for four to 4.5 years before B5 got pregnant with twins. They had an idea early on that they were having twins because the blood test numbers were so high, and they had conducted some online research. At their one week follow up, the doctor accidentally mentioned it was twins, which was the confirmation they wanted.

When B5 and her husband consulted fertility assistance, they were impressed with the clinic's thoroughness. They were offered counseling, and the couple knew that they had resources available to them. The couple went to two different clinics. They left the first when treatment did not result in pregnancy after some time. One was "more money driven," and the other was more focused on patients. Overall, the clinics tried to be considerate of their feelings. B5 and her husband realize that people can get into financial obligations over their head due to the number of financial options that exist because the medical staff just keeps pushing for more.

The process of waiting caused great anxiety, but the couple was quite optimistic. The waits between the insertion, embryo updates, and the pregnancy test were the most anxiety filled moments. The wait after their first attempt at IVF was hard because they were waiting to connect with the clinic, and they were planning to meet with one another to receive the call from the clinic. B5's husband got the result by phone unexpectedly from the nurse because the nurse was excited for them. B5's husband got to deliver the news to his wife when she got in the car.

"It definitely took a toll on our relationships with each other." The sexual relationship became work and stressful. They believe the experience is hard no matter the strength of the relationship.

Some of their friends were great, and others did not understand what was going on. A natural distance was created with some friends due to the process. Her best friend got pregnant unexpectedly early in her 20s. There was a lack of empathy on her friend's part, which distanced the two friends. "Some friendships were strengthened because of their extra support and empathy for us during such a difficult time. Many relationships strengthened for sure." The family was helpful and supportive. B5's family was there when she was having difficult times.

B5's and her husband's faith gave them strength. She relied on regular prayer and God. She had open communication with her husband throughout, and the family knew what was going on. Her husband lightened their stressful situation. They both remained positive. Although they had made an agreement early on to try up to three IVF cycles, she did not think she would get pregnant on the first try because there was so much negativity in the process. B5 worried that they would hit the end of the timeline before having a baby and that her husband would want to stop. She worried that "none of it was going to work," but they proved that they could get through the worst of times. "How miraculous it really is that it ever happens on its own naturally." The process requires that so much must go right.

B5 felt the majority of the burden due to her diagnosis, and she felt that she was causing their fertility problems. She had feelings of guilt even though her husband never made her feel that way. Now, she knows that it's not anyone's fault. She is happy she had support during the process. She doesn't forget what they went through but looks at it differently now. Looking back at the process is easier because of the result, but they are aware and empathetic toward those who do not have the same outcome. They feel guilt for those who do not have a good ending and acknowledge that science is not perfect. “There’s so many layers to this process. There’s the emotional aspect, the financial aspect, the physical aspect… It’s just draining in every area, and it’s all consuming [be]cause it’s all you’re thinking about and all you want to happen.” B5 questions whether they would have been able to maintain their relationship through the process if they were not so strong. Neither was opposed to adoption, but B5 wanted to experience the process of biological motherhood. She is grateful they had support outlets that had distance from their situation. There is stigma, and it’s very personal. The ability to communicate about it is helpful and wonderful. Everything about their life has changed now.

B6

B6 and B5 took a break over summer before their first round of IVF to reestablish their relationship. Then, they started with a new fertility specialist. They thought that taking a break and seeing a new doctor was a good move after trying so hard for so long at the previous clinic. At one point, B6 tried to determine the number of negative pregnancy tests taken through their four to 4.5 years. They already knew B5 was pregnant but took a test at home, just so they could see what a positive result looked like.

B6 said it was hard to see his wife go through the experience. “Your whole sexuality’s out on the table literally.” People were wonderful, but the process “was a very negative process for me.” For him, retrieval was awful and hard to see due to the physical pain associated with the procedure. He was stressed. Then, there was the stress of going back to the same room two days later to have the two embryos transferred. The two-day period was quite emotional. “In a couple days later, you’re making the same trip back home with all kinds of hope in the world.” They always arrived to the clinic first thing in the morning for the blood test, and they waited until afternoon hopeful for a positive result.

“My biggest worry was making sure that she wasn’t worried.” B6 tried to carry his wife’s worry. He feels they were prepared for negative outcomes due to the past years of sadness. “We were so used to hearing no that…you develop a callous.” B6 has a child from a previous relationship, and the thought that he would need to look back and see that his wife could not have a child would have hurt. He knew that was part of their relationship early on. When his wife received a diagnosis of polycystic ovary syndrome, they were told the diagnosis would not be a problem, but the couple found out how hard it would be. He did not want to have to face that he could not give her what she wanted. That would hang over their relationship. They learned much more about the body and reproduction than they anticipated. “We learned a lot about each other.” They discovered how to balance one another and the relationship, and they learned how to care for the other.

Now, he realizes how many people are affected by infertility and the impact it has on those going through it. “Your space, your time, your effort, your finance. Everything about your life changes.” They paid more than $20,000 for treatment, but there was no guarantee that treatment would turn out positively. He said adoption would cost the same amount, but the result would be something tangible. Money doesn’t always fix the problem. The experience requires so many decisions. He wonders how many people go through it and must make decisions. B6 believes treatment for infertility is harder than choosing to build a house together, and he understands that financial barriers are so hard for some. Looking back, he thinks they may have just preferred to try IVF first because they would have experienced less heartache.

B7

B7 was focused on her career and waited to marry at almost 32. She found out she was pregnant on December 26, 1992, seven days after her mother's death. B7 experienced another type of loss when she miscarried before Valentine's Day. The gynecologist started medications but was not overly concerned, and she eventually moved on to a fertility specialist. The couple's friends encouraged them to seek help because they had already been through the experience. She did not get pregnant, and when she did, B7 had one or two chemical pregnancies.

The fertility specialist recommended trying IUI. She had three rounds with no pregnancy. Finally, B7 asked if the medications could be extended longer into the cycle, and on the fourth try, she got pregnant with her son. She believes the medication may have affected the last cycle of IUI. In total, her fertility issues lasted for 2.5 years from her initial miscarriage.

Throughout the experience, B7 said the fertility specialist really listened to what she had to say. They had a good working relationship because she went to the first visit prepared. She believes the doctors treated her differently because she is a medical person herself. The doctor spent time with her a second time when she went in for another consultation. He advised her to see what would happen within a year, when she told him of her desire for another child. She got pregnant with her daughter naturally. At forty-one, she experienced another miscarriage and ceased trying to conceive after that.

B7 said clinic operations seemed routine. The staff was satisfactory, but she does not remember any support staff being overly helpful. She thinks medical professionals need to have empathy. Clinics that are money driven also need to recognize the importance of giving back to those who may not have the means to get treatment. In a specialty that is so uncertain, it is important to give back.

Her husband was quite upset about B7's difficulty having children, but her mother in law minimized the situation. B7's own mother got pregnant in her later years, so she thought she would be able to do the same. Her husband was depressed after trying for ten to eleven months. "My husband was very stressed. It meant everything to him to have kids." Due to family views, adoption would not have been an option.

B7's husband's family did not know what was going on because it was taboo. Her mother in law placed blame on her. Two of her friends knew what was going on and acted as protectors. She avoided baby showers at difficult times because the events were too emotional.

She said, "I'm a resilient personality, and I often find that I plow through things." She pushes through even when she encounters barriers. Her husband helped her through it. Looking back, it was hard. B7's husband was bothered by the situation, but she was looking for the next solution at every point of the journey. She was always hopeful. B7 could have had a life without children but doesn't know if her husband could have done the same.

B7 advises others to research before starting the journey, look for a provider who fits, and think about potential outcomes. Avoid people or situations that make the experience more difficult, “learn what the journey might be like,” and try to find someone within the clinic you can talk to, even if it is not the doctor. Talk to your partner and let them know what you need and can give. Do not place blame on the other. She had hope and was looking at all possibilities.

She discussed other people’s influence on the experience and said people can be hurtful when they ask why you didn’t have children. They fail to understand your level of pain without children. “Parenthood seems like this natural progression where you have this child and it’s a baby… It’s a nice picture.” No one prepares you for when the story does not happen that way. “Things are not [going to] work out necessarily the way you want them to when you want them to.” She wants others to realize that it may not be the way you want. She could see her own sad ending.

B8

B8 had been married a year when she started to talk with her husband about having children. Conception did not happen easily like she thought it would, so she went to a fertility specialist. She was diagnosed with PCOS. After some time at the clinic with no pregnancy, she tried a different fertility clinic. However, the cost of treatment was a burden. B8 said, “This was so heartbreaking because a medical condition was affecting my ability to become a mother and my condition was not being covered by insurance, and the astronomical cost of fertility treatments was too much for me to pay at the time.” She continued, “It was kind of disheartening that we couldn’t be parents because of monetary reasons and insurance.” B8 found that “it’s hard because no one wants to go through that [treatment] unless they have to. So, it’s not like you’re making a choice to make it easier on yourself to have a baby. It’s just horrible.” B8 continued, “Something needs to be done to make it more affordable. Before I went through the infertility process, I never knew how expensive it was.” “It was something that was out of my control, and I didn’t have the backing to help make this happen.”

Years later, B8’s employer included insurance benefits for fertility treatment. She started the process again and became pregnant. However, she went into premature labor and gave birth to her daughter at twenty-three weeks. After a bit more than a week in the NICU and a poor prognosis for her baby, B8 made the decision to withdraw life support.

After the loss of her daughter B8 conceived naturally. She experienced fear during her second pregnancy due to the loss of her first baby, but she was relieved when it ended with the birth of a healthy baby. B8 said,

> I learned how strong I can be, and I didn’t realize that I have this in me because when you first start going to the fertility doctor, having them tell you, ‘well you can’t do this procedure unless you pay $10,000,’ it was kind of like a slap in the face. You kind of feel like this is all my fault because I can’t have this baby on my own.

She continued, “I think I came out a better person.” She found that the process made her more compassionate, and she started making fewer assumptions about others and the struggles they may be going through.

Of the differences in treatment, B8 said, “The first experience almost was more like it was all about the insurance and the money, and this is how much [the procedure] costs [and] not so much of them taking an interest in kind of the mental aspect of what I’m going through, and that was disheartening.” She did not come to that realization until she sought care at the second clinic, where they seemed more concerned about the experience.

B8 said her relationship with her husband strengthened.

> We were told by many people, nurses in the NICU, and at the fertility doctor's that sometimes when they go through all these fertility treatments and then something horrific happens that it could break up a marriage because you're blaming one another… You just don't really know what to do.

B8 knew she wanted and needed her husband to be with her to get through it. She said, "He was so supportive of knowing that it was me that was having the issues and not him, but he had gone through testing."

B8 concluded, "As invasive and emotionally draining it is, at the end of the day you have a chance to be a parent and that is so special and worth all of it."

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