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Female Infertility in the United States and India:
An Analysis of Treatment Barriers and Coping Strategies

By

Devneet Singh

Submitted in partial fulfillment
of the requirements for
Honors in the Department of Sociology

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ABSTRACT

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ADVISOR: Dr. Melinda Goldner.

This research studies barriers to accessing fertility treatment in the United States (U.S.) and India, as well as the coping strategies infertile women use. Barriers include reproductive health knowledge, cost, and politics, while coping is affected by cultural stigma, family, and religion. These two countries were chosen for their different cultural contexts, healthcare systems, and political infrastructure. Ten fertility specialists across both countries were interviewed as expert informants. Reproductive health knowledge was the most important barrier to accessing care in both countries, with similar gaps in understanding when and what type of care to utilize, though social media can educate and empower patients. Cost and politics played a greater role in the U.S. because of access and coverage inequalities by state. For coping, cultural stigma was cited as the most important factor in each country despite the difference in sources of stigma, namely the historical racial differences in who has been able to utilize fertility treatment in the U.S. and the closely intertwined nature of culture and family in India. In both countries, the link between coping and family remains unclear because support is highly individualized. Religion can be a great source of support for many patients, especially in India. Recommendations include providers, patients, and governmental organizations continuing to raise awareness for infertility using media, particularly around infertility diagnosis and treatment and better, age-appropriate reproductive health education. Further medicalization of infertility can ease the burden on individuals and ultimately achieve universal health coverage.

PREFACE AND INTRODUCTION

Infertility affects millions of reproductive men and women across the world. As explained by the World Health Organization in 2020, every individual has the right to the best physical and mental health as well as the right to decide the number and timing of children, and because infertility violates these two “essential human rights”, it should be treated as such (WHO 2020). However, access to medical care for infertility is unequal and widely variable across countries, races, and other demographic factors. Care is especially difficult to access for populations that are “poor, unmarried, uneducated, unemployed, or other marginalized populations” (WHO 2020). Although infertility affects men and women equally, women in heterosexual relationships are often blamed for the diagnosis whether they are infertile or not. Women also frequently face isolation, discrimination, harassment, and divorce as a result of their infertility. Most research on infertility has been conducted from the Euro-American perspective and no prior research has compared infertility between a developed nation like the United States and a developing country like India.

This research aims to understand the relative importance of three barriers to accessing fertility care including knowledge of reproductive health (RHK), cost, and politics and three factors affecting coping with infertility including cultural stigma, family, and religion. Fertility doctors in the United States and India were used as informants. The comparison between these two countries is useful because they have different social and family structures, healthcare systems, cultures, and governments, and have not been compared in prior research.

Chapter 1 reviews prior research on barriers and coping for infertility and identifies gaps. Infertility is characterized as a growing pandemic and how the language used in infertility could be contributing to stigma is analyzed. The cultural importance of children in Western and Asian culture is investigated in an attempt to understand the high levels of discrimination and stigma documented in India. The possible role of feminism in delayed childbearing, a voluntary cause of infertility, is described. Prior studies on reproductive health knowledge and India and the United States are analyzed and important findings are used to formulate questions for this study. The options for paying for infertility treatment in the U.S. and India are explained. The importance of support from the family and spouse for coping are discussed and family structures are compared between both countries. Lastly, prior research linking disclosure (talking about the diagnosis of infertility) and stress as well as religion and stress are examined.

Chapter 2 describes the methodology for the study. First, the purpose of the research is discussed. Next, methodology for sampling the doctors, confidentiality, and logistics for conducting the interview are explained. Then, details of the interview in terms of the semi-structured format of quantitative rankings and open-ended responses as well as the thematic flow are outlined. Lastly, the process for data analysis of the quantitative and qualitative results are explained.

Chapter 3 presents the results from the ten interviews in the order of the three barriers to accessing treatment followed by the three factors influencing coping. Additional sections for feminism and counseling were also included. Each section compares and contrasts findings from both countries, followed by a discussion of the results and comparison to the literature. Chapter 4 provides recommendations for

providers, individuals suffering from infertility and their families, and governments of both countries. The medicalization of infertility is also discussed, and a case is made for medicalization to decrease stigma and increase coverage. Recommendations in this chapter are formulated from doctors' responses and are expanded on by additional research.

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CHAPTER 1: LITERATURE REVIEW

Introduction

Infertility affects a diverse range of women and is increasing in prevalence around the world. Perceptions of the infertile woman are closely tied to motivations for having children and cultural norms and values. Though the recent feminist movement has positively impacted infertile women by expanding women's role in society beyond motherhood, infertility as a medical condition continues to bear a physical, financial, and emotional burden requiring significant social support. The treatment methods utilized for infertility are associated with access to treatment and the individual's reproductive health knowledge, along with the aforementioned cultural norms and social support.

Sociological analysis highlights the different coping strategies pursued by infertile women in the United States and India, which fundamentally center around their cultural values and healthcare systems. The coping strategies pursued by Indian and American women differ based on a variety of interrelated factors including religion, social stigma, and perceived social support from their partner and family. A comparison between the experience of infertility in the U.S. and India is important as current literature addresses the issue only from the Euro-American perspective and lacks focus on the importance of sociological factors.

Fertility in a Cultural Context

The fertility rate is decreasing in both the United States and India, but more significantly in India. This decline is due in part to global trends of increasing stress and obesity in women, along with their choice to delay childbearing. While researchers

around the world have tried to study the growing infertile population, it has proved difficult in part due to the varying definitions and causes of infertility. The definitions of “infertility” and “involuntary childlessness” are similar but the former describes a medical condition while the latter describes a social experience. For the purpose of this study, female infertility encompasses both voluntary and involuntary causes. The language used to describe medical and social conditions is important for the way society views the individual, but there are additional factors affecting the perception of infertile women. Motivations for having children in American and Indian society correlate with the level of social stigma and perceptions. In developed nations like the United States, children are often a source of happiness, fulfillment, and a unique bond between child and parent. While these feelings are echoed in developing nations like India, children serve additional purposes. They ensure care for the elderly, as well as social and political power (Inhorn 2002). This, along with the popularity of extended families as opposed to nuclear family structure, subjects Indian women to greater family pressure, especially those of lower socioeconomic statuses. It is possible that the feminist movement has alleviated some of this pressure on infertile women in the U.S. and India, but that link has not yet been made clear.

A Growing Pandemic

Infertility is a condition plaguing women worldwide regardless of demographic group, socioeconomic status, or education level. Infertility can be measured using total fertility rate (TFR): the number of children a woman has in her lifetime. A TFR of about 2.1 is considered the replacement level of a population at which the population size

remains the same (Lal 2018). A fertility rate above 2.1 indicates population growth, and below 2.1 indicates population decline. Data from the United Nations show that the TFR for 83 countries is below 2.1 and population size is shrinking in the countries which account for 46% of the world's population (United Nations 2019). An alarming drop in TFR for India has been recorded, from 6.0 in the 1950s to 2.3 in 2019, and is projected to stabilize around 1.6 by 2050. Although this may seem like welcome news for the second most populous country in the world, it is causing psychological and cultural stress on India's young couples and communities. The United States also experienced a drop in TFR from 3.4 to 2 between 1950 and 2000 and is projected to stabilize around 1.8 by 2050 (Appendix A).

This decrease in fertility in the United States and India is being caused by changing lifestyles, increasing frequency in diseases, and increasing stress, that increase risk for infertility. More specifically, both countries' decline in TFR between 1950-2000 can be linked to some common causes including delayed childbearing, increasing obesity in men and women, polycystic ovarian syndrome (PCOS), and sexually transmitted infections (STIs) (Lal 2018). The link between obesity and infertility can be explained in part by menstrual dysfunction, which causes anovulation and infertility. Menstrual dysfunction is also one of the main adverse effects of PCOS. Obesity is linked to worse outcomes from assisted reproductive technologies, but weight loss programs have shown to improve both fertility and efficacy of reproductive technologies for women suffering from obesity and PCOS (Silvestris et al. 2018). Damage to the fallopian tubes from untreated STIs including chlamydia and gonorrhoea have also been strongly linked to infertility (Tsevat et al. 2018).

However, infertility can also be attributed to external factors. A study comparing Indian and Caucasian women found that Indian women are reaching menopause on average five years earlier than their Caucasian counterparts and six years before their Spanish counterparts (Iglesias et al. 2014). On an individual level, strong positive correlations have been found between Indian women's educational level, socioeconomic status, being married, and higher menopausal age and loss of fertility (Ahuja 2016). On a national level, one study posited that the earlier menopausal age for Indian women could be attributed to "environmental toxins, use of plastics, and a change in diet that also contains chemicals and genetic mutations" (Lal 2018). Research has continuously linked unhealthy diets of processed and genetically modified foods to high body mass index (BMI) and consequently, earlier menopause (Lal 2018) (Ahuja 2016).

Language Surrounding Infertility

It is important to acknowledge the ambiguity surrounding the definition of infertility and address its meaning in the context of this paper. According to India's Assisted Reproductive Technology (Regulation) Bill of 2017, infertility is defined as "the inability to conceive after one year of unprotected coitus or other proven medical condition preventing a couple from conception" (Indian Parliament 2017). The "Access to Infertility Treatment and Care Act" enacted by the the United States Congress defines infertility as "a disease characterized by failure to establish clinical pregnancy (A) after 12 months of regular, unprotected sexual intercourse or (B) due to a person's incapacity for reproduction either as an individual or with his or her partner, which may be determined after a period of less than 12 months of regular, unprotected sexual

intercourse, or based on medical, sexual and reproductive history, age, physical findings, or diagnostic testing” (U.S. Congress 2019). This paper discusses coping strategies for female infertility only.

Indian feminist Urvashi Butalia highlights an important fact about our language towards childlessness (Butalia 2013):

“Singleness is, for me, a positive state, one that is not defined by a lack, by something missing, by a negative—as for example the word ‘unmarried’ is. But with this children business, we don’t even have the language to define a positive state. I mean, there is childlessness and there is childlessness. How often have we heard that a couple is childless, that a woman who cannot bear a child is defined as barren. Why should this be? I don’t feel a sense of loss at this, my life has been fulfilling in so many other ways. Why should I have to define it in terms of a lack? Am I a barren woman?”

The language of the term ‘childless’ implies that infertile women and couples are lacking something or are unable to contribute to society, also neglecting the women who choose not to have children. Butalia and modern day feminists have recognized the additional ways women can contribute beyond having children.

To date, there is ambiguity in defining childlessness but generally ‘infertility’ is used to describe a medical condition while ‘involuntary childlessness’ is used to describe a social experience (Letherby 2002). It is possible for a woman to be both at once, but neither is a permanent departure from motherhood, as it is possible for an infertile woman to experience motherhood after treatment such as in-vitro fertilization (IVF) or the process of adoption. Similarly, the status of ‘voluntarily childless’ sometimes changes

over time as women become mothers later in life (Letherby 2002). The stereotype of an ‘infertile’ or ‘involuntarily childless’ woman is that she is “desperate and unfulfilled”, whereas a ‘voluntarily childless’ woman is “selfish and deviant” (Letherby 2002, 10). Part of the taboo surrounding conversations around infertility stem from the blurry line between voluntary and involuntary childlessness, and the privacy of the situation which can make it difficult for researchers to understand more about this choice, the social experience of being childless, and the coping strategies pursued. (Inhorn 2002).

Cultural Importance of Children

Perceptions of infertility are closely tied to motivations for having children. In Western societies, having children and pursuing a career are given somewhat equal weight, and thus childbearing is seen as a choice. Childbearing is chosen for “personal happiness, [the] unique parent-child relationship, and [the] giving and receiving [of] love and affection” (Inhorn 2002, 8). In non-Western societies, motivations for having children can be divided into three main categories. Firstly, children help to support the family with economic security and labor as well as caring for the elderly in societies where “pensions, health insurance, nursing homes”, and other governmental care structures are absent (Inhorn 2002, 9). In low-resource communities in India, economic insecurity in terms of “no support in old age, receiving fewer gifts and less land, and having fewer relations” is experienced by infertile women (van Balen and Bos 2009, 115). Secondly, children serve as a source for social power, especially in patriarchal societies. Thirdly, children serve social perpetuity, advancing the family into future generations and passing down culture (Inhorn 2002). Additionally, children are

increasingly also serving a political purpose, to ensure the survival of a political or other group (Inhorn 2002). Thus, because childbearing in non-Western societies serves many more purposes than emotional fulfillment, it is less seen as a choice but rather the next step after marriage.

For many Indian women, having children is a priority and is closely tied with reputation. This prioritization is seen increasingly with lower socioeconomic status, but is prevalent throughout the pronatalist society. The majority of women who chose to not have children are happy with their choice but face concern from family and stigma from their community. They are referred to as “childless women”, not making the distinction between “child-free” and “childless”; while the former is a choice to live without children, the latter is an involuntary state used for women and couples wanting a child (Singh 2019). In India, the “child-free” women are choosing to delay childbearing or not have children at all because they have decided it is not right for them, either emotionally, professionally, or financially (Singh 2019). Most of these women are “highly educated, urban, English-speaking professionals” with someone who supports this decision in their immediate social circle (BBC 2013). For women of lower socioeconomic status, caste, and education level, being childless is not a choice due to pressures from family and society. Women in many rural communities are bound together by their common role of being a mother and failure to be a mother results in rumors and ostracization. A meta-analysis investigated social consequences of infertility in low-resource areas in the Indian subcontinent found that in most cases, women faced social stigma and status loss, and in many cases also experienced social rejection and exclusion (van Balen and Bos 2009) (Appendix B). Harassment and pressure from in-laws was experienced by many, and

escalated to the point of exploitation and abuse in several cases (van Balen and Bos 2009). A key difference between Indian and American society are their familial structures, with nuclear families being more prevalent in the U.S. while extended and joint families being more prevalent in India. This family pressure by physically having more family members living together may be placing more pressure and social stigma on “childless” couples and warrants further research.

While infertility causes major issues for Indian women surrounding reputation and family pressure, American women struggle with the loss of personal freedom and choice when dealing with infertility. The medicalization of the entire childbearing process in the U.S., from contraception and new reproductive technologies to genetic counseling and abortion are all aimed toward giving women a choice (Inhorn 2002). Having this choice restrained from the variety of involuntary causes of infertility can put strain on a woman’s perception of her choice and freedom. However, for both the voluntary and involuntary childless American woman, the experience is described as one of “stigmatization, isolation, and alienation” (Whiteford and Gonzalez 1994, 29). Common adjectives American infertile women identified with were “shame, guilt, inadequacy, failure, de-valued, abnormal, incomplete, and not whole” (Whiteford and Gonzalez 1994, 30). Similar to Indian women but somewhat less dramatically, these women feel unable to fulfill their culturally constructed gender role.

Feminism and Cultural Shifts in Gender Roles

Motherhood is a concept which can be viewed from two perspectives from feminist theory: one, that motherhood is a unique experience unifying women, or two,

that motherhood has denied women equal rights and opportunity and has led to discrimination (Neyer and Bernardi 2011). Feminist researchers have emphasized the importance of separating the biological and social aspects of motherhood, as attributing motherhood to the “nature” of a woman denies the hard work she invests as a part of that role. Some radical feminists have connected motherhood to patriarchy, capitalism, and colonialism as a means of production, where failure to be a mother would be perceived as “resistance against these systems” (Neyer and Bernardi 2011, 166). In the last few decades, a cultural shift in women’s gender role has occurred as more women strive for financial independence and stability through careers. This has caused some women to delay childbearing to later in life, resulting in decreased fertility as fewer eggs are left. This choice is also influenced by what some call the ‘Contraceptive Revolution’. Contraception gives women a choice whether to have children, whereas previously, children happened as a product of marriage (Heer and Grossbard-Shechtman 1981). However, a tension remains between feminists and the concept of treating infertility, because while infertility causes deep psychological and social stress for a woman, supporting treatment and childbearing could further ingrain the traditional gender role as well as heteronormative families. Thus, there is a paradox between infertility and feminism: “feminists are well placed to understand the special burden involuntary childlessness places on women, but they are ambivalent about supporting women who seek infertility treatments because it seems to lend implicit support to conventional gender roles and gendered stratification” (Inhorn 2002, 52).

One of the many articles published on the Feminism in India website, the hub for the latest progressive feminist content, is an article written by a woman who grapples

with the decision not to have children based on the experience of mothers in India. She says that she “will be known by her motherhood, as the wife, the daughter, and in the process, her own identity as a human being with rights will be lost”, and the inability to secure an equal and safe environment in which the child could grow up in (Arora 2020). Indian women continue to face marital and family problems due to infertility, especially evident in lower socioeconomic classes. For Indian women in low-resource areas, marital instability during infertility results from fear of divorce or an extra wife, and in some cases escalates into going through with divorce, the husband taking on another wife, or physical abuse from the husband (van Balen and Bos 2009). The feminist movement has ignited a spark in the new generation of Indian scholars and students, but true culture change applicable to the greater Indian society is a long way away.

Access to Medical Treatment for Infertility

The population of women suffering from infertility is growing, causing the market for infertility treatment to grow with it. Beyond the social and cultural consequences for infertile women in the United States and India, pursuing medical treatment for infertility is affected by significant financial, political, and educational barriers. Without adequate financial support in both developed and developing nations like the U.S. and India, respectively, infertility treatment becomes out of reach. Infertility clinics are most commonly found in affluent, metropolitan areas which becomes difficult for women in rural areas to access, especially given the nature of treatments such as IVF which often require multiple cycles. Though assisted reproductive technology (ART) clinics in the U.S. are highly regulated, more clinics in India remain unregistered with the Indian Council for Medical Research (ICMR), resulting in unsafe and unethical practices.

The treatment method pursued is also affected by the woman's reproductive health knowledge (RHK). Studies have shown that women with greater RHK more frequently attribute biology, old age, and abortion or injury to causes for infertility and seek out medical treatment as one of the first courses of action, whereas women with less RHK were more likely to attribute infertility to old age and religious factors and chose to pursue natural home remedies first (Patra and Unisa 2020).

Politics

The importance of political infrastructure for infertility treatment in regard to quality standards and payment structures is not commonly discussed in the scholarly literature, but is one of the factors that can be fortified to help reduce social stigma and level access to care for women of different demographic groups. Political infrastructure can be defined as formal discussion in legislation and associated legal implications.

One way to enact a cultural change is to change the language and spark discussion in literature, media, and government. This macro level infrastructure can then affect populations on an individual level. Of the 20,000 clinics conducting IVF and intrauterine insemination (IUI) in India, only 2%, or 1,500 clinics, are actually registered with the Indian Council of Medical Research (ICMR) to conduct such procedures (Dey 2017). This directly leads to concerns regarding transparency for cost and quality of the procedures. While there are harrowing stories of unregistered ART clinics with "DNA mismatches, abandoned babies, and unscrupulous practices", it is more common to see couples grossly overcharged for infertility services (Lal 2018). The exponential rise in cases of infertility in India have caused a number of unregistered ART clinics to crowd

the industry, some of which are unqualified and others which are unethical, even putting the woman's life at risk. This prompted the ICMR to create the Assisted Reproductive Technology Regulation Bill in 2017 to supervise ART clinics in India to “prevent misuse and [ensure] safe and ethical practices” (Indian Parliament 2017). Though this legislation laid the groundwork for safe practices, no explicit monitoring systems were put in place and unregistered clinics continue to present safety and quality issues. Another part of the problem is that India is a popular country for medical tourism, especially surrogacy and in-vitro fertilization. In 2018, India made commercial surrogacy illegal, strictly limiting surrogacy to only when medically necessary and for Indian couples only, as poor Indian women were being exploited while international surrogacy companies collected all the profits (American Surrogacy n.d.). IVF is also commonly sought in India because of the low out of pocket cost, availability of good technology, English-speaking staff, and because India is a country open to medical tourism more broadly (The Indus Parent n.d.).

In the United States, there are 448 certified ART clinics regulated by the Centers for Disease Control (CDC 2017). There are fewer in the United States than India, due in part to a smaller population and higher levels of standardization, quality control, and monitoring from the government. The most important ART-related legislation is the Fertility Clinic Success Rate and Certification Act of 1992 (FCSRCA) requiring that “each ART program shall annually report to the Secretary through the Centers for Disease Control and Prevention (CDC) pregnancy success rates achieved by such program through each assisted reproductive technology and the identity of each embryo laboratory used by such program, and whether the laboratory is certified or has applied for such certification” (FCSRCA 1992). The Federal Trade Commission also has

requirements regarding truthfulness of advertising and marketing for ART clinics, such as posting both the numerator and denominator for percent success rates following an investigation into misleading success rates (Adamson 2002). Additional infrastructure supporting pronatalist culture in the U.S. can be seen in the Earned Income Tax Credit (EITC), which reduces the tax owed because of a child in the household (National Academies 2016). While there are no similar child tax credits in India, there are some tax deductions that can be taken (Bank Bazaar n.d.).

Cost is the number one barrier to treatment of infertility globally (ASRM 2015). IVF is the most effective treatment, but is also invasive and expensive. One cycle of IVF includes egg and sperm retrieval, fertilization, and embryo transfer. Throughout the process, the woman takes hormones and medications to increase the chance for successful pregnancy. If she is not pregnant after the procedure, she can choose to go through more IVF cycles (Mayo Clinic n.d.). IVF has a success rate per cycle of approximately 21.3%, though this varies between women, fertility clinics, and a variety of other factors (Penn Medicine 2018). Treatment success rates are affected by the woman's age, how long the woman has been attempting to conceive, and the cause of infertility, but also the skill of the doctor performing the procedure, average number of cycles completed per patient per clinic, and how many severe cases of infertility the clinic treats (Michigan Medicine 2019).

Like most medical treatments in India, IVF cycles are paid out of pocket and the average IVF cycle ranges from INR 100,000 to 350,000 (approximately \$1,362 to \$4,770 U.S. dollars), excluding medications and additional procedures (CNY Fertility 2020). The average IVF cycle cost in the U.S. is between \$10,000 and \$15,000, but varies based on

the patient's insurance, individual characteristics including BMI and stress levels, and treatment center (Penn Medicine 2018). In 2019, Congress decided to “require health insurance coverage for the treatment of infertility” as an essential healthcare cost (Congress 2019). Some examples of IVF payment options in the U.S. include self-pay packages for single and multiple cycles, which bundle all costs associated with a cycle rather than charging for each step in the process. The Advanced Reproductive Care (ARC) is an organization that helps people finance fertility treatment by having a network of board-certified fertility specialists, discounted multi-cycle packages and pharmacy packages, and financial options (Penn Medicine n.d.). However, individuals in the U.S. most commonly turn to their insurance plans first. Some plans only cover a limited number of cycles, others cover the cycles but not accompanying injections and medications, while some plans do not cover infertility at all (Fike n.d.). The combination of high cost for IVF treatment and limited access to ART clinics based on safety and geographic location make medical treatment for infertility difficult for many women, especially with less financial resources.

Reproductive Health Knowledge (RHK)

The type of treatment that women seek is affected by their differing levels of reproductive health knowledge (RHK) because this affects the perceived causes for their infertility. A study published in the *Journal of Biosocial Science* developed the Reproductive Health Knowledge Index (RHKI) to assess women's knowledge on concepts including “knowledge of male and female reproductive organs, length of menstrual cycle, knowledge of [the] most fertile period”, among other metrics, and their association with perceived causes of infertility and coping strategies (Patra and Unisa

2020, 3). The higher the RHKI score, the more the individual knew about reproductive health. Researchers applied the RHKI to women in West Bengal and found that women with higher RHKI scores more often attributed infertility to biological factors, old age, and abortions/injuries and more often sought allopathic treatment, whereas women with lower RHKI scores attributed infertility to old age and religious factors, and often first turned to traditional home remedies, religious guidance, or no medical treatment (Appendix C) (Patra and Unisa 2020). Women with an average RHKI score of 3.35 which is considered relatively low also turned to Indian Traditional Medicine, including Ayurveda, Yoga, Unani, Siddha, and Homeopathy (AYUSH). Interestingly, any exposure to the media increased women's RHKI score. While some women's RHKI was higher than others, knowledge was lacking throughout this subpopulation and the study cited barriers to treatment including "low level of education, lack of awareness of the risk factors of infertility, poor knowledge of human reproduction, poor knowledge of a woman's most fertile period and the menstruation cycle, poor menstrual hygiene and lack of access to, and unaffordability of diagnostic and treatment facilities" (Patra and Unisa 2020, 8). It is also common for Indian women to attribute some part of infertility as an act of God, especially when no medical cause for the infertility can be found, believing that the gift of motherhood must be bestowed by God and infertility is a punishment for bad karma from an erroneous act in a previous life (Mishra and Dubey 2014).

A similar study investigating reproductive health knowledge in the U.S. identified a "concerning lack of awareness of reproductive-age women" on the factors affecting infertility including obesity, being underweight, smoking, and sexually-transmitted infections (Lundsberg et al. 2014, 772). Younger women possessed less knowledge on

conception, fertility, and ovulation, while older women were more likely to believe common misconceptions like “women’s ovaries continue to create new eggs” and “lying on one’s back with hips raised increases chance of pregnancy” (Lundsberg et al. 2014, 774). Though this study collected data from a diverse range of women across ethnicities and socioeconomic groups to mirror the demographic of the United States, the study failed to analyze differences in reproductive health knowledge against these demographic metrics.

Coping Strategies

Effective coping strategies are especially important during infertility treatment because stress negatively affects the efficacy of assisted reproductive technologies. Stress is disproportionately skewed toward women of lower socioeconomic status. Support from the woman’s partner is most important, and the experience of infertility can both improve or deteriorate marital satisfaction, depending on the number of cycles and unsuccessful treatments. However, this research is quite generalized and does not take into account differences in stress and social support between cultures.

Coping strategies women choose within and across countries differ especially based on “the values and socio-cultural norms of the community in which they live”, perceived sources of social support, and social stigma (Wiersema et al. 2006, 1). A main difference between American and Indian societies are their major religions, degree of religiosity, and social structure. Indian society is tied closely to the Hindu religion, which emphasizes the importance of holistic wellness, including the biological, psychological, and spiritual elements. Many Indians also cite religion as an important steering factor

when making decisions. In contrast, American society exhibits a greater separation between medicine and faith. However, there exists a general gap in knowledge regarding the role of religion in infertility treatment.

Support

Increasing stress is correlated with a decrease in efficacy for ART; thus, it is important to understand the interrelated factors with the emotional response to infertility. Because stress is disproportionately distributed in women of lower socioeconomic and educational levels, “social health has a special importance in fertility” (Zeinab, Zohreh, and Gelehkolaee 2015, 18). Greater perceived stress by women of lower socioeconomic status puts them at greater risk for psychological harm as they have weaker social support networks and less resources. The strength of the social network is directly related to the ability to problem solve and effective coping strategies, but even brief training or counseling can help these women better deal with their problems (Zeinab, Zohreh, and Gelehkolaee 2015). Counseling programs are especially important in infertility clinics as “infertility is a chronically stressful factor that can affect every aspect of people’s lives, disrupt their relationship with others, and make them avoid socialization, leading to lower self-belief” (Zeinab, Zohreh, and Gelehkolaee 2015, 18).

A literature review of marital satisfaction in infertile couples discussed the importance of psychological and family supports including counseling for the spouse and spouse’s family, educating families about how to interact with infertile couples, and financial security during treatment (Samadaee-Gelehkolaee et al. 2015). First, social support was divided into marital satisfaction and perceived social support, as from family

and friends. While the most important source of support is the spouse, any support from friends and family served as a buffer between unsuccessful treatments and the emotional response for infertile women (Verhaak et al. 2005). Secondly, among infertile couples, those with higher familial pressures faced significantly higher rates of depression, but counseling and education of both the couple and family was found to increase levels of marital satisfaction and better psychological health. Thirdly, couples with higher socioeconomic status were able to combat low levels of marital satisfaction by providing the financial support for medical treatment. Marital satisfaction and stress were also influenced by the type and duration of fertility treatment. Highest levels of stress, depression, and anxiety were found in women six months after their first failure (Samadaee-Gelehkolaee et al. 2015). Women who continued to pursue treatment despite several failures exhibited higher levels of stress compared to women who accepted life in the new state of childlessness (Verhaak et al. 2005).

Active coping mechanisms such as “seeking contact from fellow sufferers and finding a new meaning of life to replace the unfulfilled wish for a child and parenthood” can help to reduce anxiety, depression, and other health problems and are often a reflection on strong perceived social support (Lechner, Bolman, and van Dalen 2007, 289). Passive emotional coping mechanisms such as “avoidance, withdrawal from external contacts, and fixation on children” have opposite, negative effects and are often evidence of weak perceived social support (Lechner, Bolman, and van Dalen 2007, 289). Researchers in the United Kingdom tested the hypothesis that a high perception of stigma would lower disclosure rates, thus decreasing social support and increasing anxiety. For male respondents, higher perceived stigma was associated with lower disclosure rates and

higher stress overall, but no link was found between disclosure and support. Female respondents reported a high disclosure rate correlated with an increase in stress (Appendix D) (Slade et al. 2007). Additional research also corroborates these findings that people who experience infertility choosing to share only with their partner have lower stress, and that this connection may be related to self esteem (McEwan et al. 1987) (Folkman et al. 1986). A gap remains in the literature in regards to the applicability of these findings in the U.S. and India given cultural context, which warrants further research.

Religion

Coping strategies used by women in India are influenced largely by religion, as eight in ten Indians cite religion to be a “very important” factor in how they live and make decisions (Wike and Simmons 2015). Hinduism is the most common religion in the country (80%), followed by Islam (13%), and less than 1% of the population is not affiliated with any religion (World Population Review 2020). The importance of religion is reflected in Indians’ holistic view of illness, believing that every illness has a biological, psychological, and spiritual element and thus all three elements should be treated (Queensland Health 2013). The duty to produce a child after marriage is a theme commonly repeated in Indian religious texts, ingrained in women from a young age (Mishra and Dubey 2014). When asked what they were doing to treat infertility, many Indian women reported visiting religious places and performing rituals for the baby according to their own religion but also according to the religions and rituals recommended by friends and family (Mishra and Dubey 2014). Most women recognized

the importance of both medical and religious treatment and pursued both simultaneously. Previous research on religious coping strategies has found to decrease psychological distress but not significantly improve mental well-being. Mental wellbeing is instead improved by seeking approval from the community because while the inability to have children and meet social norms can reduce feelings of self-worth, recognition from the community for other skills and capabilities can improve self esteem (Nouman and Benyamini 2018).

The U.S. historically has had a greater separation of medicine and religion than exists in India. The editor of the American Medical Association's *Journal of Ethics* explained that while efforts have been made to separate medicine and religion in the United States, "as two important ways that people respond to human suffering, religion and medicine are bound to intersect" (Shinall 2009). A study investigating the link between religiosity and fertility in the United States found that women citing religion as a "very important" factor in their daily life had a higher fertility rate, significantly correlated to traditional family values and higher intended family size (Hayford and Morgan 2008). Women who stated that religion was either "somewhat" or "not at all" important in their daily life had intentions of having less children thus decreasing their fertility rate (Hayford and Morgan 2008). While this provides some insight into voluntary behavior regarding fertility, there is little research on the link between religiosity and which types of medical and nonmedical treatments were sought for infertility as has been done in the Indian subcontinent. In the United States there is a general gap in research in regards to the religious and spiritual dimensions of holistic care and in infertility treatment especially.

Conclusion

Research on infertility centers around the discussion of the medicalization of infertility and prevalence of reproductive technologies, which originate from Westernized societies of the United States, United Kingdom, and Australia (Inhorn 2002). Thus, most literature is from the Euro-American perspective and “rarely acknowledges the reproductive desires and dilemmas of infertile women and men living outside the West” (Inhorn 2002, 6). Additionally, it has been recognized that most research on reproductive health knowledge has been in countries including Australia, Europe, Israel, and Canada (Lundsberg et al. 2014). This warrants a deeper look into the social experiences of women experiencing infertility in developing countries, especially in terms of the feminist movement, political infrastructure, the roles of partner and family support, reproductive health knowledge, and religion. Comparing the effect of these factors in the United States and India, two countries with different cultural contexts, healthcare systems, and social and political infrastructures, may be able to shed more light on the importance of sociological factors in the experience and treatment of infertility.

It is also important to use data gathered about the social experience toward how to better care for this growing infertile population with culturally appropriate recommendations. There is evident lack of reproductive health knowledge for reproductive age women as well as misconceptions about infertility. Seventy-five percent of women report learning about reproductive health from their female healthcare providers, emphasizing the importance of female doctors globally (Lundsberg et al. 2014). Implications of this research identify the global need for better education on

fertility for reproductive age women, access to affordable and safe treatment, and infertility awareness in greater society.

CHAPTER 2: METHODOLOGY

Purpose

This research aims to understand the importance of barriers to pursuing medical infertility treatment including knowledge of reproductive health, cost, and politics, and importance of factors influencing coping strategies including cultural stigma, family, and religion. Secondly, the research compares these barriers between the United States and India, countries with rising infertile populations but differences in infrastructure and culture. By understanding how each society is uniquely affected by these barriers, we can understand more about the social experience of infertility and how macro-level factors influence patients on an individual level. This information may also inform decisions to improve reproductive health knowledge and access to infertility treatment in these countries and globally.

Methods and Sampling Population

Formal Human Subjects Review approval was obtained from Union College. Reproductive endocrinologists and obstetrician-gynecologists with expressed interest in infertility with public Instagram accounts were eligible for the study. Doctors with Instagram content regarding fertility education and awareness were selected by searching terms such as “infertility” and “doctor” in the Instagram search bar, and this same procedure was used to find participants in both India and the U.S. Participants were provided additional information about the research, the consent form, and opportunity to participate in an interview. The consent form can be found in Appendix E. Participants chose whether or not to give permission for a recorded interview. The name of participants or their clinic were not recorded for confidentiality. During a roughly thirty-

minute Zoom interview, doctors were asked to answer several questions and responses were either transcribed or recorded through Zoom, if permitted.

Interview

The survey was semi-structured and delivered virtually through Zoom, following COVID-19 pandemic-related college restrictions, with questions requiring doctors to rank the importance of certain barriers to and coping strategies for infertility. The full interview questionnaire can be found in Appendix F. The first two short answer questions asked the doctor to explain the services provided at their clinic as well as the general race and socioeconomic status of their patients. The next series of questions asked participants to rank the importance of knowledge of reproductive health, cost, and politics as barriers to accessing infertility treatment for their patients. Participants assigned numbers 1, 2, and 3 to signify a barrier that they perceived was not important, moderately important, or very important, respectively. The next question asked participants to rank the importance of cultural stigma, family, and religion as factors influencing coping strategies for their patients using the same scale of 1-3 described above. For each barrier and coping strategy, participants were asked to elaborate on their ranking. Participants also had the opportunity to mention additional barriers they felt were important but not included. The final question allowed participants to share their opinion on how to improve access for patients and facilitate support during the coping process.

Data Analysis

Ten doctors were interviewed in total, four from the U.S. and six from India. All doctors from the U.S. were reproductive endocrinologists, and all doctors from India were obstetrician-gynecologists with additional training in fertility treatment, which is the standard equivalent for the United States. Interviews were transcribed. Responses were stratified by question and compared by country, looking for similar themes across responses. Themes were compared and explained qualitatively. Ordinal responses for the importance of each barrier and coping strategy were averaged by country and compared between the U.S. and India. Closing recommendations for improving access and facilitating support were combined by country and compared qualitatively.

CHAPTER 3: RESULTS AND DISCUSSION

Overview

Reproductive endocrinologists in the United States and obstetrician-gynecologists with additional training in infertility in India were interviewed for this study. The doctors were asked to assess the importance of knowledge of reproductive health (RHK), cost, and politics as barriers to accessing fertility treatment for women. They were then asked to assess the importance of cultural stigma, family, and religion in the coping process. Quantitative responses to the importance of each aforementioned item are displayed in Tables 1 and 2. Research was exploratory and compared data across the U.S. and India for their differences in cultural context, healthcare systems, and social and political infrastructure.

Of the barriers to accessing fertility treatment, reproductive health knowledge (RHK) was ranked as the most significant barrier and was comparable across both nations, while cost and politics were secondary and were more significant in the US. RHK was lacking in both countries on topics including when to seek help for fertility treatment, the scope of practice for fertility specialists, and the equal responsibility of men and women in the infertility diagnosis. Media, including celebrities, social media, and movies, was cited as having both positive and negative effects by increasing awareness but sometimes spreading misinformation. While cost was an important barrier in both countries, the conversation among the doctors from the United States centered mainly on the lack of insurance coverage across the nation and the complexities in coverage within states with fertility benefit mandates. In India, there is no health insurance and almost all patients pay out of pocket. However, doctors explained that

costs are in line with other procedures such as a delivery or C section. Politics was a highly important barrier for doctors in both countries. In the United States, doctors were primarily concerned with the increasing politicization of women's reproductive health issues and how geography can affect a patient's health outcomes. In India, concerns in this realm centered around the inequalities between public and private hospitals in the Indian health care system and controversial portions of the new ART and Surrogacy Bills.

In regards to coping strategies utilized by women in both the U.S. and India, cultural stigma was crucial. In both countries, there is a lack of social support and recognition for fertility issues in comparison to other medical conditions like cancer or diabetes. In the U.S., doctors discussed the racial differences in those who have historically utilized fertility treatment versus those who have not. In India, the stigma primarily originates from the pronatalist culture of having children directly after marriage and deviance from the norm if a couple does not. In both countries, doctors were unable to identify demographic trends in women who received family support versus those who did not, indicating that this is a complex, individualized, and interpersonal issue. However, Indian doctors more frequently mentioned the role of family pressure than their American counterparts. Lastly, religion was cited as an important barrier to treatment for strongly religious groups in both countries, but was used as a coping mechanism more widely in India. In both countries, doctors welcomed the hope that religion provides as an important source of strength throughout the difficult infertility process.

Barriers to Accessing Fertility Treatment

Table 1. Barriers to Treatment (n=10)

Doctors were asked to assign a rank of importance to barriers to accessing treatment as either 1 = little to no importance, 2 = moderately important, or 3 = very important.

	United States					India						
	Dr. 1	Dr. 5	Dr. 8	Dr. 10	Average*	Dr. 2	Dr. 3	Dr. 4	Dr. 6	Dr. 7	Dr. 9	Average*
Reproductive Health Knowledge	3	2	3	3	2.75	3	3	3	3	3	2	2.83
Cost	3	3	3	3	3	2	3	2	3	2	3	2.5
Politics	3	2	2	3	2.5	3	1	3	1	2	2	2

*Responses for each item were averaged across respondents from each country.

Knowledge of Reproductive Health

As illustrated in Table 1, reproductive health knowledge (RHK) was cited as a ‘very important’ barrier to accessing fertility treatment by 80% of participants overall, including 75% of the doctors in the U.S. and 83% of the doctors in India (n=10). It is important to be aware of the basic treatments available and know when to see a doctor to get tested. The doctors interviewed said that couples should seek help as early as possible after 12 months of being unable to conceive because egg quality and receptivity to treatment will be better. As one doctor from India explained, it can be the case that some female patients end up waiting until after ages 38-40 to get pregnant, at which point their anti-Mullerian hormone (AMH) is too low to conceive naturally. As one doctor from the United States explained, after the ages of 35 and 45, these rates of success go down and other options like donor egg and sperm need to be used. Only in rare cases is male factor infertility untreatable, and in certain cases where female infertility is caused by a fallopian tube obstruction (Mayo Clinic Staff n.d.) (Columbia Doctors n.d.). Otherwise, in most cases, early treatment and detection can help the couple get pregnant naturally.

In general, the biggest gap in knowledge appears to be understanding when to seek help from a fertility specialist, in both the U.S. and India. In the U.S., this gap is prevalent across socioeconomic groups, ethnicities, and education levels. A doctor from the U.S. mentioned that her patients with careers in science and medicine, sometimes even other doctors, show up at her clinic later than they should be. For patients suffering from polycystic ovarian syndrome (PCOS), this delay is further exaggerated, which only speaks to “how poor the knowledge is, even within the medical community”. Another doctor from the United States linked historical context to delayed childbearing. She explained that the civil rights and women’s rights movements opened up education and job opportunities for women in the 1960s and 1970s, and now the feminist movement is setting women up for academic and professional success, all which have decreased women’s reliance on their husband for financial stability and satisfying social expectations. This in turn has raised the age women have their first child on a population level. It is a fact that fertility decreases over time, so delayed childbearing is becoming a larger proportion of the causes of infertility. An interesting trend noted by informants across both countries was the notion that “infertility gets overshadowed by IVF” and not enough information is known about the wide range of fertility issues and services provided by fertility clinics, as explained by a doctor from the U.S. In India, one doctor said that knowledge of the basic science and procedures at infertility clinics is sometimes so lacking that some people think treatment involves “a magical blood test and results in a test tube baby”. However, fertility services offered by doctors interviewed included a variety of surgeries, IUI, IVF, counseling, ultrasounds, and medications.

Though there are similar gaps in RHK, physicians in India associated this gap more strongly to the “culture, tradition, and inability to speak with parents [about reproductive health]” in India. Accurate, scientific knowledge of male and female anatomy, sexual intercourse, and conception were also commonly cited gaps in RHK. Family plays an important role in the proactivity with which patients show up at fertility clinics in India. One doctor stated that within two to four months of marriage, if an Indian couple has not become pregnant, the extended family will often pressure the woman to seek help and it’s not uncommon for her to be accompanied to the clinic by her mother, mother in law, or aunt.

Inaccurate information on costs for treatment was also cited as a problem in both countries. In the US, one doctor stated that “some [people] assume that treatment is not covered,” even though some states like New York and New Jersey have a state mandate requiring most employers to offer some type of benefit for treatment. In India, a doctor explained that some couples from the lower middle class think infertility treatment costs are totally out of reach, without realizing that the cost is on par with other medical treatments. Costs in India also vary widely between hospitals, especially between private versus governmental hospitals, which is also causing “false assumptions about cost”. Patients’ knowledge about general costs and payment methods of fertility treatment have not been discussed in prior research so this research identifies another gap that requires awareness.

Gaps in RHK are attributed in part to the fact that “sexual education as a curriculum is not handed over in a structured way [in India], especially about reproductive organs and the fertile period”. This is an issue in both countries. One doctor

from India explained that while students may learn about their body in seventh and eighth grade, both the teachers and students rush through the material and as young adults, most information is learned from the internet, which has both credible and noncredible information. A similar sentiment was expressed by American doctors, one who expressed the paradox that early in the American education system, young girls are taught about “pads and tampons and how not to get pregnant”, but then when the appropriate time for pregnancy comes, there is little direction or guidance and young women’s lack of knowledge of a problem results in the delay of seeking a fertility specialist.

Knowledge and responsibility of the male factor of infertility was cited as a gap in knowledge by 90% (9 of 10) respondents in both countries. The male factor of infertility is addressed differently in different cultures, but it is simply not widely recognized that infertility is just as likely to affect men as it is women. One doctor from India painted the picture that when couples come to his clinic, “the opening statement is “My wife is unable to conceive,”” which he finds problematic in that it unjustifiably places blame on the woman without knowing the root cause of infertility and demonstrates a lack of knowledge. An American doctor stated that while the biggest gaps in RHK “used to be male factors, that’s changing as males become more engaged in the process”, either by supporting women in their choices for contraception, learning about women’s health, or attending fertility appointments with their female partners. Physicians in both countries perceived and identified certain ethnicities to have especially difficult times dealing with male factor based on culture, namely Latino, Arab, Nigerian, and Black populations in the U.S., and the Muslim population in India. Several doctors from India say that it is not uncommon to see the sentiment that if the wife is unable to conceive, the husband should

divorce her and find someone new. However, the inability to conceive can just as easily be attributed to the male factor, so when infertility occurs again in the second marriage, this forces men to get tested and treated. This demonstrates a lack of knowledge of causes for infertility and the importance of acknowledging the male and female factors.

Spreading awareness in both societies that infertility is equally as likely in both males and females can relieve blame on women and reduce emotional burden, as well as more effectively target treatment.

Social media was mentioned positively across interviews in the United States and India as a way for doctors to easily spread accurate information to a wide audience of men and women directly. One doctor from the United States says that she and her colleagues were shocked by the lack of knowledge of basic reproductive health of women of all education levels, and they were inspired to start an Instagram page and application where individuals can ask questions to hundreds of experts on-demand and can get connected to certain clinics that offer free and reduced consultations. Another doctor from India mentioned that in her years of practice, she came to know of patients' friends and relatives spreading inaccurate information on infertility which they didn't know much about, motivating her to start sharing information on Instagram and through pamphlets distributed throughout the hospital in which she works. While the Indian Council of Medical Research (ICMR) is the governing body overseeing accreditation, supervision, and regulation of ART and ART clinics in India, another doctor from India mentioned that social media and the internet are also keeping physicians and clinics accountable and increasing transparency (Indian Council of Medical Research 2005). Even through the process of recruiting participants for this study, it was apparent how

vocal and supportive the infertility community of both doctors and patients is on Instagram.

Misinformation spread by Bollywood movies in India including the false portrayal of conception and the seemingly haphazard process of fertility treatment are proving detrimental to women trying to get pregnant or in need of treatment, as explained by one doctor from India. Though media was not part of the interview questionnaire, Bollywood movies were cited as a source of misinformation by three of six doctors from India. Doctors cited these movies as inaccurately representing the process of conception in that “once you kiss or touch someone you become pregnant”, especially hyping up the notion of the “first night [after marriage]”. More specifically, the popular movies “Chori Chori Chupke Chupke” and “Good Newwz” were cited for their misinformation. In the first movie, an infertile couple asks a prostitute to carry their baby as a surrogate. The prostitute becomes pregnant by having sex with the husband only once instead of using a fertility clinic or proper surrogacy methods available to the wealthy couple, and the movie also ignores the fact that getting pregnant naturally is not instantaneous. The second movie is a comedy, where two couples with the same last name approach a fertility clinic to undergo IVF, only to find later that their sperm were switched. Though the content of these movies were created as jokes, “they have become ingrained in people’s minds”, one doctor states. Bollywood movies are accessed by millions of people across all demographics of India and “despite people knowing that it’s a fictional movie, they feel that it could still be a possibility”.

Media in the United States was cited as having both positive and negative effects on infertility awareness. Media was cited as a source of misinformation but also as a way

to increase representation of all types of women facing this disease and to spread education. Recently, older women have been sharing their stories of pregnancy, sometimes even after the age of 40, which are most frequently due to fertility treatment or donor eggs, explained by a doctor from the U.S. When not supported by the accurate information on how these pregnancies occurred, it can sometimes create misconceptions; thus, it is important for women to “recognize the realistic age for pregnancy” despite the exceptions that make it into the media. However, celebrities and influencers publicly sharing their pregnancy and infertility journeys have also raised awareness about the prevalence and non-discriminatory nature of the disease. One doctor from the U.S. stated that she uses examples from the media to show how many celebrities of color have utilized fertility services. She finds this important because “women of color have internalized that this is something other people can do”, or that infertility treatment is “foreign, fake, or unnatural”. She says that by highlighting the stories of other women like Tyra Banks and Gabrielle Union, patients of color especially can see that there are more people utilizing these services than one might think. While the choice of whether or not to share their journey with infertility publicly is obviously the patient’s, encouraging patients to be transparent and sharing the infertility journey in their small circle of friends, family, and coworkers can help “break down barriers around [patients] to alleviate the burden on [them]”.

Discussion of Reproductive Health Knowledge

The biggest takeaway from the perspectives of doctors in the United States and India was the overall lack of reproductive health knowledge, which is supported by a

breadth of research conducted in both countries. Specific gaps in knowledge identified were when to seek help for fertility issues and the scope of practice of fertility specialists, which are new findings. This research builds on the work done by Patra and Unisa (2020) utilizing a reproductive health knowledge index (RHKI) on women in rural India by using providers as informants for larger patient populations and by expanding the research to women across India and the U.S. This research came to similar conclusions in regards to the perceived causes of infertility being biology and old age in both countries, and also due to religious reasons and “God’s will” in India. In Patra and Unisa (2020), knowledge of ‘biology’ as a factor in infertility was not broken down into male and female causes of infertility, which this research found to be a significant gap in knowledge. This fact is slowly becoming more well known as men are more engaged in the treatment process, but resistance from males regarding testing still remains an issue in the U.S. and India among specific ethnic groups. Research conducted in the U.S. by Lundsberg et. al (2014) corroborated this gap in knowledge as respondents in that study more infrequently attributed a cause of infertility to “increasing age of male partner” (Lundsberg et. al 2014). Interestingly, this research also revealed an overemphasized view of IVF from these physicians’ perspective, as it is the most well known and perhaps only treatment most individuals know about, whereas it is actually an advanced course of treatment for infertility used after other methods have proven unsuccessful.

While there exists some research on how media can spread general health knowledge, little research covers the specific link between media and fertility awareness. In the research done by Patra and Unisa (2020), they stated that “any exposure to media increased RHK”, but this study expands on that finding by showing both positive and

negative effects. In order to improve gaps in knowledge, informants of this study explained their initiatives for sharing information through social media, especially Instagram. Bollywood movies in India were cited as a unique source of misinformation for patients. Lastly, there has been little research on women's sources of reproductive health knowledge information in India, but a 2014 study of RHK in women in the U.S. stated that 75% received most of their information was from female health providers (Lundsberg et. al 2014). This ties directly to the ASHAs mentioned by one informant from India and identifies key informants for distribution of RHK and infertility in both countries.

Cost

United States

Given the difference in infrastructure between payment systems in the U.S. and India for medical treatments, it was no surprise that sentiments from each country were different. While 100% of U.S. doctors cited cost as a 'very important' barrier, doctors from India were split evenly between cost being 'moderately' and 'very' important with averages of 3.0 and 2.5 respectively, as seen in Table 1. While one doctor from the U.S. stated that cost "used to be the number one barrier but isn't anymore", another stated that treatment "can be very expensive and is probably the number one barrier for women who don't access care". In the United States, geography is an important factor for determining coverage as 16 of the 50 states mandate fertility benefits of insurance companies (NCSL 2021). The National Conference of State Legislatures contains a summary of each of these states' unique mandate, ranging from mandating insurance to only offer fertility

benefits or cover infertility treatment to some degree. This complexity in coverage can cause confusion for patients regarding cost when seeking ART as explained by one doctor, but any level of financial coverage is helping providers to improve access to care. In states where there is not an insurance mandate for infertility care, the patient populations of infertility clinics become more “homogeneous because care is very expensive”, as described by one U.S. doctor. In addition to cost, bias of the referring physician and whether they believe that the patient can afford the treatment prevents patients, especially those that are publicly insured, from gaining access, as mentioned by two American physicians. One of these physicians went on to say that this a “disservice to the infertility community because lower income people represent a segment of the population that’s not represented in the infertility space, not because they have less infertility (in fact they have more), but because they are unable to access care”. This highlights a barrier to accessing care that requires change in coverage as well as in provider behavior.

While we know insurance coverage is important for increasing access to care, one U.S. doctor emphasized the importance of coverage by noting the link between coverage and ART outcomes. Patients with insurance coverage have more successful treatment than those who do not, due to the increased probability of success with additional cycles. Continuing to pursue cycles after failing takes an enormous emotional, physical, and financial toll, and insurance coverage can partially alleviate this burden. Additionally, patients with insurance coverage are more inclined to use IVF compared to those without coverage who will sometimes attempt less expensive yet less effective treatments for longer than recommended.

The struggle of insurance coverage for fertility treatment was discussed in every interview with a U.S. doctor, and the majority expressed the importance of getting coverage nationwide. Efforts beginning in 1999 tried to have infertility covered under the Americans with Disabilities Act by classifying reproduction as a major life action that people suffering from infertility are unable to perform (Omurtag 2020). The famous *Saks v. Franklin Covey Co.* case tried to exploit this loophole by arguing that “unlawful discrimination occurs when a woman is denied coverage for infertility treatments that can only be performed on women” (Saks v. Franklin Covey Co. 2003). Though the United States District Court for the Southern District of New York ruled against Saks, it was important in creating momentum for coverage even though national coverage remains incomplete. However, instead of lobbying the state and federal government for legislation mandating insurance coverage, one of the U.S. doctors recommended lobbying to Fortune 500 companies to provide benefits for their employees instead. The informant believed that as more chief executives ascend to positions of power, they are more likely to know someone who suffers from infertility or have experienced it themselves. This personal connection will convince employers to cover benefits for their employees. Insurance coverage for fertility treatment satisfies “capitalist and altruist motives equally”: coverage increases volume for doctors and increases profits for doctors and other entities while also increasing access for patients.

India

In India, the common sentiment expressed by doctors about cost was that though treatment is expensive, “the cost is justified for the services given the number of things

required”. This highlights a key contrast in sentiment from the U.S., where cost transparency in healthcare, especially for procedures, can be unclear. While treatment in India may be expensive, several doctors noted that the cost is “no more than other medical treatments”: a normal delivery without complication might cost 1.2-1.3 lakhs, while an IVF cycle might cost 1.8-2.0 lakhs. Regardless, among patients of the lower and middle class, accessing fertility treatment is “taboo” because they perceive it to be very expensive and pursued by primarily wealthy couples only, relating back to a gap in knowledge of cost of treatment. Cost for services in India varies by hospital and is especially different between government versus private hospitals. One doctor explained that couples with more money often choose to have their outpatient reproductive care in a private hospital while poorer patients can only afford the government hospitals. While the tests will be the same in private and government hospitals and doctors are equally qualified, the quality of care in government hospitals is inferior due to the lack of human and physical capital and sheer number of patients. However, in general, the doctors from India felt that while the cost is important for some patients, “if you can convince them that it will provide results and achieve a pregnancy, it’s not as important as other aspects”.

Even though the costs are not as inflated as they are in the United States, Indian citizens face a different type of problem with the healthcare system. Because India is a country with a large proportion of citizens at and near the poverty line, another doctor explained the importance of publicly funded government hospitals offering infertility treatment. Though it is seen as a “higher-end” treatment, offering fertility care at private hospitals only excludes large segments of the population from accessing care. Quality of

care at government hospitals needs to be improved to equalize the difference between public and private hospitals, even though the tests may be the same: this desire was expressed by two of the six of the doctors from India. Lastly, several doctors from India stated that hospitals are readily accessible to patients, but additional money can provide a path to better quality care with more physical resources, staff to care for patients, and better technology for the hospitals.

Discussion of Cost

The discussion of cost as a barrier to accessing care is unique for both countries. The conversation among the doctors from the United States centered mainly on the lack of insurance coverage for ART across the nation. Only four states in the U.S. offer a comprehensive mandate for ART which includes four cycles of IVF (Sunderam et. al 2018). Thirteen additional states have a variety of different mandates, in which benefits range from just consultation up to a few cycles of ART (Armstrong and Plowden 2012). Doctors expressed frustration over the lack of standardization of coverage which excludes segments of the population from accessing care including minorities and people of lower socioeconomic class, which aligns with current literature on ethnicity and ART. A study in 2012 investigated the interrelatedness of ethnicity, infertility incidence, cost, insurance coverage, and utilization of ART. Researchers found that infertility incidence is higher among African-American and Hispanic women, both of which have lower utilization rates for ART than their white counterparts (Armstrong and Plowden 2012). In environments with lower-cost treatment and better access to care, African American women's utilization of ART increased but Hispanic women's utilization did not change.

In Massachusetts, a universally mandated state, Caucasian women of higher socioeconomic status still utilized ART at much higher rates (Armstrong and Plowden 2012).

In this research, provider bias, both implicit and explicit, was expressed as a concern for minority and publicly insured patients as a barrier to care, specifically in terms of referrals for fertility treatment. This finding supports current literature which found that providers may see some minorities as hyperfertile, perceive African Americans to be less educated, and believe patients of lower socioeconomic status to be less compliant with treatment (Armstrong and Plowden 2012). The notion of hyperfertility in African Americans was discussed by American sociologist Patricia Hill Collins in her book *Black Feminist Thought* in relation to controlling images of Black women and their oppression at the intersectionality of race, class, and gender. Collins describes the stereotype of the hyperfertile Black woman in the controlling imagery of the “breeder” woman during slavery and the “welfare mother” in the post World War II welfare state as women who produced many children (Collins 1991). Informants in this study believed that these biases are affecting the likelihood of minority patients being referred to fertility clinics, especially in states without mandates. All of these findings emphasize the importance of cultural competency and bias training for medical professionals and for national fertility coverage.

In India, fertility treatment is not covered under insurance, but a few doctors explained that costs are not exorbitant and are on par with other medical treatments. Additionally, access to hospitals in India is not an issue according to the respondents; however, the quality of care between private versus government hospitals is not equal due

to a lack of resources and staff. According to the Commonwealth Fund, Indian citizens can get free inpatient and outpatient services at any government hospital. Recognizing the inequality between public and private hospitals, a new payment scheme known as National Health Protection Scheme was introduced to help low-income families access care at private facilities as well (Tikkanen et. al 2020). Overall, this research aligns with the previous literature in that cost is not the most significant barrier to accessing care in India.

Politics

United States

Doctors in the United States and India cited politics and regulation as an important barrier for different reasons: in the U.S., state-by-state politics was a barrier, while in India, national legislation was the barrier. Politics was ranked by half of the U.S. doctors as ‘moderately important’, while the other half ranked it as ‘very important’ as seen in Table 1. Of the doctors that said politics and regulation is an important barrier to accessing fertility treatment, all were passionate in their responses. After being asked to elaborate on this barrier, one doctor immediately replied “I don’t know why people are trying to control women’s bodies”. Another said “if we were able to release women’s health care from the grip of governmental policy, that would be so beneficial”. In the United States, this barrier is important because “many issues become highly politicized that don’t need to be, and women’s health is one of those issues”. Though America is supposed to have a separation of church and state, “many conservative policies are based on some religious backing/opposition”, and this negatively affects couples who are

trying. It was clear that the American doctors in this study were all against the politicization of women's health issues.

Geography and politics of different regions in the United States is affecting fertility treatment. One doctor expressed sadness that women have to travel to different states for certain reproductive health rights including termination of pregnancy. Targeting of Planned Parenthoods across the nation also demonstrates the divisiveness and politicization of women's health, which is rare in other countries. In regards to the state mandates mentioned in the previous section on costs, loopholes in state legislation prevent smaller employers and patients of Medicaid from having infertility benefits, which was experienced by some patients of one of the doctors. One doctor found it shocking and unfair that depending on where patients live and the party affiliation of their governor, they may or may not have access to medical care.

Another doctor from the U.S. expressed that he would normally rank politics as having 'little importance' on access to fertility treatment, but "given the recent political climate", he had to rank this item as 'moderately important' instead. Specifically, there have been efforts to "whittle away and overturn *Roe v. Wade*, and the Trump administration, through judicial appointments, has provided a direct pathway for opponents to overturn it". Considering the federal government's role in a federal mandate for infertility benefits, this doctor stated that this is unlikely because "1) unfunded mandates are unpopular for many politicians, 2) the federal government has too many problems to be legislating IVF coverage and will leave this up to the states, and 3) energy is better spent in the private sector because employers want to feel as they are agents for change". This doctor recommended approaching employers and their HR departments

with data supporting the number of employees that would utilize the infertility benefits, and stated that they are much more likely to provide coverage.

India

Doctors from India ranked politics to be ‘moderately important’ with an average of 2.0, but responses varied widely from ‘little importance’ to ‘very important’, as seen in Table 1 on page 28. The state-by-state nature of issues discussed for the U.S. were absent in India; in fact, one doctor who rated regulation as having little importance stated “health and reproductive rights are the same across the country”. However, another doctor from India stated that “this is a very important factor and couldn’t be stressed more”. Discussion of politics in India focused largely on the tightening legislation on egg donation and surrogacy with the passing of the ART Bill of 2020 and Surrogacy Regulation Bill of 2019. Frustration revolved around the laws’ impracticability and disconnect between the policymakers making the law and the input of doctors who have to abide by it. For example, one doctor expressed frustration with the clause that states that doctors cannot take more than six eggs from egg donors, saying that this is impractical because that could mean taking six eggs of good quality or six eggs total, but it is not clear which. Additionally, another doctor cited the Surrogacy (Regulation) Bill of 2019, which bans commercial surrogacy in India, an industry projected to grow by 4 billion in just a few years (Gupta and Chaturvedi 2020). This bill attempts to regulate surrogacy by only allowing “altruistic” surrogacies with eligibility rules including that the intended couple must be married for at least 5 years with documentation of infertility, only “close relatives” of the intended parents can be surrogates, and surrogate women

must be between the ages of 25-35 and can only be surrogates once (Gupta and Chaturvedi 2020). This has made it extremely difficult for Indian couples to find surrogates, a service which was previously accessible through hospitals, as explained by one doctor.

Several doctors from India discussed the Indian health care system's influence on infertility treatment. Currently, infertility is a lesser known disease compared to other well known diagnoses like diabetes. Thus, one doctor stressed the importance for the first points of contact to the health care system, like primary care physicians, to understand the importance of recognizing and treating infertility. One doctor mentioned that the community health workers known as ASHAs (accredited social health activists) should also be well versed in recognizing and explaining the basics of infertility, as they mostly frequently focus on the health of women of a village. ASHAs were an effort part of National Rural Health Mission of 2012 by the India's Ministry of Health and Family Welfare to "counsel women on birth preparedness, importance of safe delivery, breast-feeding and complementary feeding, immunization, contraception and prevention of common infections including Reproductive Tract Infection/Sexually Transmitted Infections (RTIs/STIs) and care of the young child" (National Health Mission n.d.). ASHAS are required to be a resident of the village, between 25 and 45 years old, and trained for a wide variety of responsibilities (National Health Mission n.d.). The doctor noted this valuable resource to reach the women most vulnerable based on their educational level, geographic location, and socioeconomic status.

Unregistered fertility clinics were well-documented in the literature and cited as an important issue in India. When asked about unregulated or unregistered infertility

clinics, several Indian doctors responded that they had not heard of such practices and only knew of registered and reputable clinics within their area, while only one doctor's response aligned with what was described in the literature. This doctor stated that "there are a lot of unregistered clinics, which offer treatments at cheap prices. The medicine or treatments are not of good quality which can result in complications and then the whole fertility segment of the country is blamed and put in a bad light". This doctor went further to state that the doctors running unregistered clinics did not go through the registration process or were unable to successfully register because they didn't meet the quality standards "yet continue to practice which is dangerous". A second doctor offered the perspective that the conception of unethical or unregistered clinics may be stemming from the difference in training for fertility specialists in India compared to the United States. In India, there is not an independent reproductive endocrinology degree, so OBGYNs with enough money are able to start fertility clinics without necessarily having the expertise in infertility, or can hire other doctors. Yet another doctor responded that while "in the past there may have been an issue [of unregistered clinics]", with social media and the ICMR guidelines clinics requiring more transparency, it makes it difficult for unregistered clinics to succeed. This doctor explained that with clinics' certification required for certain kinds of insurance coverage, hospitals being required to have a special certificate to perform IVF, and doctors' registration and CME requirements have all helped to curtail illegal activity. Possible reasons for these mixed responses by doctors are posited in the discussion of this section.

Discussion of Politics

Politics was a highly important barrier for doctors in both countries. While prominent ART regulation in both countries clearly defines infertility as a medical condition, there appears to be a disconnect between the legislation and insurance coverage (Indian Parliament 2017) (U.S. 116th Congress 2019). In the United States, doctors were primarily concerned with the intrusion of government and politicization of women's reproductive health issues. Several of them found the politicization inappropriate and found it alarming that the state in which one lives can affect reproductive health outcomes. Research by the Guttmacher Institute on reproductive health legislation in 2020 found that states enacted 89 policies expanding reproductive health including 14 pieces of legislation that expanded access to contraception and infertility care and 8 that improved sex education (Nash et. al 2021). Though there do remain geographical barriers to accessing care in the U.S., these data show that the country is moving in the right direction.

In India, legislation was cited as a barrier to care in regards to the new ART and Surrogacy Bills, the structure of the Indian health care system, and unregistered clinics. Primary frustration with the two new laws are their impracticability due to lack of input from doctors; the new ART Bill places restrictions on egg donation, and the Surrogacy Bill greatly restricts who is eligible for a gestational surrogacy and to be a surrogate mother. While prior research suggests that the ban on commercial surrogacy and increased stringency for surrogates was to curtail unethical practices and protect rights, this study highlighted a contrasting perspective of the difficulty in finding a surrogate even for Indian citizens (American Surrogacy n.d.).

Data on unregistered clinics in India were unclear, with two doctors discussing poor quality care and inadequately trained physicians running clinics, while the remaining doctors believed that with increased transparency and tighter guidelines by the Indian Council of Medical Research (ICMR), prevalence of these clinics has declined. There is a disconnect between the literature which cites a high prevalence of unregistered clinics in India, while the majority of doctors interviewed stated that these unregistered clinics are few and far between (Dey 2017). This could be because the doctors interviewed worked in primarily urban areas, which may have little to no presence of these unregistered clinics. Conversely, this could indicate that recent regulation by ICMR and social media have curtailed unregistered clinics and that the literature is out of date.

Factors Influencing Coping Strategies for Infertility

Table 2. Factors affecting coping for infertility. (n=10)

Doctors were asked to assign a rank of importance to barriers to accessing treatment as either 1 = little to no importance, 2 = moderately important, or 3 = very important.

	United States					India						
	Dr. 1	Dr. 5	Dr. 8	Dr. 10	Average*	Dr. 2	Dr. 3	Dr. 4	Dr. 6	Dr. 7	Dr. 9	Average*
Cultural Stigma	3	3	3	3	3	3	3	3	3	2	3	2.83
Family	3	2	2	2	2.25	3	3	3	3	3	2	2.83
Religion	"secular society but is challenging for some"	"depends"	"dimension for coping or an added stress"	"important for those that need it"	n/a	3	3	1	3	2	2	2.33

**Responses for each item were averaged across respondents from each country.*

Cultural Stigma

United States

In the United States, all four doctors rated culture and social stigma as a ‘very important’ influencer of coping as seen in Table 2, and many interesting dimensions of this factor were identified. A doctor from the U.S. stated that while it is well documented that suffering from infertility causes the same elevated level of cortisol (stress hormone) as the death of a loved one, American culture does not offer the same societal level of support. The doctor then went on to give the example that “when someone has cancer, people run marathons and wear special colors. When someone dies, there is a gathering of support. But when someone has infertility, they are told they should just relax or go to Hawaii”. This quotation captures the sentiment that infertility does not receive the same level of legitimacy as other medicalized conditions. One doctor posited that American women feel as though they have little support, are isolated, and that something is wrong with them, a similar sentiment of women suffering miscarriages.

The sources of stigma against infertility in the U.S. remain unclear but could be attributed to insufficient RHK and the mixture of ethnic backgrounds of the population. One doctor posited that one of the biggest sources of stigma is that society assumes that pregnancy is something that is supposed to be “natural and just happen”, but with adequate medical knowledge we understand it is not as simple. Stigma could also be originating from the different ethnic backgrounds represented in American society. The U.S. population is very heterogeneous with people from countries around the world and it is possible that the cultural stigmas of these different ethnicities add onto the general stigma against infertility due to lack of RHK. For example, one doctor felt that based on experience with her heterogeneous patient population, women whose families immigrated from Africa and India feel an especially greater burden of stigma not only from their cultural background, but also of that in American society.

Half of the doctors from the U.S. discussed the history of racial differences in utilizing treatment for fertility and attributed this to the stigma of accessing treatment as well. Unfortunately, there still is still a social stigma about infertility treatment “because the patient population has looked a certain way: namely, white women who can afford it and have the means”, and women of color have internalized that “this [treatment] is not for you--this is something that other people can do, afford, and deserve”. Another doctor gave the example that “if you are a privileged white female in the U.S., you’ve been seeing imagery of celebrities that look like you doing IVF for a long time. However, if you’re a black female, you haven’t seen anyone that looks like you until recently”. Infertility was seen almost exclusively as a “white people thing”, but with more “outspoken underrepresented minorities” in the media like Halle Berry, Janet Jackson,

Michelle Obama, and Beyonce, this is changing. A third doctor stated that the only negative to using these celebrities as role models is that celebrities can also make infertility seem like “a far off thing” rather than a disease that someone you know might be going through. However, the doctor states that infertility treatment is not only for celebrities because “everyone has the right to have their organs function as they’re intended to!”.

Two doctors from the U.S. mentioned that implicit and explicit bias on the side of providers may also be deepening these racial differences. One doctor gave the example that a physician may think that they have seen many black women with no problem getting pregnant, making them less likely to believe a black woman presenting with possible infertility, even though we know that infertility touches people of all races. This doctor also noted that black women statistically show up to fertility clinics much later and emerge with worse outcomes, but it is unclear what is causing this trend. Another doctor mentioned that additional research is warranted to understand how racial and cultural barriers contribute to the emotional burnout of minority patients, which is only exacerbated by the baseline burnout of all patients commonly seen in ART cycles. In addition to racial stigmas, male factor infertility continues to be stigmatized for both white and black men, as mentioned by one doctor from the U.S.

India

In India, doctors’ ranking of culture and stigma averaged at ‘2.83’, leaning toward it being a ‘very important’ influencer in coping, as demonstrated in Table 2. The racial differences in utilization of infertility treatment seen in the U.S. are not apparent in India,

most likely due to the homogeneity of the Indian population. Most notably, the social stigma against infertility in India is rooted in the close-knit social structure that results in the intrusiveness of friends and relatives. This was cited as the most important source of stigma in four of the six interviews, but was frequently tied to the family and family structure factor. It was mentioned by several Indian doctors that though the young couple may not be concerned about having children yet, within as early as two to four months after marriage, friends and relatives begin to question why the woman has not yet gotten pregnant. These friends and relatives are usually not ill-meaning, but wanting everyone to start a family at a young age is a sentiment “that just runs in our [Indian] blood”, said one doctor. This priority of having children early is ingrained in Indian culture and is expected to be a newly married couple’s first responsibility. Support from the family can be very important to help women battle the social stigma and by giving the couple space to decide what is best for themselves. The link between language and stigma in India was also mentioned by two doctors. One mentioned her clinic’s use of the term “subfertility” as opposed to “infertility” in order to reduce taboo, and the other mentioned that classifying someone as “infertile” causes the individual to be seen as incapable of something rather than possessing a medical condition. However, as will be discussed in the next section, doctors shared that it is not uncommon for women to hide their infertility from everyone but their spouse.

Discussion of Cultural Stigma

In regards to coping strategies utilized by women in both the U.S. and India, cultural stigma were crucial factors that are well-documented in the research. Physicians

reported that women feel isolated, ashamed, and assume blame for their infertility in both countries, which are similar to adjectives self-reported by infertile women in the U.S. in a study conducted by Whiteford and Gonzalez (1994). In both countries, lack of social support and recognition in comparison to other medical conditions like cancer or diabetes was mentioned. A few doctors mentioned the need for campaigns for fertility awareness, workup, and treatment, which is supported by research from the literature review: possible topics for these workshops suggested in the literature include the effect of increasing stress, changing lifestyle, and delayed childbearing for women in today's society (Lal 2018).

In the United States, there was additional discussion about the racial differences of those who have historically utilized fertility treatment, and the stigma that infertility is a “white people thing”, as one doctor put it. This is supported by current research, which found that minorities in the U.S. have much lower ART utilization rates in part due to cultural beliefs. African American and Hispanic women have greater perceptions of stigma associated with the diagnosis of infertility, more ethical concerns with treatment, and African American women specifically were less likely to be voluntarily childless and less likely to receive family support for treatment (Armstrong and Plowden 2012). Culture in Arab-American and African American populations focused greatly on parenthood and having children, causing a more detrimental effect to the social status of infertile couples. Both ethnic groups have also faced discrimination in the U.S. healthcare system resulting in distrust of the healthcare system and Hispanic population demonstrated distrust of physicians (Armstrong and Plowden 2012). Because the United

States is such a melting pot of cultures, additional research in fertility treatment and utilization with special detail to ethnicity is needed.

The link between language and stigma was also noted by two doctors, one from the U.S. and one from India, who believe the term “infertility” is emphasizing an inability or shortcoming. This contrasts from the work of one Indian feminist discussed in the literature, Urvashi Butalia, who suffers from infertility herself. She chose to remain childless and stated that she was able to find fulfillment outside of children, which does not seem to be a common sentiment among women in both countries as was described by doctors. However, Butalia’s belief that current terminology imposes a “lack” of something was echoed by doctors and identifies an area of infertility that can be changed (Butalia 2013).

Another area of discussion between the literature and the results of this research is in the perspective that women lose their rights or individuality with or without children. An article published on the Feminism in India website argued that becoming a mother consumes women’s social identity and erases their individuality (Arora 2020). However, from the interview discussion about family intrusion in both countries and unsolicited advice from friends and family could be seen as a loss in women’s rights to privacy and the couples’ right to choose the treatment method right for them. Several doctors from India mentioned young women showing up to their clinic after only two to four months after marriage and sexual intercourse, when infertility is defined as the inability to conceive after twelve months. As discussed in Inhorn and van Balen (2002), the interviews with Indian doctors emphasized childbearing as a result of family pressure

more than by choice, or as the byproduct of both and the next logical step after marriage. This was corroborated by the Indian doctors interviewed in this research.

An Additional Coping Strategy: Counseling

As part of the conversation about cultural stigma, the importance of counseling was raised in four interviews across the United States and India, two in each country. While the importance of counseling especially throughout the infertility process is well-documented in the literature and well over half of patients suffer from depression and anxiety, it is still not as widely utilized in both countries due to the stigma against mental health and seeking help, as noted by one doctor from the United States. Another doctor from the U.S. stated that “stress reduction is unrealistic because life is inherently stressful”; however, counseling is about “stress management, therapy, and healthy coping strategies”. She went on to say that couples counseling is especially important because men and women have different coping mechanisms and the emotional struggle of males throughout this process is under-recognized. A similar sentiment was echoed from the perspective of doctors in India, stating that learning coping mechanisms are especially important in infertility treatment because patients have to be prepared for disappointment, as successful infertility treatment usually requires a few cycles. This doctor added that counseling should not stop once a baby has been conceived but should continue through the nine months of pregnancy which are difficult as well. However, another doctor from India said that counseling is scarce in India and the support groups started at clinics in large cities are not doing well. Along with the barrier of stigma, participating in counseling services has additional time, cost, and transportation barriers. A doctor from

the U.S. shared that counseling services and support groups in her clinic are free of charge, because “women already paying for fertility treatment will not want to pay extra or have time for extra counseling services”, and she has seen very high utilization rates from her patients. By taking away the cost barrier and offering counseling in-house, more women can utilize the services.

Discussion of Counseling

Counseling was cited as an important coping strategy by three doctors across both countries, but due to the stigma against seeking support of mental health, is not utilized as widely as it should. Given the high cost of infertility treatment alone, it was posited that spending any more time or resources for counseling is difficult for women. In India, social stigma was cited as the most important factor in preventing use of counseling services rather than cost. As was discussed by Zeinab, Zohreh, and Gelehkolaee (2015), counseling is important for anyone going through infertility because it is a “chronically stressful factor” affecting “all aspects of people’s lives” (Zeinab, Zohreh, and Gelehkolaee 2015, 18). These authors stated that infertility can cause individuals to avoid socializing and the risk of harmful comments explicitly or implicitly, and this avoidance was relayed by physicians in both countries. Counseling is especially for individuals of lower socioeconomic status who often have weaker support networks, which emphasizes the importance for free counseling to be provided in conjunction with care (Zeinab, Zohreh, and Gelehkolaee 2015). Problems in the interaction of family with the infertile couple was cited as detrimental in three of the four interviews in the U.S., adding to the

importance of counseling for family as well, highlighted by research published in the *Global Journal of Health Science* (Samadee-Gelehkolaee 2015).

Feminism

United States

A majority of doctors from the U.S. felt that the feminist movement does not necessarily resonate with infertile women because they still feel inferior for their inability to conceive. Though feminism has helped improve education on women's health, it has not yet touched "the emotional aspect and struggles of infertility", as one doctor put it. While some women in American society are prioritizing career over family, feminism is partially constructing this "we can have it all mindset", which is not true. One doctor replied that as of now he does not see much overlap between feminism and infertility, although a tangible link between feminism and infertility could be that as time goes on, "more women will ascend to positions of power within the next decade, more women of color especially, thus policies will shift to be more pro-family". Another doctor was the only one who believed feminism was somewhat positively tied to infertility. She believed that the feminist movement in general has helped to "empower women, allow more conversation, and remove stigma". However, she said this could be attributed not only to feminism but also the general shift in the healthcare system from a paternalistic to more patient-centered structure, as patient input becomes more important in clinical care. Both of these factors have empowered women's voice and autonomy.

India

In India, the majority of doctors believed that only a small proportion of India's population is knowledgeable about and has gotten involved in the feminist movement. One doctor posited that about 25% of women choose to postpone pregnancy, and while only 7% of this could be tied to feminist beliefs, the remaining 18% do it in order to ensure financial stability for their family. Another doctor said that the concept of delaying pregnancy for career is a mindset found more frequently in developed countries and two doctors believed that "most of India does not have the culture of postponing pregnancy for career".

Contrastingly, one Indian doctor believed that "the feminist movement has caused the problem of infertility", as the best time to get pregnant is between ages 25 and 29, but this is also the peak time for career advancement and development. She stated that this problem is especially important for Indian women, as recent research has shown that their ovaries age earlier, around age 34 as opposed to age 40 due to a diminished ovarian egg reserve, reducing fertility potential. For a large proportion of Indian women, motherhood does define them at some point in their life, so the feminist movement "may be causing more harm than good because saying you can get pregnant when you want to is not the full information", as another doctor says.

Discussion of Feminism

The feminist movements in general have not significantly impacted the infertility sphere, but were perceived negatively by doctors in both countries because they believed that when discussing delayed childbearing for a career, women are not given the full

information in regards to the consequences. Most believed that it has caused misinformation that having children can wait, but the years between 25 and 29 are the most important both professionally and biologically. Specifically for Indian women living in both the U.S. and India, the fact that their ovaries age earlier was pointed out by one doctor and established in the literature review (Iglesias et al 2014). However, the majority of doctors in India stated that the feminist movement has not been widely accepted in India and is not making any significant impact on childbearing age.

Family

United States

Doctors in both India and the United States stated that hiding the entire experience of infertility was common due to shame and a perceived (or actual) lack of support. Among the doctors interviewed in the United States, family averaged a ranking of '2.25' as seen in Table 1, leaning toward being a 'moderately important' barrier for coping. All of the doctors in the U.S. were unable to generalize the support of family for all patients, because while some patients receive overwhelming support, others did not share their infertility experience, and this seems to be on a very individualized basis not following any pattern. One doctor described family support as "a two way street, because while fertility affects relationships, relationships affect fertility". This doctor went on to say that a patient's level and quality of their support system is important for their treatment success in terms of dropout rate, depression, and anxiety. All of the U.S. doctors stated that the partner's support was the most important, and the family support "is not as important as it should be". One doctor explained that the support of the spouse

throughout this process is critical because of the intimate making of the baby, but it is important that the couple support each other, as men's mental health and stress as it relates to this journey is not recognized as much. Because extended families in the U.S. usually do not live under the same roof, there is less involvement of the family, but family support or pressure can have a huge impact on how women cope, as was described by two doctors. The one exception here is in the case of single women wanting to have a baby, as they rely exclusively on family support and the family is usually responsible for encouraging the woman to go forward with treatment, as noted by one doctor.

One doctor posited that about one in four women in the U.S. choose not to share their infertility journey with family or friends, and this "secrecy causes another layer of burden". Another doctor hypothesizes that some women choose not to share their infertility because they have faced negativity from someone who has blamed the infertility to be their fault because they are stressed and don't require medical treatment. Attending a family dinner where relatives are making comments such as "When will I get a grandchild? Why aren't you pregnant yet?" can be extremely painful for these women as recounted by one physician. This can cause anxiety and avoidance in women with their families.

India

The factors of culture and family were almost interchangeable for doctors from India. Family was ranked as a 'very important' factor in coping for all but one doctor, as seen in Table 2. Joint families and extended family living under the same roof or in very close proximity is extremely common in India and plays a large role in the increased

scrutiny and pressure of young couples. Thus, issues of infertility are discovered by the family quickly and women are inundated with advice and information that may or may not be accurate. Additionally with this family structure, “planning a pregnancy is not a couple’s matter but becomes a whole family matter” as was described by one Indian doctor. Another doctor said that occasionally, the extended family finds fault in “the person who is outside of the family” which is extremely painful for the woman but is “just the Indian mentality”. One doctor posited that about 85% of couples get full family support, while 15% choose not to reveal infertility to their family. The relationship between daughter in laws and mother in laws was mentioned in several interviews, positively in that sometimes the mother in law is more involved than the partner when it comes to support and going to appointments, but negatively in that she may also overpower the patient and ask the doctor to “please fix her”, without recognizing the possibility of male factor infertility in her son. One doctor concluded by saying that ideally, support of the family should not invade the couple’s privacy and respect their choices. Overall, doctors stated that the partner is usually supportive, but it is difficult to judge what will determine if the women will have good family support, because it is not as clear a link to financial independence or education, for instance.

Half of the doctors from India brought up the unfortunate circumstance of male partners divorcing or remarrying due to infertility between the couple, in the most extreme cases. For Muslim men, some take on second wives to try to give them a child. In Hinduism, a second wife cannot be taken until the first wife is divorced, making it more difficult. One doctor posited that out of 100 patients, about 5 patients will go through divorce or the taking on of another wife to have a baby. Some of these cases of

infertility are due to the male factor of infertility rather than female, in which remarrying or a second wife does not solve the problem. Then, the doctors stated, the male usually comes back to the clinic to get treated and tested. This is not common but does reflect some women's lack of support from their spouse and family.

Discussion of Family

The relationship between family support and coping with infertility is complex and highly individualized. The only finding constant throughout all ten interviews was that the spouse's support through ART is of primary importance and if the family is involved, their support is secondary, and this aligns with existing literature studying emotional adjustment in American women after several cycles of ART published in the *Human Reproduction Journal* (Verhaak 2005). Though prior research has demonstrated that partners and families of African American women are less encouraging of pursuing ART, there is sparse research on the link between family and other ethnic groups in the United States (Armstrong and Plowden 2012). The quotations from Indian doctors' interviews are representative of the harassment, ostracization, and social rejection of infertile Indian women as was discussed by van Balen and Bos in 2009 of being childless in poor-resource areas, but adds to the research as these doctors served as informants for patients in urban areas (van Balen and Bos 2009). Prior research linked marital instability in infertility to low socioeconomic status, but this research further breaks the details of how men of Islam and Hinduism are religiously permitted to find another woman to conceive (van Balen and Bos 2009). Stigma and cultural expectations play a large role in whether couples are willing to disclose their infertility, and both high and low rates of

disclosure cause high levels of stress according to doctors in both countries, which was demonstrated in prior research published in the *Oxford Human Reproduction Journal* (Slade et al. 2007).

Religion

United States

Doctors across the board from both countries explained that religion can be a great source of support and strength for some patients but is also the greatest barrier to accessing treatment for other groups of patients. Thus, none of the doctors from the U.S. felt comfortable ranking religion as a coping strategy across their patient population, as demonstrated by the lack of rankings but rather sampling of representative quotations for each doctor's response about religion in Table 2. One doctor noted bias in the patient population she sees "because the fact they're coming through the door indicates they believe in science whereas people who have strong religious concerns in science wouldn't come in the first place". This doctor went on to say that strict followers of Catholicism have been some of the most challenging patients, as it can be tricky to balance the fine line between utilizing the infertility technology that works "so well but is not allowed", especially in IVF and IUI. This doctor stated that of her patients, she has seen that most Catholics in the U.S. can be flexible and do not follow exactly the Pope's beliefs in regards to contraception and treatment. A possible solution when working with these patients is to retrieve eggs but only fertilize two to make the process as natural seeming as possible. Another example by another doctor was given of a patient who is a Catholic school teacher, for whom assisted reproductive technologies are specifically

prohibited in her contract. At this point, the doctor described that some of his patients come to an important crossroads in their relationship with religion: “sometimes people will compromise, and others won’t”. Some patients following Christianity and Judaism have also struggled to find the balance between religion and treatment, but new organizations such as Fertility for Colored Girls and the PuaH Institute led by ministers and rabbis help their followers to understand how treatment fits into the scope of religious practice, as shared by one of the doctors.

India

Doctors from India ranked religion as a coping strategy for patients in India at a ‘2.33’, leaning toward moderately important, with individual doctors’ responses occupying the full range, as seen in Table 2. Several dimensions of religion were highlighted, from religion as a coping strategy, as a barrier to treatment, and as a player in ending marriages. Several doctors expressed the sentiment that if religion or rituals bring a patient peace and hope by putting faith into a higher power, it is great for the patient. Two doctors explained that faith and faith in the doctor are tied to the endocrine system and reducing hormones, which increases the success of fertility treatment. The medical profession in India has the utmost respect and one doctor explained that patients travel far just for their blessing. For Hindu patients, one doctor noted that about 20-30% go to a mandir (Hindi temple) prior to seeking medical treatment, but most seek help from pandits and doctors in conjunction. One doctor joked that pandits (specialists in the Hindu religion) probably get approached more frequently than fertility specialists in India, which speaks volumes about the importance of religion in the country, and could

be a possible untapped avenue for spreading infertility awareness and recommending medical help. Yet another doctor joked that “part of my treatment is also done by the pandit, as there has to be a “muhurat” for everything” (“muhurat” translation: auspicious timing for certain special ceremonies, in this case treatment or ART cycles). However, patients from all regions and religions in India seem to pursue some sort of ritual, temple, or spiritual being at some point in their treatment. In conclusion, both religion and spirituality are important as patients need hope going into fertility treatment, which is extremely taxing and has the possibility of not resulting in pregnancy.

As was discussed in the previous section, some men in India divorce their wives or take on a second wife after being diagnosed with infertility. While this is not common, it does happen and religion can dictate how some men deal with infertility in their partner, in the example of polygyny in Islam. Similar to the U.S., some Indian doctors also believed religion to be a barrier to accessing treatment, especially in Muslim religion where egg and sperm donation and fertility treatment are prohibited.

Discussion of Religion

The use of religion as a coping strategy varied significantly between the U.S. and India. Religion was not as common a resource for coping in the U.S. In fact, religion was instead cited as a barrier to treatment for certain religious groups including Catholics, Jews, and Christians. In India, religion was cited as a coping strategy used for a majority of the population. Similar to research published in 2015 which stated that 80% of Indians say that religion helps steer decisions in their daily lives, over 80% of Indian doctors in this study cited religion as a ‘moderately’ or ‘very’ important coping strategy (Wike and

Simmons 2015). Certain religious rituals or prayers to aid with infertility was cited as a coping mechanism by a minority of the Indian doctors which aligns with prior research, but as those authors found, these practices are often performed in conjunction with medical treatment (Mishra and Dubey 2014). Two doctors joked that pandits (individuals with advanced knowledge of Hinduism) are approached with problems of infertility as often as fertility specialists, highlighting a possible avenue for education and awareness. In India, religion was also cited as a player in divorce or taking on a second wife to conceive children in extreme cases of infertility. Similarly to the U.S., select groups of people in India struggle with religion as a barrier to treatment, especially Muslim patients. Overall, in both countries, doctors welcomed the hope that faith and religion provide as an important source of strength throughout the difficult infertility process.

Conclusion of Results

In conclusion, knowledge of reproductive health was the most important barrier to accessing care in both the United States and India, with similar gaps in knowledge of when to seek help and scope of practice for fertility specialists. Social media is making great strides in bridging the gap in knowledge in both countries allowing physicians to reach patients directly. Conversely, Bollywood movies in India are reinforcing inaccurate information and causing some distrust in fertility treatment. Politics was also cited highly as a barrier to accessing treatment: in the United States, access was restricted on a state-by-state basis, whereas in India access was restricted by the new legislation surrounding egg and sperm donation and surrogacy. Cultural stigma was cited as the most important factor influencing coping in each country, despite the difference in sources of stigma

between the two countries. In general, there is a lack of communication between the medicalization of infertility as a disease and the general population, insurance companies, and family, and misinformation being spread by celebrities, relatives, and the media.

In conclusion, there is a lack of communication between major health organizations which recognize infertility as a medical disease and the general population, insurance companies, and families, which can be improved by awareness efforts from the side of providers, patients, and the government.

CHAPTER 4: RECOMMENDATIONS

Introduction

The prevalence of infertility is rising in countries across the world, yet it remains stigmatized and hidden. With such successful technologies for ART, it is important for the medical community to understand the barriers patients face in their journey to consult with a fertility specialist and pursue this treatment, and how to make the coping process easier for these patients who are going through emotional, mental, physical, and financial stress. Throughout the interviews with fertility specialists in the United States and India, many recommendations were brought up that physicians hope to see in the future or have already begun implementing themselves. This chapter will build upon these recommendations by targeting them to providers, society, and the government with the goals of improving access and support coping for infertile couples. In general, the recommendations are organized from smaller, more feasible action steps to larger goals that can be achieved over time. Recommendations are for audiences in both the United States and India, unless specified otherwise.

Application of Feminist Theory

This study unearthed unintended consequences of feminist theory for modern women in both countries, especially in regards to increased delayed childbearing, primarily in the United States. While women are being empowered to pursue careers and are choosing to delay childbearing, it is important for them to understand the consequences in terms of fertility and that egg freezing is not a guarantee. Feminism in its

current state does not currently have much to say regarding infertility, but awareness and reproductive health knowledge efforts from feminist organizations could be helpful.

Several findings in this study demonstrate the gendered nature of defining infertility and seeking treatment, most notably the lack of equal blame on both partners for the infertility diagnosis, the reluctance to have a sperm test for men especially in India, and the politicization of women's health issues especially in the U.S. Feminist theory in medical sociology aims to understand the gendered nature of diseases and treatment and is very relevant to the barriers for infertility treatment and difficulties with coping cited by physician informants. The gendered abuse resulting from stigmatization of infertility has been recorded on the level of the couple, household, and society by a study conducted in Punjab, Pakistan, a country with similar cultural context to India (Mumtaz, Shahid, and Levay 2013). Within the couple, women are more likely to be abused by their husband in the case of female infertility, but not if the cause is male infertility. In the male's family, the female was more likely to be blamed for the cause of infertility even when infertility was proven to be due to the male factor. Additionally, it was documented that women living in joint households faced a greater burden than those living in nuclear households because of the hindered development of the couple's relationship and the lack of privacy when making decisions about treating infertility (Mumtaz, Shahid, and Levay 2013). At the societal level, women are faced with countless questions and infertile Pakistani women are excluded from a variety of social events, but men are rarely suspected to be infertile and do not face similar exclusion and stigmatization. This study also described a widely different pattern for seeking infertility treatment between men and women; primarily, that women were often pushed by mother

in laws or marital family to seek treatment months after marriage, whereas most men refused a semen analysis and only came for testing after failing to have children with a second wife as was found in this study as well. Lastly, remarriage after proven infertility was only discussed for males both in the research conducted in this study but also in that of the Pakistani study (Mumtaz, Shahid, and Levay 2013). These examples demonstrate the sexist treatment of females regardless of their responsibility in the infertility diagnosis. Gender, health, and politics are intertwined in the healthcare systems of both countries, but especially in the U.S. Women's health is a hotly discussed topic in politics, yet male health is almost never discussed. The choices women make about their body are being restricted by male-dominated politics in both the U.S. and India, and in other countries in the world.

Recommendations for the Provider and Medical Community

The most feasible improvements can be made by doctors because they are educated, deal directly with patients, have credibility, and their duty is to advocate for their patients. The primary recommendation for doctors and other health care professionals is to spread knowledge about infertility. For example, just from the sampling methodology used in this study, it was evident that all ten doctors are vocal advocates for infertility awareness on social media, which seems to be a great way for providers to reach patients and interested individuals directly. Infertility doctors on social media in both the U.S. and India have created a strong community sharing information, especially on Instagram. Knowledge can also be spread by educating professionals at the first point of contact for individuals to health care systems. For example, the ASHA

system in India which empowers women to be health advocates in their own villages would be a perfect target to educate to recognize infertility and share knowledge about the condition and treatment. Primary care and women's health physicians should also be knowledgeable about infertility and be ready to refer patients to infertility specialists, as they were cited as the main sources of reproductive health knowledge according to a study conducted in the U.S. (Lundsberg et. al 2014). The key points of information for these providers to share are as follows.

1. If the couple has been trying to conceive for 12 months and has been unsuccessful, they should seek help.
2. Reasons for infertility are equally as likely to result from the male or female.
3. Seeking help for infertility does not immediately mean receiving IVF, but rather there are several other types of treatments and conditions that can be treated without the use of IVF.
4. Cost for treatment is variable by state and insurance provider in the U.S., and by hospital in India. Information on ART success rates are publicly available online in both countries.

The second recommendation for providers that was mentioned by doctors in both countries was the importance of giving patients hope, while managing expectations. As one doctor stated, infertility is like any other medical condition that has treatment options. Another doctor stated that with all of our focus on the science and technology in infertility treatment, we also need to recognize patients' feelings emotionally. If, as the doctor, you believe that the patient has a good prognosis, it is important to say it aloud. For example "I want you to know that I think you're a good candidate for this

[treatment], and I'm feeling positive about our plan". Using small sentences throughout consultation to ensure the patient's understanding is important for patients to feel a part of their care. However, it is also important to manage patient expectations and ensure that they understand ART and egg freezing are not a guarantee, and these kinds of treatments usually require several cycles of failure before success. It is often the sequence of unsuccessful cycles that cause many patients stress and depression.

The penultimate recommendation for providers not exclusive to infertility is addressing physician burnout, which is rising to alarmingly high rates and affecting health care systems and patients' quality of care. Providers prioritizing their mental health and wellbeing is important for them to be their best at work, especially to be emotionally available for their patients. One doctor suggests curing burnout by addressing three energies: physical, emotional, and spiritual. These three energies, when replenished, can cure the three main symptoms of burnout measured by the Maslach Burnout Inventory (MBI) (Hoden 2020). First, replenishing physical energy through exercise, sleep, and nutritious food mitigates the first burnout symptom of "exhaustion". Second, replenishing emotional energy by building and growing relationships with friends and family can mitigate the second symptom of "compassion fatigue". Third, replenishing spiritual energy by rekindling connection with God, community, or a sense of purpose outside of the workplace can mitigate the last symptom of "apathy" (Hoden 2020). However, doctors cannot eradicate burnout themselves. Research from the Mayo Clinic found that the responsibility for alleviating burnout is 20% on the individual and 80% on the organization (Shanafelt 2017). Simple, low-cost methods such as "department leaders keeping doctors informed, supporting their career development,

asking for their opinions on how to improve the work unit and recognizing their good work” can all help mitigate physician burnout (Shanafelt 2017). With effort on the part of organizations and doctors, burnout can be reduced and doctors can be re-energized to work with patients to deliver the best care possible.

Lastly, it is important to discuss the importance of the medicalization of infertility. Medicalization has been defined as “the process by which human problems become defined and treated as medical problems” (Sadler et. al 2009). In an article written by Dr. George Blackburn published in the *AMA Journal of Ethics*, he discusses the benefits and drawbacks to the medicalization of obesity, and we will draw some parallels. Dr. Blackburn believes that medicalization has impacts on the individual, society, and the healthcare system (Blackburn 2011). Most importantly in the case of infertility, medicalization can reduce stigma for the individual by shifting the attention off of individual control and onto biological factors (Blackburn 2011). However, as we see in research regarding the way infertile women describe themselves and the language we use for infertility, medicalization has also left individuals feeling inadequate, unable to perform a natural biological function (Butalia 2013). Language such as “*inhospitable womb*”, “*incompetent cervix*”, “*geriatric mother*”, “*failed pregnancy*” and “*barren woman*” are all examples of strong negative language to describe a medical condition, often perpetuating blame on the woman regardless of whether she is responsible for the infertility or not (Hill 2020). Given the significant cultural barriers and social stigma surrounding infertility, we argue for the removal of responsibility from the individual through medicalization. This benefit outweighs the disadvantage of feeling inadequate

due to this medical condition which is a factor that will probably not worsen with medicalization.

Infertility is sufficiently medicalized by reproductive endocrinologists in the United States and fertility specialists in India. Medicalization efforts now should be focused on primary care physicians and women's health providers, who are the ones to refer patients to these specialists. According to the work by Peter Conrad on medicalization, this interaction between doctors and patients exemplifies the interactional level of medicalization, where the "physician defines the problem as medical" and provides treatment (Conrad, 1992, 211). With adequate medicalization for these frontline providers, patient complaints of infertility will be treated more accurately as a medical condition and result in more specialist referrals. This will also help these primary care doctors identify causes and symptoms of infertility through increased emphasis in medical education for all doctors, not just OBGYNs.

Considering the effect of medicalization on medical education, similar to obesity, we foresee only benefits (Blackburn 2011). Medical schools would spend more time discussing infertility and its causes which evidently remain a mystery to even some female medical professionals who show up at these fertility clinics. Not only would this broaden understanding, but could also be an avenue in which to emphasize cultural competency training in regards to which patients are diagnosed with infertility and referred to infertility specialists. This is especially important for people of typically highly fertile ethnic groups whose infertility may be brushed off or for those who are publicly insured may not appeal to have financial resources to pursue treatment. Blackburn argues that more attention in medical school would result in more attention by

“physicians, health administrators, health insurance companies, and employers, resulting in more access to quality care” (Blackburn 2011).

Recommendations for Infertile Individuals and Their Families

The primary recommendation for individuals struggling with infertility is to share their diagnosis among their close circles of friends, family, or coworkers, if they feel comfortable. Part of the stigma surrounding infertility can be diminished if more people were aware of how many people are diagnosed with infertility and have had ART. This relates to Peter Conrad’s conceptual level of medicalization, which involves using medical vocabulary to define the problem at hand in order to further medicalize the condition (Conrad 1992). Medicalization can then shift blame from personal responsibility to biology. If more people shared about their struggle with infertility not only could it reduce their own stress, but also help others feel less alone and ashamed. This could be done in a number of ways, from informally sharing with close family and friends, chatting on online forums and support groups, or on a more vocal scale through social media, in-person support groups, or at health fairs. Additionally, some older women who utilize ART cause misconceptions to those who do not know about their use of ART to conceive, so sharing honestly about the process can also help dispel misconceptions.

Secondly, for individuals in the U.S. who have infertility, one doctor suggested tackling the insurance coverage issue from a grassroots and private level rather than relying on a government mandate in states that do not mandate coverage, and we agree with this recommendation. While trying to get a state mandate can get tied up in state

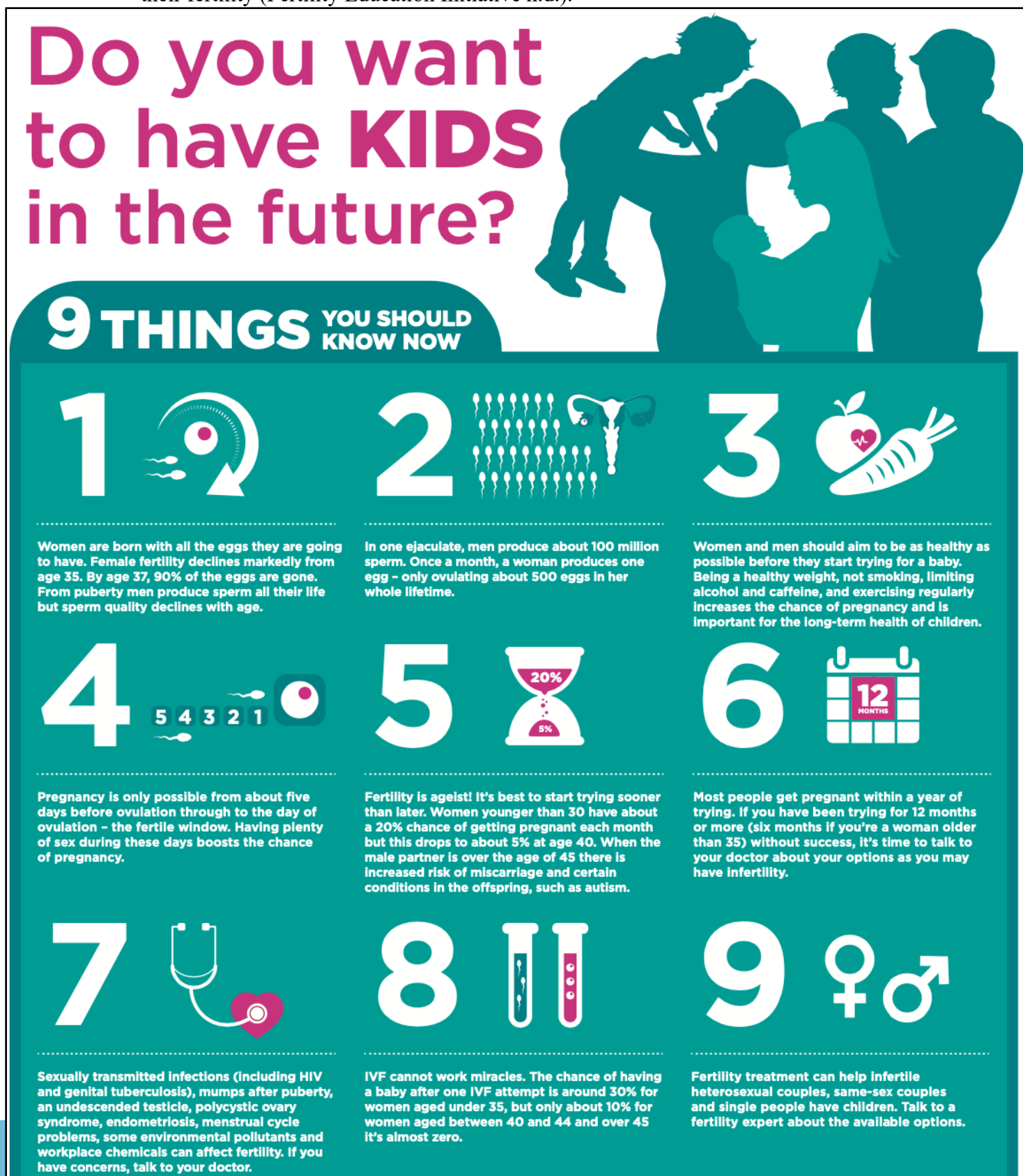
politics, mobilizing employees and lobbying employers to provide benefits is a better use of time because employers are much more likely to add benefits to their coverage with data supporting the prevalence of infertility. Letter writing campaigns are effective and low cost, and fertility advocacy organizations such as RESOLVE: The National Infertility Association have free templates available on their website. Coverage for fertility benefits relies on individuals to ask for benefits, and for institutions to provide benefits, as expanded on in the next section.

The last recommendation is for families of infertile individuals. In joint families and other family structures in which extended families are highly involved or living under one roof (which are especially prevalent in India), it is well-documented in prior research as well as findings from this research that the burden of infertility is much greater. Given that many women choose not to share their infertility diagnosis for fear of stigma, it is imperative that families respect the couple's privacy and be supportive of whichever option they choose whether it be fertility treatment, adoption, surrogacy, or remaining childless. The majority of doctors from India described the delicate balance between space and support. Families should educate themselves on dealing with infertile couples and recent research is also investigating counseling for the families of infertile couples as well, though this can be difficult logistically. Fertility centers might consider providing educational materials to the couple to share with family and close friends about the prevalence of infertility, treatment options, and how to best support those going through it. The research conducted in this study especially in regards to cultural stigma, family, and religion could be helpful in highlighting cultural nuances in stigma and providing culturally sensitive recommendations.

Recommendations for Government and Policy

A feasible recommendation for governments and public institutions are campaigns and awareness efforts for infertility and its detection. Informants in this study stated that infertility causes the same levels of cortisol, or stress hormone, in the body as the death of a loved one, yet in neither the U.S. nor in India is there the same level of societal support, if at all. One doctor from the U.S. mentioned that similar to how support for breast cancer is represented by the color pink and there are special marathons and national awareness days, infertility needs to be met with similar kinds of support. Such campaigns could be supported by hospitals, medical schools, and public health initiatives. These institutions could offer free consultation with fertility specialists or OBGYNs and resources from fertility advocacy organizations. A doctor from India mentioned how they were aware of awareness campaigns for issues during pregnancy such as hypertension and UTIs, cervical cancer screening, and puberty, but no information on what to do if you cannot get pregnant after 12 months. The following Fertility Education Campaign in Figure 1 shared by the British Fertility Society lists the nine most important facts to know about fertility which is a great start to sharing just a little knowledge that can go a long way.

Figure 1. The following fertility education campaign infographic shared by the British Fertility Society shows the nine most important things individuals should know about their fertility (Fertility Education Initiative n.d.).



In a similar theme of spreading awareness, both countries should prioritize better, age-appropriate sexual and reproductive education for children and young adults. As one doctor from the U.S. mentioned, almost all sexual education focuses on preventing pregnancy but provides no information on what to do once you want to get pregnant or family planning guidance. In the U.S., legislation on sex education is under the jurisdiction of each state, which means the information children in public schools receive varies widely across the nation, as states may or may not mandate sex ed, require education to be medically accurate, be inclusive of sexual orientation, among other critical factors (USC School of Social Work Department of Nursing 2017). Sexual education is important for preventing some causes of infertility, such as obesity, smoking, excessive drinking, and STIs (Fertility Education Initiative n.d.). Research on educational interventions on reproductive health for adolescent girls in India show promising results, demonstrating significant increases in knowledge about menstruation, ovulation, fertilization, and pregnancy, contraception, transmission and prevention of STDs (Malleshappa, Krishna, and Nandini 2011). While education in middle and high school is the easiest to incorporate because of state and national mandates, education in colleges and universities would be even more impactful because individuals are older and more likely thinking about sex and family planning. Educating populations on reproductive health and focusing on preventative causes for infertility can also reduce costs to the healthcare system and lead to better health outcomes.

While headway is being made slowly in both countries, it is imperative that insurance coverage or fertility benefits are made available to patients. Because infertility is a condition that does not discriminate by sex, race, or socioeconomic class, mandatory

coverage for fertility care will open up access for everyone. Coverage is in everyone's best interest, as it increases patient volumes and revenue, while also providing necessary medical care for a problem that is increasing in prevalence. However, coverage is especially important for those of lower socioeconomic status, and for cancer patients that need to preserve their gametes. In India specifically, additional funding and resources are required for fertility clinics in government hospitals as they are crowded and lack sufficient resources. In the U.S., legislation regarding mandatory fertility benefits would come from the federal government while funding comes from private sources such as employers or from Medicaid. In India, government programs like the National Health Protection Scheme which recognize the inequality in care for low-income individuals and help with healthcare costs can expand their services to cover fertility care as well.

Medicalization of infertility is most important for economic and policy implications, especially for achieving universal coverage and fertility benefits in both the United States and India. Medicalization at this institutional level as described by Peter Conrad involves vilifying a medical approach to the problem which also requires financial support from the institutional level (Conrad 1992). Dr. Blackburn in his *AMA Journal of Ethics* article posits that pushing for medicalization might receive opposition from those trying to decrease health care spending, as twelve conditions that underwent medicalization were responsible for \$77.1 billion in annual healthcare costs in the U.S. (Conrad, Mackie, Mehrotra 2010). In order to get equal access to insurance coverage for patients in the U.S., Blackburn succinctly concludes that "access to adequate medical treatment for patients must acknowledge that this biological illness is widespread, that it is important that it be treated effectively, that appropriate third-party payment for

physician-provided treatment is critical for it to become part of the mainstream of our nation's health care delivery system, and that medical specialty care provides the most effective benefit to patients and therefore our society" (Blackburn 2011). Based on potential benefits, we are in favor of the medicalization of infertility to ease the burden on the individual and advocate for additional scientific research to ultimately achieve universal health coverage in the United States, India, and across the world.

Limitations and Future Research

As with all research, there were some limitations when conducting this research. Firstly, only reproductive endocrinologists or fertility specialists were interviewed for this study. These specialists are the highest experts in their field and are rarely patients' first point of contact for infertility issues. Thus, their patient populations had already crossed several hurdles in terms of accessing care, and already possessed a certain belief in science and medicine. Additional research could include speaking with OBGYNs and primary care physicians to understand more about the general patient population of infertile individuals and the barriers and stigma they face, especially to capture patients who did not receive referral to a fertility specialist or who did not pursue the referral. Another limitation of the research was the small sample size as additional respondents would have provided more information with their unique patient populations' experience. For instance, selecting doctors in a way to be representative of each country's states or with rural versus urban patient populations could have provided more minute details. Two doctors (one from the U.S. and one from India) shared their shock at the lack of reproductive health knowledge in their patients, motivating them to take matters into their

own hands and begin Instagram pages. While this was not part of this research, it would have been interesting to ask each of these physicians what tangible effect their social media pages have on patients' reproductive health, if any. Lastly, due to the relatively general nature of this research, additional research investigating the role of religion and family as coping strategies is warranted. Understanding individuals of different religions in the U.S. use religion as a coping strategy could help providers understand groups of patients better and help them recommend more customized coping methods. Similarly, understanding the types of family structures most prevalent in both countries and investigating the link between structure and coping could also be beneficial for providers.

Studying barriers to infertility treatment and the coping strategies utilized is important as infertility continues to affect millions of couples worldwide. Findings from this study and future research can help the medical profession provide better quality care that is individualized for each patient by enhancing cultural competency and being aware of provider bias. These findings also highlight the stigma associated with infertility in both countries and fuel more awareness efforts from the side of doctors, public health, and the government. Lastly, more research on the social determinants of health and sociological factors playing a role in the infertility experience will highlight areas of improvement to support our populations with infertility.

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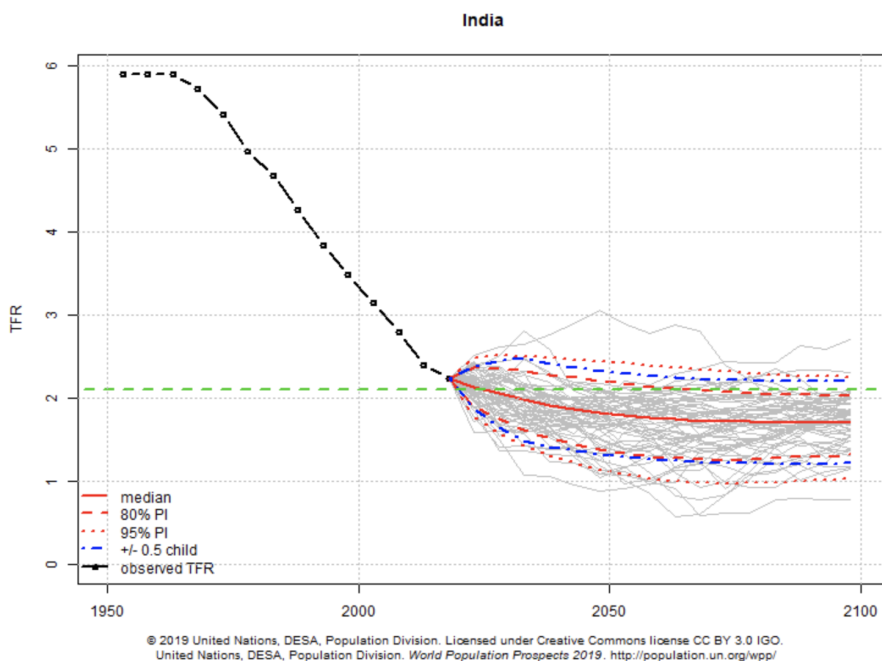
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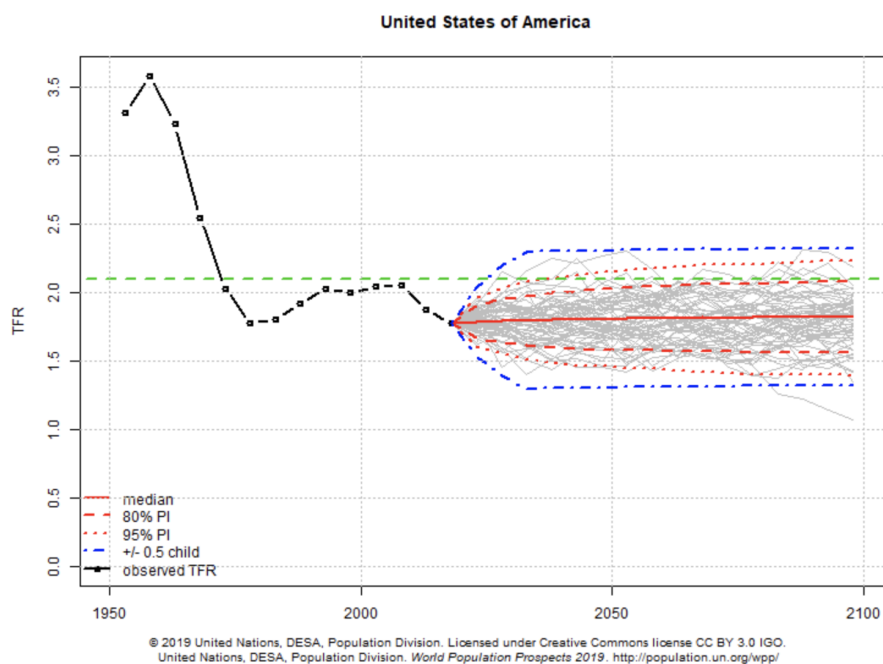
APPENDICES

Appendix A: Probabilistic Projects of Total Fertility for India and United States (United Nations 2019).

Probabilistic Projections of Total Fertility using fertility estimates
 Projections of Total Fertility: Median, 80% / 95% prediction intervals



Probabilistic Projections of Total Fertility using fertility estimates
 Projections of Total Fertility: Median, 80% / 95% prediction intervals



Appendix B: Social consequences of infertility in low-resource areas in the Indian subcontinent (van Balen and Bos 2009).

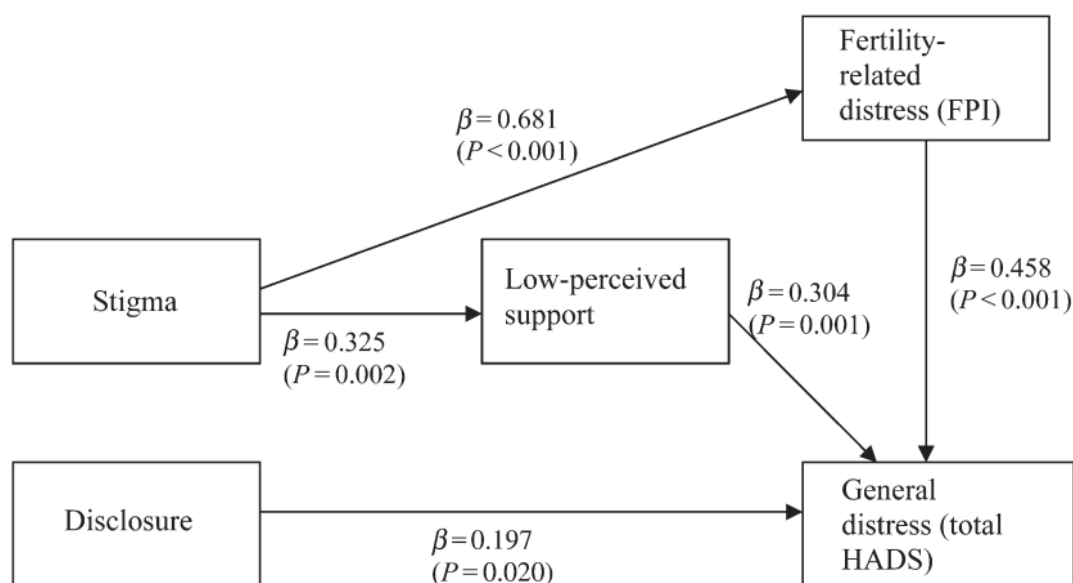
Study	Area/culture/class	Community effects	Economic and in-law relation effects	Legal and marriage effects	Religious/spirit effects	Sample, and Methods	Setting and Focus Limitation (if explicitly mentioned)
INDIAN SUB-CONTINENT							
Bhatti et al., 1999	Pakistan Low income Urban	Isolation (one)	Pressure by in-laws (one)	-	-	17 infertile women; In-depth interviews	Clinic and community based Having no children
Neff, 1994	India Tribe	Stigma (margin) (ni)	-	-	-	Anthropological fieldwork and case study (no numbers mentioned)	Community based No indication of kind of infertility Limited to: Social construction of infertility
Bharadwaj, 2000	India Several big cities	Stigma (almost all) Isolation (ni)	Harassment by in laws (ni)	-	-	45 semi structured interviews in IVF clinics (women and men)	IVF clinics Primary infertility (by implication)
Mulgoankar, 2000a/2000b	India Urban slum	Status loss (ni) Verbal abuse (ni) Stigma (ni)	Cost of IVF (some) Harassment by in-laws (ni)	Fear of divorce (ni)	-	225 childless couples semistructured interviews (results based on women's reports)	Community based on household survey Being childless
Riessman, 2000a/2002	India Middle class	-	Harassment by in-laws (all) Exploitation by in-laws (one)	Fear of divorce (some)	-	Narrative analysis 3 childless women of upper class; In-depth interviews	Community based Childless women
Riessman, 2000b	India rural Kerala	Status loss (almost all) Ridicule (often) Stigma (all) Outcasts (some)	Pressure by in-laws (all)	Fear of divorce (some)	-	31 in-depth interviews with infertile women, participant observation	Infertility clinic and village based childless women
Unisa, 1999	India Villages	No respect (some) Verbal abuse (some) Stigma (common) Isolation and Exclusion (ceremonies) (frequently)	-	Fear of divorce (few) Extra wife (some) Physical abuse husband (some)	-	332 childless women: questionnaires; 60 childless women: semi structured interviews (not reported on)	Community based on household survey Childless women
Apte et al., 2004	India Sex workers	Stigma (all)	-	-	-	107 childless female sex workers; Interviews and group discussion	Data collected in workplace area (community) Childless women Limited to: Stigma
Meera Guntupalli and Chenchelgudem, 2004	India Tribe	-	-	Divorce (some)	-	5 infertile, 22 cured and 11 fertile women. Participant observation, in-depth interviews, and informal interviews	Community based Childless wome
Nene et al., 2005	India Urban	Stigma (distinction) (almost all) Rejection (humiliation at gatherings) (almost all)	Harassment and rejection by in-laws (many) Exploitation by in-laws (very common)	-	-	40 couples with sexual dysfunction; Semi structured and in-depth interviews	Fertility clinic Childless couples with sexual dysfunction
Widge, 2005	India Middle class	Verbal abuse (many) Stigma (many)	Cost of IVF (all) Rejection in-laws (some)	-	-	4 couples and 18 women in treatment; In-depth interviews	Infertility clinic Being childless
Nahar, 2000	Bangla Desh Poor urban	Status loss (many men) Ridicule (ni) Stigma (all women) Physical abuse (ni) Rejection (all women)	No work (many women) Rejection by in-laws (some women) Exploitation by in-laws (some women)	Fear of divorce (frequent women) Rejection by husband (many)	Not to touch (all women) Responsible for illnesses (one woman)	20 infertile women; In-depth interviews, and 60 men and women general population	Community based Being childless
Nahar, 2007	Bangla Desh Poor rural and middle class big city	Social failure (often) Stigma (all) (especially in rural area) Mobility restriction (Rural: mostly) Isolation (all)	Cost treatment (almost all) Old age (rural: mostly) Social Support (especially: rural) Child earnings (rural: mostly); Rejection in-laws (common)	Inheritance restricted (all) Fear of divorce (all) Fear of extra wife (all) Extra wife (rural: common)	-	Rural: community based Urban: personal network and snowball method 20 rural poor women, 11 urban middle class women and keypersons; Life story interviews	Community based and social network Being childless

Appendix C: Perceived of causes of infertility by reproductive health knowledge index (RHKI) (Patra and Unisa 2020).

Perceived cause	Percentage stating cause of infertility			χ^2
	No/Low RHKI	Medium RHKI	High RHKI	
Biological factors	57.1	75.0	98.0	24.597***
Psychological and marital factors	41.1	25.0	23.5	4.884*
Religious factors	73.2	30.8	9.8	47.313***
STIs and the side-effects of family planning	32.1	50.0	78.4	23.198***
Environmental factors	33.9	34.6	70.6	18.416***
Old age	75.0	71.2	94.1	9.724**
Repeated abortions/accident/injury	58.9	76.9	92.2	16.008***
Other	19.6	28.8	47.1	9.549**
Number of women (N=159)	56	52	51	

*** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$.

Appendix D: Distress related to stigma and disclosure rates for women in the United Kingdom (Slade et al. 2007).



Appendix E: Sample consent form for informants of this study.**INFORMED CONSENT FORM FOR INFERTILITY RESEARCH**

My name is Devneet Singh, and I am a student at Union College in Schenectady, New York, U.S. I am inviting you to participate in a research study, which is part of my senior thesis under the direction of Professor Melinda Goldner in the Department of Sociology at Union College. Involvement in the study is voluntary, so you may choose to participate or not. A description of the study is written below.

I am interested in learning more about the experience of infertility and treatment methods utilized by infertile women in the United States and India. You will be asked to answer qualitative and quantitative questions about the experiences of your female patients with infertility and the effects of cultural context, feminism, politics, cost, knowledge of reproductive health, religion, and social support. This will take approximately thirty minutes and the interview will be conducted over Zoom. If you are comfortable, I will be recording the interview to transcribe at a later time. There are no foreseeable risks to taking part in this study. If you no longer wish to continue, you have the right to withdraw from the study, without penalty, at any time.

All information will be kept confidential, as I will only be collecting de-identified data including your medical specialty, type of clinic in which you work, and geographic region of your clinic.

By signing below, you indicate that you understand the information printed above, and that you wish to participate in this research study.

Printed Name of Participant

Signature of Participant

Date

I give my permission for the researcher to record the Zoom session:

Yes _____

No _____

Signature of Participant

DEVNEET SINGH

Name of Investigator

Date

Appendix F: Semi-structured interview questionnaire developed for this study.

1. Tell me briefly about the services provided at your clinic.
2. What are the demographics of your patient population in terms of race and socioeconomic status?
3. I am trying to understand the barriers to accessing infertility treatment. Rank the following items from 1-3, and explain why.
1=Little to no importance, 2= Moderately important, 3= Very important
 - a. **Knowledge of reproductive health (menstrual cycle, causes of infertility, etc.) =**
 - i. What factors do you think play the biggest role in your patients' knowledge of reproductive health?
 - ii. Where are the biggest gaps in reproductive health that you find among your patients?
 - b. **Cost (also health insurance coverage) =**
 - c. **Politics (also including legislation, and government regulation) =**
 - i. What are the key forms of legislation and/or regulation that affect women's access, if any?
 - ii. How do you think unregistered clinics affect perceptions of infertility treatment, if at all?
 - iii. Does the structure of the healthcare system affect their access? If so, how?
 - d. Are there any other barriers to treatment that we didn't talk about?
4. I am trying to understand what influences coping strategies for infertility, and explain why. Again you will rank 1-3. (*1=Little to no importance, 2= Moderately important, 3= Very important*)
 - e. **Cultural stigma =**
 - i. What are the key sources of stigma, if any?
 - ii. Has the feminist movement affected views on infertile women in your opinion, and if so, how?
 - f. **Family =**
 - i. How would you differentiate/attribute support from the partner/spouse versus other family members?
 - ii. How does the nuclear/extended family structure of India/US affect the experience of infertility, if at all?
 - g. **Religion (or spirituality) =**
 - h. Are there any other coping strategies that we didn't talk about?
5. Is there anything from the individual level, to the clinic level, and to societal levels (social reform or healthcare system) that needs to change to support this patient population? Please explain.
6. Is there anything that you want to add?