



Investigating Socioeconomic Disparities in Patient Experiences of Infertility in the US

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**Investigating Socioeconomic Disparities in Patient Experiences of
Infertility in the US**

A dissertation presented

by

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to

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Investigating Socioeconomic Disparities in Patient
Experiences of Infertility in the US

Abstract

Infertility is a common problem in the US, affecting approximately 1 in 8 couples of childbearing age, or over 7 million women nationwide. But while infertility affects women from across the socio-economic spectrum, it is by no means egalitarian in its distribution, nor uniform in its lived experience. Rather, evidence shows significant disparities by race, income, and educational status, in terms of overall prevalence of infertility, drivers and underlying causes of infertility, access to infertility services, and success rates after receiving infertility treatments.

This dissertation seeks to examine some of the specific mechanisms and pathways by which these disparities arise and persist. First, I report findings from a document review of online reproductive health materials, concluding that information about the risks of infertility is differently available and targeted to different sectors of the population. This can lead to disadvantaged women having less information about strategies to prevent infertility, as well as being less likely to have symptoms of an infertility-causing condition diagnosed and treated in a timely way. The second paper builds upon and extends these hypotheses, investigating through key informant interviews how such targeted provision of infertility information comes to affect lived

patient experiences of infertility. Finally, the third paper examines disparities in the way patients find and receive social support during an infertility journey. It undertakes a “cyber-ethnography” of an online infertility patient forum, examining how the forum’s discourse produces dominant and counter narratives of infertility, and enforces categories of belonging that impact how support is offered to users of the site.

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I. Introduction

Infertility is clinically defined as “failure to achieve a pregnancy after twelve months of unprotected sex” [1]. It is a common problem in the United States, affecting approximately 1 in 8 couples of childbearing age, or over 7 million women nationwide [2].¹ But while infertility affects women from across the socio-economic spectrum, it is by no means egalitarian in its distribution, nor uniform in its lived experience. Rather, available evidence shows significant disparities by income, race, and educational status, in terms of overall prevalence of infertility [3, 4], drivers and underlying causes of infertility [5-10], access to infertility services [3, 5-7, 10-18], and success rates (as measured by live birth) after receiving infertility treatments [7, 12, 19-23]. While the details of these findings are complex, the studies have robustly shown that women with lower income, racial and ethnic minorities, and women with lower educational attainment are more likely to be infertile, less likely to seek and access medical services for infertility, and—once treatment is initiated—less likely to have a successful outcome, compared to their middle- and upper-class, Caucasian, and educated counterparts. Moreover, infertility is not only a problem with reproductive physiology; rather, it causes significant emotional distress, constrains social and familial relationships, and can be experienced as a “major life crisis” [24].

As such a profound determinant of both physical and mental well-being, differential patterns of infertility prevalence and treatment are crucial to understand not only as a public health issue, but also as a site of contention for social justice. Shellee

¹ This dissertation focuses predominantly on female experiences of infertility. This is because, regardless of physiology, the burden of infertility treatment is predominantly borne by women, in terms of necessary tests and treatment. Rapp (2011) argues, “women bear the physiological burden of most interventions even when the failure to achieve a pregnancy is owed to male infertility factors.” Therefore, I focus on women’s experiences navigating through the health care system when seeking treatment for infertility.

Colen coined the term “stratified reproduction” to describe how the reproduction of certain groups is privileged, while that of other groups (typically low-income, minority, and immigrant populations) is discouraged and controlled [25]. The differential provision of prevention, timely diagnosis, treatment, and social support for infertility is a crucial way in which social inequality is manifested in human bodies, in individuals’ ability (or lack thereof) to exercise reproductive agency.

As yet, a gap in our knowledge remains about the specific mechanisms by which disparities in infertility arise and persist. This dissertation seeks to address that gap, by probing the social, cultural, and political context within which infertility takes place, and therefore characterizing some of the forces that impact patient journeys. To do this, my dissertation employs methodological triangulation [26], utilizing a combination of document reviews, key informant interviews, and cyber-ethnography [27].

The first of the three papers in my dissertation is a document review of reproductive health materials available online. It explores the hypothesis that health information about the risks of infertility is differently available and targeted to different sectors of the population, depending on factors like age, socioeconomic status, and education level. This can lead to disadvantaged women having less information about strategies to prevent infertility, as well as being less likely to have symptoms of an infertility-causing condition diagnosed and treated in a timely way. It also explores the related hypothesis that infertility, when mentioned at all in health education, is often discussed solely in the context of STIs, leading to misunderstanding and even stigmatization of the topic of infertility among young adults.

The second paper builds upon and extends the hypotheses explored in the first, investigating how the targeted provision of infertility information observed in the document review then comes to affect lived patient experiences of infertility. Key informant interviews with 54 infertility patients investigated how women had thought and learned about infertility before receiving a formal diagnosis, as well as what possible barriers or obstacles had impeded their having open conversations about the subject. Interviews then explored how these differences in awareness and education about infertility had affected patients' clinical courses, in terms of time to diagnosis and initiation of infertility treatment.

Finally, the third paper in my dissertation examines how disparities in infertility are formed not only in the course of infertility prevention, diagnosis, and care, but also in the way patients find and receive social support during their infertility journey. To do so, it undertakes a "cyber-ethnography" and discourse analysis of the online infertility patient forum, "Finding a Resolution for Infertility." It characterizes the language, norms, and values of this virtual space created specifically by and for infertility patients; it then examines how this discourse produces dominant and counter narratives of infertility, enforcing categories of deserving and belonging that impact how emotional support is differentially offered to users of the site.

Taken together, these three papers that make up my dissertation seek to expand upon what is already known about disparities in infertility prevalence and treatment, characterizing the complex mechanisms and pathways by which disparities arise, as well as how they become embodied in women's lived experiences as patients. As a result, this

research has important practical applications for policymakers, public health workers, and clinicians, as well as infertility patients themselves.

Infertility Awareness on the Internet: Gaps in Reproductive Health Education Materials Online

Abstract:

This study investigates differing levels of infertility awareness as a potential mechanism of socioeconomic disparities in infertility in the US. As people increasingly go online for their primary source of health information, the way that the Internet represents and treats infertility can have important implications for patients' awareness of infertility risk and prevention, time to diagnosis, and initiation of fertility treatments.

In this document review, Google search returns for the queries "Infertility," "Fertility," "Reproductive Health," and "Sexual Health" were compiled and analyzed. The goal was to examine what reading materials an individual newly concerned about infertility would first encounter on the Internet, as well as how infertility is represented within larger health education discourses.

I conclude that information about infertility was differentially accessible and targeted to different sectors of the population, potentially leading to different levels of awareness and knowledge. In content and tone, websites returned for the "Infertility" and "Fertility" queries appeared targeted at older individuals; while discussions of reproductive health geared for younger audiences concentrated heavily on contraception and safe sex. In these latter discussions, infertility was either overlooked, or mentioned solely as a consequence of STIs, potentially leading to misunderstanding and even stigmatization of the topic of infertility among young adults.

In this first paper, I test and refine several hypotheses drawn from a pilot phase of in-depth interviews with infertility patients, clinicians, patient advocates, and policymakers [28]. These interviews suggested that, first, reproductive health education for young people in this country does not adequately cover fertility issues; rather, infertility is eclipsed in most curricula by the supposedly more pressing concerns of contraception and safe sex. Secondly, interviews suggested that information and awareness about the risks of infertility are unevenly distributed in the population. Socioeconomically disadvantaged women and members of racial/ethnic minorities may be less aware of infertility, and possess less information about strategies to prevent it; this would present a major obstacle to having symptoms of an infertility-causing condition diagnosed and treated in a timely way. Finally, patients noted that when they did hear about fertility in their youth, it was solely as a possible consequence of STDs. This made

them hesitant to enter into conversations about fertility with their doctors, family members, or friends, for fear of provoking negative assumptions and judgments about their sexual behavior.

Driven by these insights, this paper undertakes a document review of reproductive health information and educational materials available online. Access to the Internet has now become virtually universal; according to the most recent data, 98% of Americans currently have access to Internet communication [29], with the highest levels of usage in the youth population. As the Internet revolutionizes communication and connection in almost every sector, more and more people have begun to engage in health information seeking via the Internet [30]. In this paper, I examine how the most widely accessed sources of information about reproductive and sexual health engage with the topics of infertility risk, prevention, evaluation, and treatment. I also examine the related hypothesis that discussions about infertility are often confined to the realm of discussions about STIs and safe sex, which can lead to misunderstandings of infertility risk and stigmatization of infertility in the minds of young adults.

Background:

Disparities in Infertility Prevalence and Drivers:

While infertility is prevalent across the social spectrum, actual rates and experiences of infertility vary widely across social groups. Data from the National Survey of Family Growth reveal that infertility rates for black (19.8%) and Hispanic (18.2%) women are multiple times higher than for white women (6.9%)[3]. Similarly, in a national survey of 10,847 women of reproductive age in the US, Jain et al reported that

Black, Hispanic, and other non-Caucasian women reported infertility more often than Caucasians [4]. The same authors also reported that infertile women in the former categories were more likely to have household incomes lower than \$100k, as well as less than 4 years of post-high school education. This points to the difficulty of disentangling the effects of race and income when examining overall socioeconomic status; as Nancy Krieger states, factors like income and education can be seen as not confounders, but mediating variables on the effect pathway between race and income [31].

Beyond just prevalence, socioeconomic status also shapes the clinical picture of infertility. Among affluent, educated, and White women, infertility is most commonly a problem of advanced maternal age [5]. Meanwhile, in poor and ethnic minority communities, infertility stems mainly from “occupational hazards, environmental risks, and lifestyle factors, including smoking and obesity... and delays in treatment of reproductive tract infections, including those that are sexually transmitted and those that result from poor-quality medical care” [6]. According to the CDC, obesity is 50% more prevalent in Blacks, and 20% more prevalent in Latinos, as compared with Whites; obesity can lead to hormonal dysfunction and is commonly linked to menstrual irregularities and infertility [32, 33]. Sexually transmitted infections (STIs) are also many times more prevalent in ethnic minorities as compared to Whites; for example, the rate of chlamydia among black women is over six times the rate among white women (1,613.6 and 260.5 per 100,000 females, respectively) [34]. Untreated sexually transmitted infections can lead to pelvic inflammatory disease (PID), which causes scarring of the Fallopian tubes and greatly reduces chances of natural conception.

Importance of Prevention:

The importance of early detection of potentially infertility-causing conditions has been much discussed clinically. On the one hand, it is difficult to quantify the value of early diagnosis, because more severe cases of disease are both diagnosed earlier, and more likely to lead to infertility. For example, women with cases of endometriosis severe enough to be diagnosed in adolescence are more likely to also have trouble conceiving later in life; in this way, earlier diagnosis appears to be linked to worse fertility outcomes [35]. In the absence of randomized clinical trials, however, the judgment of most clinical experts is that timely diagnosis of endometriosis means that specific treatment can be initiated earlier, leading to improved fertility potential [36]. On the other hand, when symptoms of endometriosis go unrecognized and undiagnosed for years, scarring and adhesions can progress to the point that the number of treatments that are available, and the likelihood that even those treatments will succeed, are significantly reduced.

A similar argument can be made for the importance of timely detection in polycystic ovarian syndrome (PCOS) in young women. Studies have shown that “early diagnosis and timely suppression of excess ovarian androgen production” are critical to minimizing the clinical features of PCOS in young adolescent girls. However, early symptoms, which include irregular menstrual bleeding and hirsutism, are often missed or attributed to normal components of the final stages of puberty. As a result, in many cases, “diagnosis is not made until later in life when endocrine and metabolic dysfunctions have been firmly established”[37], resulting in progression of the disease, lower fertility potential, and worse treatment outcomes in future years.

A third important preventable cause of infertility is pelvic inflammatory disease, which is a clinical sequela of untreated STIs. While, on the one hand, this paper seeks to elucidate how the constant discursive linkage between infertility and STIs ultimately impedes awareness about other causes of infertility, I simultaneously wish to explore whether the former conversation does, in fact, sufficiently address the reproductive impact of STIs on fertility. Much of the discourse young people are subjected to about STIs takes place in schools, where there is evidence that STIs are discussed inadequately and inaccurately; this topic is treated in more detail in the following section.

Overall, a CDC working group on infertility concluded that for many of infertility's causes, "early diagnosis and treatment of underlying medical conditions (secondary prevention) may lead to effective restoration of fertility"[38]. Therefore, it stated in its White Paper, a key strategies for better prevention is building greater "awareness of risks...[which] may lead some people to adopting corrective behaviors [to] maintain fertility." The Paper took care to note that awareness of risk alone will not mean that individuals have the knowledge and tools to take preventive measures; thus, concomitant with increased awareness must be the implementation of "strategies that minimize the risk of infertility," in order to provide individuals with both information *and* resources to enable them to seek more timely evaluation, diagnosis, management, and treatment for infertility.

Sexual Education In Schools and Online

There is strong evidence that lack of awareness and education about infertility stems from a wider inadequacy in the state of sexual education in the US. Multiple

evaluations of US sexual education (or “sex ed”) curricula programs have found them grossly lacking in both reach and content [39]. Only 22 states require that sex ed be taught in schools at all, and only 13 of those states have in place legal standards requiring those schools to teach information that is medically accurate [40]. Moreover, most of the heated debates over what to include in these curricula concern the choice between abstinence-only programs—in which abstinence is presented as the only real way to prevent pregnancy—and programs that acknowledge other contraceptive alternatives. According to a 2007 study from Mathematica Policy Research, the federal government allocates over \$50 million for abstinence-only education under Title V; combined with states' grants, nearly \$100 million in government funds goes to abstinence-only education each year [41].

The glaring gaps that follow from this conception of sexual education—regarding topics ranging from LGBTQ orientation to relationship abuse, not to mention STIs and pregnancy— are far too numerous and important to be given short shrift here. For now, I point out only that by presupposing that the only content necessary to impart to young people is how to *prevent* pregnancy, sex ed categorically excludes any discussions of infertility, infertility-causing medical conditions, or how to protect or preserve fertility potential. As a result, many young women experience early symptoms of conditions like endometriosis and PCOS—both of which are common in the US population and often present in adolescence—without having been exposed to any information or instruction about their implications in their health education. Moreover, large numbers of young people also complete school without being given accurate information about the prevention or treatment of STIs—including recognition of early symptoms, how to get

tested, and what to do after a positive test in order to prevent PID, scarring, and future fertility complications. This is a particularly pressing issue in light of the stark differences in current rates of STIs in Blacks and Latinos, as compared to Whites; it confirms the CDC's statement that "preventable causes of infertility... [such as] STIs that may lead to infertility if untreated... disproportionately affect the less privileged"[38].

Finally, evidence suggests that current reproductive health education may "inadvertently convey inflated reproductive efficiency," in an effort to communicate the importance of abundant caution and reduce unplanned pregnancies. This fosters further misinformation and can make adolescents even less likely to seek medical attention for warning signs of infertility [42]. It is thus increasingly urgent that we provide more complete and accurate sources of information regarding infertility, as well as reproductive and sexual health more broadly. On the opposite side of the policymaking divide, there is evidence that there is genuine desire among young people for more education about fertility. Although fertility is not commonly seen as a concern among young people, compared to more immediate concerns like contraception, pregnancy planning, and safe sex, Burke et al noted that a majority of adolescents expressed a desire to know about their future reproductive potential[43].

To fill the vacuum created by an absent or incomplete sex ed curriculum, many young adults turn to the Internet as a primary source of information. As stated previously, the Internet now holds a special status as the primary source of public information about a wide range of topics, including health; according to the most recent data, 98% of Americans currently have access to Internet communication [29], with the highest levels of usage in the youth population. In a survey conducted by the Kaiser Family Foundation,

60% of adults say they have turned to the Internet for health information, while 68% of youth aged 15-24 said they had done so [44]. (To put this in perspective, this was more than the percentage of individuals who said they had used the Internet to check sports scores, buy something, or participate in a chat room.) 44% of online youth said they had looked up information about reproductive health, including pregnancy and STDs. Moreover, interviews conducted from 2013-2015 [28] confirmed that the Internet was a major source of information for individuals seeking to learn more about their fertility, especially when they were just beginning to explore the topic. Although several interviewees expressed awareness that Internet materials are not always 100% reliable, they nevertheless put a great deal of faith in online information sources, especially those maintained by professional organizations.

Given this substantial reach and impact of online health information on the youth population, this paper seeks to examine these online health materials' quality, comprehensiveness, accuracy, and accessibility.

Methods:

This study comprised a document review of reproductive health materials available on the Internet, recognizing it as an important communication medium for awareness and education about infertility. It undertook an in-depth examination of the top 10 Google search returns (henceforth "hits") for four search terms: "Infertility," "Fertility," "Reproductive Health," and "Sexual Health." These terms were purposely chosen to be broad, and to generate search results that would represent the first line of information available to people seeking to find out more about potential fertility

problems. All terms were searched in scare quotes, in incognito windows to avoid personal cookies affecting the search results.

Searches were conducted and analyzed over a period of six months, so that all websites that were in the top 10 Google Hits at least once during the study period were included in the analysis. As a result, for each keyword, more than 10 sites in total were reviewed; the complete list of websites reviewed is presented in Table 1.1. All content on the websites was reviewed up to being two links “deep”; that is, all written content accessible within two clicks from navigating to the site was included in the analysis.

Table 1.1. All primary websites reviewed

Search Term:	“Infertility”	“Fertility”	“Reproductive Health”	“Sexual Health”
	WebMD	Wikipedia	CDC	CDC
	Wikipedia	WebMD	Wikipedia	Medline
	Mayo	Ovulation Calendar	WHO	WebMD
	Medline	Fertility Friend	UNFPA	KidsHealth
	Womenshealth	Parenting	HHS	WHO
	Resolve	FertStert	NIEHS	Planned Parenthood
	CDC	Livestrong	Latina Institute	Health.com
	FASTSTATS	Mayo	PRH	CSIRO
	MedicineNet	NICHD	RHJ	Mayo
	Resolve Male	Resolve Scorecard	HHS Adolescent Health Office	ISSWSH
	Resolve FAQ		ARHP	ASHA

For all the sites, textual content was examined for three categories of words: those related to contraception (including *contraception*, *contraceptives*, *birth control*, and *family planning*); those related to sexually transmitted infections (including *STI*, *STD*, *infection*, and *infectious*); and those related to fertility (including *fertile*, *fertility*, *infertile*, and *infertility*). Next, ratios were calculated for the relative frequency of mentions of each

word category (including derivatives of the search terms). Calculating these results provided a proxy measure of the relative emphasis these topics were given within this body of reproductive health information heavily accessed by the general population.

In addition to this quantitative analysis, qualitative analyses sought to provide additional insight into the meanings and implications behind these observed patterns of word frequencies. All materials on the websites (including text, images, and videos) were examined qualitatively for content, formatting, style, and intended audience. In terms of content, I examined how, in what contexts, and with what level of detail the topics of infertility, STIs, and contraception were discussed. Regarding formatting, I noted for each site whether words of interest were included in main body text, or rather within sidebars, frames, and peripheral links. Thus, while a main body and peripheral mention counted the same within the quantitative analysis, peripheral inclusions were noted in the qualitative analysis as signifying weaker engagement with the topic, and as a potential source of bias in the data, since they could falsely inflate the measure of the website's emphasis on the topic of interest. In terms of style, I noted the reading material's level of formality (second vs. third-person writing, as well as reading and vocabulary level), and thus sought to extrapolate who was their target audience. I also noted what health concerns were discussed alongside these topics; links to page about menarche and menopause, for example, gave important clues as to the websites' intended audiences. Finally, I noted whether and when infertility was linked to a conversation about the dangers of STDs, and when other potential risk factors and predisposing conditions were discussed.

Results:

One first, striking observation was that the four search terms, while chosen to be broad and inclusive, brought the user to very different kinds of sites. Searching “Infertility” and “Fertility” brought up mainly clinical, patient-oriented sites; by contrast, searches for “Reproductive health” and “Sexual health” brought up more public health-focused sites, many run by nonprofit organizations (see Table 1.1). The discourse on infertility in these different types of sites, therefore, varied greatly.

Table 1.2 presents the aggregate data from all four searches, with each search represented in a separate row. The columns present the number of hits for each word category observed within that search, with the number of mentions of that word category relative to fertility shown in parentheses (thus, all the values in the first column are normalized to 1). This data is also displayed visually in Figure 1.1. The details of these findings are discussed in detail below.

Table 1.2. Aggregated searches: overall number of hits per category (normalized to number of hits for fertility)

Query:	# Words relating to...		
	Fertility	Contraception (normalized to fertility)	STDs (normalized to fertility)
INFERTILITY	4937 (1)	127 (0.026)	243 (0.049)
FERTILITY	1897 (1)	37 (0.020)	15 (0.0080)
REPRO	845 (1)	1049 (1.24)	629 (0.74)
SEX	340 (1)	409 (1.20)	1864 (5.48)

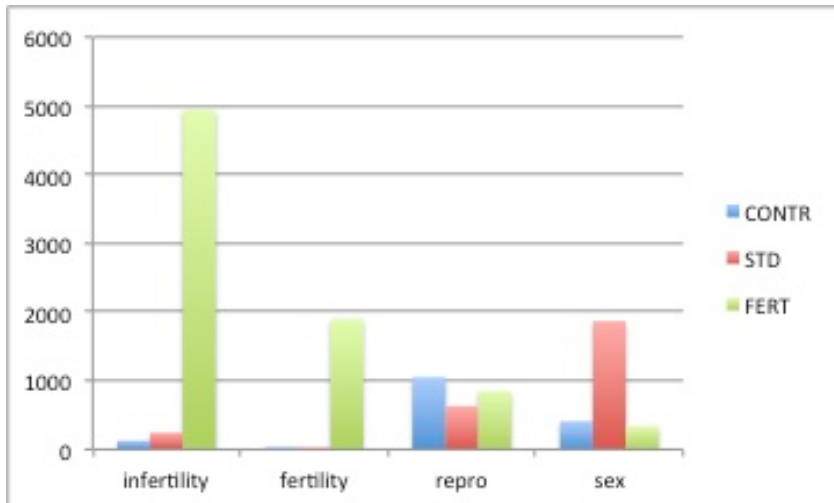


Figure 1.1. Aggregated searches: overall number of hits per category

Infertility and Fertility:

The searches for infertility and fertility yielded similar types of hits. Many were clinical sites, such as WebMD and Mayo Clinic, seeking to provide online health information and advice for potential patients. Material on these sites moved quickly beyond introductory material, to information about recognizing symptoms, getting a medical workup and formal diagnosis, and choosing between various treatment options. In addition, the tone of the sites was sophisticated, although not overly technical; an example sentence from WebMD reads:

Laparoscopy is minimally invasive surgery that involves making a small incision beneath your navel and inserting a thin viewing device to examine your fallopian tubes, ovaries and uterus. Laparoscopy may identify endometriosis, scarring, blockages or irregularities of the fallopian tubes, and problems with the ovaries and uterus.

These sites appeared to address an older and mature audience who, while not necessarily possessing a medical background, were presumably highly educated; moreover, it was

presumed that they had the necessary resources to take active, and most likely expensive, measures to manage and treat infertility.

The search results for “Fertility” were largely similar to those for Infertility, although they appeared somewhat less clinical: two of the top results for this search were sites like FertilityFriend and Parenting.com, which were targeted at individuals and couples who were trying to conceive, but as of yet had no fertility problems. Although these sites generally used fewer technical terms, they still were written to a high reading level, and appeared to address an educated audience: for example, the website Fertility Friend’s article on intercourse timing reads:

Frequent intercourse within a narrow fertile window increases your chances of conception and can ultimately reduce the time it takes to conceive. Identifying your fertile window in advance, however, can be something of a challenge since the only certain indicator of ovulation (your temperature rise) occurs after your fertile window has passed.

Of note, these sites exclusively gave information and advice for conception, pregnancy, and early parenthood, without any discussion of infertility risk or prevention. Another article on WebMD, titled “Boost Your Fertility,” discussed the potential impact on fertility of factors like weight, coffee, alcohol, lubricants, and pesticides, but completely omitted discussion of any medical conditions that might lead to infertility.

Because of the observed similarities between returns from the two queries, tallies were combined from the “Infertility” and “Fertility” search results for the final quantitative analysis of word frequencies. These results are presented in Table 1.3. There were a total of 6,834 mentions of infertility related words in the top 22 hits for infertility and fertility combined; meanwhile, there were only 164 hits for contraceptive-related words and 258 hits for STI-related words. Thus, these sites appeared to be wholly

focused on the topic of infertility, rather than “linking out” to larger conversations about reproductive and sexual health (at least, within 2 clicks of each primary site). As a ratio, words relating to infertility were mentioned 42 times more often than words about contraception, and 26 more times than words relating to STIs (see Figure 1.2). This quite stark imbalance points to a relative compartmentalization, or even sequestering, of the topic of infertility within the larger conversation about reproductive health online.

Table 1.3. Combined searches – number of hits per keyword

Query:	# Words relating to...		
	Fertility (normalized to fertility)	Contraception (normalized to fertility)	STDs (normalized to fertility)
INF+FERT	6834 (1)	164 (0.024)	258 (0.038)
REPRO+SEX	1185 (1)	1458 (1.23)	2493 (2.10)

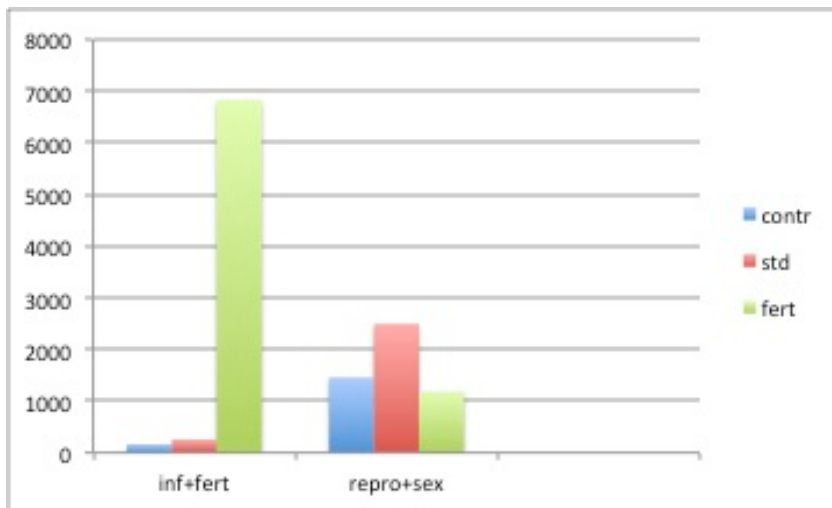


Figure 1.2. Combined searches – number of hits per keyword

Overall, it was clear that with few exceptions (see later sections), the top sites returned for the searches for “Infertility” and “Fertility” were targeted at patients who either 1) seriously suspect or have already been diagnosed with infertility, and are primarily concerned with treatment options, or 3) are just beginning a fertility journey without suspecting any problems. In the former, the condition of infertility was almost

always taken as a given starting point for the discussion, with little to no discussion or prevention, early evaluation, or diagnosis. While some of these sites did mention medical conditions that could cause infertility, like endometriosis and PCOS, these discussions usually did not include any information about how to recognize early signs and symptoms, and what options are available to prevent progression to infertility. Meanwhile, in the latter, the topic of medical infertility was given very little treatment at all. Thus, none of the sites spoke at all to young people who have concerns about their fertility, but are not yet actively seeking to conceive a baby.

Reproductive and Sexual Health:

The top returns for the queries “Reproductive Health” and “Sexual Health” were substantially less clinical than those for “Infertility” and “Fertility.” Instead, these sites focused primarily on public health, often tying in to discussions of global health. Moreover, the discourse on these sites appeared to be concerned with the health of younger populations, as well as to address younger individuals as their target audience. For example, in response to the “Reproductive Health” query, the HHS Office for Adolescent Health featured among the top search returns. In the “Sexual Health” search, top results included Planned Parenthood and Kidshealth.com; these sites both spoke directly, in the second person, to teens about their sexual health choices, behaviors, and risks.

As in the previous section, results of the “Reproductive Health” and “Sexual Health” queries were combined for analysis because of their similar features. Here, content analysis revealed considerably less discussion of diagnosis and treatment of

medical conditions; instead, there was much more emphasis on preventive health.

However, this consisted mainly of discussions about preventing unplanned pregnancies and sexually transmitted infections, with almost no mention of preventing infertility. (The two searches differed somewhat in their emphasis: the reproductive health results, while wide-ranging, dwelled mainly on various forms of contraception, while the sexual health results concentrated more narrowly on topics directly relating to sexual behavior, with a heavy emphasis on the prevention of STDs.)

Meanwhile, infertility was strikingly absent from these reproductive and sexual health discussions targeted at young people. Overall, contraception was about 25% more frequently mentioned than fertility; moreover, many of the hits for fertility were actually not discussing it as a medical condition, but explaining basic reproduction with words like “fertilize.”² For consistency, these were included in the analysis, but may have significantly inflated the number of fertility hits observed. Meanwhile, STIs were mentioned more than twice as frequently as fertility (see Figure 1.2; data in Table 1.3). This disparity is even more striking when considering the “Sexual Health” search results alone, in which STIs were mentioned 5.5 times more often than fertility (see Figure 1.1; data in Table 1.2). Even those sites focused on educating young people about STIs often completely neglected to discuss any potential fertility implications, despite discussing other health consequences and the importance of treatment (see further discussion, next section).

It was also notable that mentions of infertility were unevenly distributed across websites: more than half of the top websites, including the UNFPA, Planned Parenthood,

² An illustrative example from KidsHealth.com is, “When a sperm fertilizes, or meets, an egg, this fertilized egg is called the zygote.”

and professional organizations like Physicians for Reproductive Health (PRH) and the Association of Reproductive Health Professionals (ARHP) barely mentioned fertility at all, with less than 10 hits per website. The aggregate number of fertility mentions was substantially driven up by the CDC, which had pages discussing Infertility and ARTs in great detail (although not without its own issues, as will be discussed in the next section).

Furthermore, many of the websites that generated hits for infertility-related words were still organized around contraception and safe sex as main themes, with discussion about infertility consistently relegated to a sidebar or a page several clicks deep into the website. This was despite many websites' acknowledgement of fertility as key component of reproductive well-being. For example, the HHS website on Reproductive Health defines: "Reproductive health relates to the maintenance of one's reproductive health system and fertility. It includes a broad range of topics such as birth control, sexually transmitted infections, your ability to become pregnant and infertility." While this seems like a logical, thorough framework by which to conceptualize reproduction, this attention to infertility is not manifested in the site's actual layout or content. The rest of the site is split into three columns, "General," "Contraception" and "STIs." Infertility is discussed as the seventh of eight topics in the General column (in between "Urinary Tract Infections" and "Vaginal Discharge"), while Contraception and STIs each have columns to themselves. Similarly, on the WHO website, a fact sheet about family planning stated, "Family planning... is achieved through use of contraceptive methods and the treatment of infertility," but then immediately went on to clarify: "this fact sheet focuses on contraception." Thus, despite acknowledgements of infertility's core

importance in the conceptualization of reproductive health, there was remarkably little attention or webspace actually devoted to the subject.

A revealing case study of how completely infertility was neglected, and eclipsed by contraception and safe sex, in these conversations was found in Kidshealth.org, a website run by the children's health non-profit organization, Nemours Foundation. The entire site was broken into five categories: "My Changing Body" (ultimately, Puberty), "Guys," "Girls," "STDs" and "Birth Control." Again, fertility was excluded as one of the core topics of interest for this population. None of the 110 pages within two clicks of the homepage treated infertility as a primary topic; the pages on endometriosis and irregular periods, despite their obvious relevance to infertility, bore no mention of the word. On the other hand, the pages on dysfunctional uterine bleeding (DUB) and PCOS did note that infertility might be a potential complication, but gave very little information about what could actually be done to preserve or manage fertility, instead offering a single line stating that the conditions "can be treated." Finally, the pages on gynecologic and well-women visits, while aiming to give young girls an idea of what to expect from these checkups, did not discuss having the doctor ask or answer any questions about fertility. Rather, discussions centered again on contraception and STDs. Even the routine screening question girls are told to expect, "when was your last menstrual period?" was explained in the context of the doctor wanting to check for "hormonal imbalances or pregnancy," not fertility.

Link Between Infertility and STIs

I next examined the linkages and associations between the topics of infertility and STIs in this body of online materials. It was notable that, in most of the top hits for the infertility and fertility searches, the words “STI” or “STD” were used very sparingly when discussing possible causes of infertility. As noted above, these sites appeared to be targeted to older and more educated readers; and here, terms like “STI” were replaced with more euphemistic words like “infection,” “PID,” or even just “scarring” or “blockage.” For example, WebMD’s Infertility and Reproduction Health Center website—the very first hit in the Infertility search—stated: “In about 80% of couples, the cause of infertility is either an ovulation problem, blockage of the fallopian tubes, or a sperm problem.” There was no further discussion of the term “blockage,” except in terms of how it could be diagnosed and managed. In this way, for this particular intended audience, websites appeared to shy away from implying that infertility was a result of risky or irresponsible sex.

On the other hand, a very different trend was evident in the (very few) discussions of infertility *prevention* observed within this study, within sites about reproductive and sexual health targeted towards younger audiences. Here, the link between infertility and STIs was drawn consistently, and so strongly as to overshadow or crowd out discussions about other causes of infertility. For example, the CDC’s “Infertility Prevention Program” website (representing a program which actually ended in 2013, but is still an active link) *exclusively* discussed the chlamydia and gonorrhea screening and treatment initiative, targeted to low-income, sexually active young women in the US. The only other website to explicitly discuss infertility prevention was Medline, a service maintained by the US National Library of Medicine. This site linked to a document by

ASRM, entitled “Protect Your Fertility: A Guide for Prevention.” This document also focused heavily on the importance of avoiding STDs, while also mentioning behavioral and “personal responsibility” risk factors like weight, smoking, and alcohol. Neither of these hits included any discussion about the importance of recognizing and treating other infertility-causing conditions, such as endometriosis and PCOS. In this way, within materials apparently targeted to younger audiences, discussions of infertility were reliably associated with discussion of STIs—in fact, the former topic seemed to lead almost inexorably to the latter.

Remarkably, this relationship appeared quite unidirectional; that is, conversations about STIs rarely led to discussions of fertility implications (at least not thorough and informative ones). For example, in the HHS Reproductive Health website, fertility was barely discussed anywhere in the extensive STI section, with only 1 page out of 11 bearing any mention of fertility. Similarly, the website of the American Sexual Health Association (ASHA), while citing a legacy of fighting venereal disease in NYC since 1914, included only 3 mentions of infertility within two clicks of the starting page, as compared to 240 mentions of STI-related words. Thus, the results suggested that individuals concerned about their STI risk, and searching online for information, could easily remain unaware that infertility is an important potential concern for them.

Discussion:

Both quantitative and qualitative analyses revealed a critical dearth of information about infertility risk management and prevention in reproductive health educational materials available online. First, it appears that conversations around infertility are taking

place apart from, and perhaps even in forums closed to, young people. In both content and tone, the hits for “infertility” and “fertility” searches appeared targeted at older individuals, and infertility conversations were compartmentalized away from discussions of contraceptive or safe sex concerns geared for younger audiences. On most of the websites returned from this query, there was little to no talk of infertility prevention in early life stages. With so few sites appearing to address their concerns and their demographic, younger individuals could therefore be discouraged or diverted from taking beneficial steps for fertility preservation.

Moreover, in the few websites within this search that did engage with the topic of infertility prevention, the focus was placed heavily on the importance of STI control. While establishing the link between STIs and fertility is crucial for improving infertility awareness in the population, it is not comprehensive as an infertility prevention approach, and must be complemented by education and surveillance for other infertility-causing conditions. An overly STI-focused approach to infertility education may have a doubly negative effect, of not only under-educating young people about the true scope of infertility risk, but also stigmatizing the topic of infertility. This can ultimately impede open discussions about infertility among young people, and discourage them from actively pursuing evaluation if they have any fertility concerns.

Finally, I found that in materials about reproductive and sexual health, which were mostly concerned with and targeted to younger populations, infertility and its risk factors were seriously under-discussed. Even on websites that defined fertility as a core component of reproductive health and well-being, the topic appeared to be largely eclipsed by conversations about contraception, and even more often, the dangers of

unsafe sex. When included at all, infertility discussions were at least one or two links deep into a document, instead of being centrally featured. Even the link between STIs and infertility often went unmentioned, evidencing the lack of consideration of infertility and reproductive potential as a relevant topic for youth.

These findings contribute to our understanding of *disparities* in infertility in several ways. First, in diction and tone, the way in which many infertility websites appear to address an intended audience of older, educated readers can alienate and exclude younger and less educated women. In so doing, they may also disproportionately exclude lower-income and minority readers, since epidemiology shows that minority and low-income infertility patients are likely to be younger and to have less education than their white and more affluent counterparts). Women from these demographics who navigate to these sites may feel that the infertility discourse they encounter is not meant for women like themselves. This can delay or prevent them from researching their fertility concerns, and having their symptoms recognized and managed appropriately. Moreover, the effect of this exclusion from the online discursive space of infertility can be compounded by other practical barriers to care, including the prohibitively high expense of infertility treatment, and lack of clinical decision support.

Secondly, in a situation where reproductive health materials targeted at younger audiences are so inadequate and incomplete regarding infertility, only highly educated and well-resourced youth may have other means of accessing the necessary information to research their concerns, pursue medical evaluation, and procure a formal diagnosis if necessary. The social resources necessary to do this include not only education, which affects reading level and background knowledge, but also social capital and mobility that

can allow them to seek out and ask other adults or authority figures for assistance. Meanwhile, youth without such resources would remain far less likely to have any concerning symptoms evaluated, and to receive a diagnosis of an infertility-causing condition in a timely manner.

Finally, the linkage consistently drawn between infertility and STDs, and the way in which it precludes a fuller discussion of infertility risk, can also contribute to disparities in patterns of infertility. Literature in the fields of medical anthropology and sociology has shown how extensively cultural stigma attached to the topic of STDs—including gonorrhea, chlamydia, herpes, and syphilis, not to mention HIV/AIDS—permeates our society, essentially equating infection with an STD to a “blemish of character” [44]. Nack writes, “STDs have been socially constructed as symbols of moral corruption in that risk of infection has been linked to promiscuity”; as a result, the diagnosis of an STD, and in particular a chronic one such as HPV or genital herpes, carries with it an inescapable assignment to the category or “tribe” of the “bad girl or the fallen woman” [45]. This fact persists despite the facts that many of these STDs are eminently curable in the early stages, and even those that are chronic can be rendered virtually symptom-free with appropriate treatment.

As noted above, the distribution of STDs is staggeringly uneven in our society [30]; there is evidence that this epidemiology has informed a negative cultural stereotype about the sexual irresponsibility of minorities [46]. This stereotype can burden and oppress the minority community, such that minority individuals may feel the need to disprove or contradict these negative stereotypes in their own lives. In this context, the constant and inexorable conflation of infertility and STDs in online reproductive health

materials can particularly negatively affect minorities. Young minority women may wish to avoid any discussions and actions that could carry the stigma of STDs; this may impede them from seeking information about infertility risk and prevention, and thus sustain observed disparities in infertility diagnosis and treatment patterns. These hypotheses are further explored in Lee [24].

As a final note, the recommendation to de-conflate conversations about infertility and STDs does not mean that the fertility implications of diseases like gonorrhea and chlamydia are currently being adequately discussed. This document review also highlighted obvious gaps in discussions about the fertility implications of STDs; given the disproportionate distribution of STDs in the population, this may also be contributing to racial/ethnic disparities in infertility in and of itself. Accurate and appropriately targeted information about preserving fertility potential after an STD diagnosis is crucial for appropriate management of infertility risk in all populations.

Limitations:

This study was limited by the lack of a second analyst, which introduced potential subjective bias to the conclusions, especially regarding the tone and targeting of websites. All hypotheses and conclusions were formulated primarily by the author, in discussion with a team of mentors and colleagues.

Despite these limitations, this study also had multiple strengths. To the best of the author's knowledge, it is the first to undertake a review of online information available about infertility, from the point of view of a lay Internet user, and to characterize its limitations within the context of a larger conversation about reproductive and sexual

health. It is also the first to employ this approach towards a critical examination of online sexual health educational materials, and especially the critical but problematic linkage it draws between STDs and infertility.

Future Directions:

These data provide evidence of the critical need for better awareness and education about infertility, which can lead to improved fertility management and early preventive care. Policy implications of these findings are many: First, we can seek to improve targeted education and counseling for young women with infertility risk factors, such as endometriosis and polycystic ovarian syndrome. This document review revealed that there is no overall lack of information about infertility available online; rather, there is a wealth of information that is not currently available and accessible to the populations who could benefit from it. Younger women who may not yet have experienced “infertility,” as clinically defined, but may be experiencing the first warning symptoms of a potentially infertility-causing condition, should have ready access to information that can help them to understand, recognize, and manage their conditions.

In addition, we must increase awareness and open avenues for communication about the management of fertility in the general population. In a reimagined approach to sexual education, we can seek to educate young people not only about how to curb their fertility, but also how to prepare for their future families as they imagine and desire them. Thus, alongside messages about contraception and safe sex, we can include messages that highlight the importance of caring for fertility potential. By decoupling conversations about infertility from those about unsafe sex and “irresponsible” sexuality, we can create

a stigma-free space for young women to prepare for a lifetime of informed reproductive choices. At the same time, this work can—and must—occur in conjunction with efforts to improve secondary prevention of infertility through better education about STDs.

With their widespread accessibility and readership, many of the websites surveyed have tremendous potential for disseminating messages to youth seeking to learn more about their reproductive health. There has so far been a disconnect between these rich sources of communication, and the academic researchers who study how these messages can best be formulated and targeted to groups in need. As such, there is a great untapped potential for collaboration between academia, policymakers, and public health organizations in the area of online health communication about infertility. This collaboration can have critical repercussions for infertility awareness, education, and prevention in the community.

I Wish I Had Known Sooner: Barriers to Awareness, Time to Diagnosis, and Initiation of Treatment of Infertility-Causing Conditions

Abstract:

Infertility affects 1 in 8 couples in the US, yet many couples report feeling blindsided by the diagnosis. This study seeks to investigate the current state of awareness and knowledge about infertility, including its risk factors, causes, early symptoms, and prevention, and to evaluate the impact of this knowledge on patients' longitudinal infertility journeys.

Interviews were conducted with 54 infertility patients recruited from an online infertility patient forum. Interviews explored patients' early understandings about infertility; experiences with sexual health education; and experiences of early infertility symptoms. They then investigated how differences in how infertility awareness affected patient trajectories, especially in regards to time to diagnosis and initiation of fertility management and treatment.

Our interviews revealed a concerning lack of informational and support resources for young women with concerns about their fertility. Many older participants expressed regret that they were not educated earlier about age-related fertility decline, which led them to delay childbearing too long. Meanwhile, many patients with infertility secondary to medical conditions like endometriosis and polycystic ovarian syndrome reported that their early symptoms of disease were either missed, or diagnosed without concomitant counseling about their fertility implications, leading to lost opportunities to manage their fertility. These interviews suggested that infertility is largely overlooked as a topic relevant for youth in sexual health curricula, and eclipsed by discourse about contraception and safe sex.

This paper sought to investigate socioeconomic disparities in infertility by means of key informant interviews, gathering together diverse insights from infertility patients, patient advocates, clinicians, and policymakers. Specifically, this paper explores the hypothesis that disparities in patient experiences of infertility stem in part from differences in knowledge about risk factors for infertility, as well as strategies for its prevention. Many patients have infertility secondary to age-related diminished ovarian reserve, and suffer from a lack of awareness about the decline of fertility with age. On the other hand, for patients whose infertility is caused by medical conditions like endometriosis and polycystic ovarian syndrome (PCOS), improved education and

awareness could be crucial in recognizing early symptoms, achieving a timely diagnosis, and initiating appropriate management and fertility-preservation measures.

Background:

In a previous ethnography, Friese et al describe the common “biological clock” discourse surrounding infertility as:

...The notion that the public domain, organized around paid labor, interferes and competes with a woman’s fertile years. By the early 1980s, the biological clock came to be stereotypically identified with a cohort of largely Caucasian, educated, upper-middle class, baby-boom women... Subsequently, women who chose to have children in their mid-to-late 30s triggered a much-publicized ‘infertility epidemic’, characterized as women anxiously pursuing pregnancy before it was ‘too late.’” [48]

Friese’s work documents attitudes consistent with this phenomenon, showing that, “many women were upset that they did not have adequate information in making their reproductive decisions, and some became vocal advocates engaged in [education] about the implications of age and fertility.” Women felt that the risks of age-related infertility had not been adequately represented and explained to them, either by the medical profession, or in the messages in popular media.

While this narrative accurately describes the journeys of many infertility patients, it applies most readily to patients who are White, educated, and middle- to upper-class, in whom infertility is predominantly a problem of age-related fertility decline, as opposed to tubal or uterine factor infertility or ovulatory dysfunction [49]. However, epidemiological data indicate that the actual clinical picture of infertility in the population is much more varied. First, the overall prevalence of infertility is actually higher outside of the White

demographic. Data from the National Survey of Family Growth indicate that infertility rates for black and Hispanic women are multiple times higher than those for White women (19.8% and 18.2%, respectively, compared to 6.9%)[3]. Similarly, in a national survey of 10,847 women of reproductive age in the US, Jain and colleagues reported that Black, Hispanic, and other “non-Caucasian” women reported infertility more often than Caucasian women [4]. The same authors reported that infertile women in these categories were also more likely to have household incomes lower than \$100k, as well as less than 4 years of post-high school education. (This points to the difficulty of disentangling the effects of race, income, and education when examining overall socioeconomic status; as Nancy Krieger states, while controlling for factors like income and education can seem to eliminate the predictive power of race, these factors can in fact be seen as mediating variables, rather than confounders, on the effect pathway. [50])

Also, in non-White populations, infertility is relatively less likely to be due to advanced maternal age. Two other leading causes of infertility in the US are endometriosis and PCOS. Endometriosis is a disease involving growth of tissue resembling the endometrium (uterine lining) in places outside the uterus. Endometrial implants may grow on the peritoneum (the lining of the abdomen and pelvis), sometimes causing scarring that involves the ovaries and Fallopian tubes, resulting in infertility [51]. Endometriosis is present in 25-40% of infertile women [52]. Meanwhile, PCOS is a hormonal disorder characterized by a constellation of symptoms including irregular or absent periods, lack of ovulation, weight gain, acne, excessive facial hair and infertility. It is very common, affecting 5-10% of the US population. It is the leading cause of female infertility, being responsible for about 75% of cases of anovulatory infertility. PCOS is

more common in African-American females (8%) and Latinas (13%) than among Caucasians (4.8%) [53].

Finally, poor and ethnic minority communities are disproportionately impacted by infertility stemming from “occupational hazards, environmental risks, and lifestyle factors, including smoking and obesity... and delays in treatment of reproductive tract infections, including those that are sexually transmitted and those that result from poor-quality medical care” [6]. According to the CDC, obesity is 50% more prevalent in Blacks, and 20% more prevalent in Latinos, as compared with Whites; obesity can lead to hormonal dysfunction and is commonly linked to menstrual irregularities and infertility [32, 33]. Rates of STIs are also strikingly higher in minority groups than Whites; the rate of chlamydia, for example, among black women is over six times the rate among white women (1,613.6 and 260.5 per 100,000 females, respectively) [54]. Untreated sexually transmitted infections can lead to pelvic inflammatory disease (PID), which causes scarring of the Fallopian tubes and greatly reduces the likelihood of conception in utero. Thus, a CDC working group concluded that, “preventable causes of infertility... [such as] STIs that may lead to infertility if untreated... disproportionately affect the less privileged”[38], and that there was still a great need for better surveillance and treatment in this area.

In the case of these infertility-causing medical conditions, early detection, diagnosis, and initiation of treatment can be critical to managing fertility, and preserving childbearing potential. When symptoms of endometriosis go unrecognized and undiagnosed for years, scarring and adhesions can progress to the point that few

treatments remain likely to succeed. On the other hand, with appropriate medical management, scarring can be minimized so that fertility potential remains high. Similarly, concerning polycystic ovarian syndrome (PCOS) in young adolescents, early symptoms like irregular menstrual bleeding and hirsutism are often missed or attributed to normal components of the last stages of puberty. This means that in many cases, “diagnosis is often not made until later in life when endocrine and metabolic dysfunctions have been firmly established”[37], resulting in progression of the disease and lower fertility potential in adulthood. However, studies have shown that “early diagnosis and timely suppression of excess ovarian androgen production” are critical to minimizing clinical sequelae like infertility. Thirdly, as discussed above, immediate recognition and treatment of STIs like chlamydia and gonorrhea can completely prevent the PID and scarring that would otherwise lead to infertility.

Currently, the major challenge to improving prevention of infertility in this regard is the current state of sexual education in the US. Sex ed curricula range from extremely limited in scope to even nonexistent [39]; only 22 states require that sex ed be taught in schools at all, and only 13 of those states have in place legal standards requiring those schools to teach information that is medically accurate [40]. According to a 2007 study from Mathematica Policy Research, the federal government allocates over \$50 million a year to abstinence-only education under Title V; combined with states' grants, nearly \$100 million in government funds goes to abstinence-only education each year [41]. These programs present abstinence as the only real way to prevent pregnancy, completely excluding any mention of other contraceptive alternatives, STIs, and other conditions that can affect fertility.

Overall, a CDC working group on infertility concluded that for many of infertility's multiple causes, "early diagnosis and treatment of underlying medical conditions (secondary prevention) may lead to effective restoration of fertility"[38]. Therefore, it stated in its White Paper, a key strategy for better prevention is building greater "awareness of risks...[which] may lead some people to adopting corrective behaviors and maintain fertility." It also took care to note, "the general public [also] needs to be educated on strategies that minimize the risk of infertility," since awareness of risk alone will not mean that individuals have the knowledge and tool to take better preventive measures. Individuals must be given both information and resources to enable them to seek earlier medical evaluation for symptoms of infertility-causing conditions, leading to more timely diagnosis, better management, and better long-term outcomes.

Methods: Key Informant Interviews

This paper sought to investigate qualitatively, through key informant interviews, how infertility awareness, and access to information and counseling about fertility management, create and perpetuate disparities in experiences of infertility and infertility-causing medical conditions like endometriosis and PCOS. Interviews were conducted in two waves: the first in the fall of 2013, and the second in summer and fall of 2015.

The goal of the first wave was to capture a broad range of different personal and professional views on infertility and disparities in infertility experiences. Patients were recruited for interviews in response to a posting on the websites of two major infertility advocacy organizations: RESOLVE, the National Infertility Association, and the Tinina Cade Foundation. RESOLVE was founded in 1974 as "the only established, nationwide

network mandated to promote reproductive health and to ensure equal access to all family building options for men and women experiencing infertility or other reproductive disorders.” The Cade Foundation was founded in 2005, and holds as its mission to provide “information support and financial assistance to help needy infertile families overcome infertility.” Moreover, in order to place patient perspectives in a larger context of voices from the health care and political systems, several types of infertility experts were also interviewed, including clinicians, patient advocates, and policymakers. Experts were identified mainly with the help of RESOLVE, based on their demonstrated leadership in the fields of infertility and/or health disparities; interviewees could also suggest colleagues to be interviewed. In this first wave, a total of 16 patients, 8 clinicians, 2 policymakers, and 2 patient advocates were interviewed. All interviews lasted between 30 and 60 minutes, using a semi-structured interview guide with open-ended questions. Different but overlapping guides were used for patients and the different types of experts. Interviews were conducted in-person when time and location permitted, or over the phone.

While the first wave of interviews was hypothesis-generating, the second wave of interviews aimed to support and refine these hypotheses. The second wave of interviews was conducted between May and September of 2015, and was conducted exclusively with patients, seeking to elicit more detailed patient narratives and gain further insight into the hypotheses formulated during the pilot phase. Again, patients were recruited for interviews in response to a posting on the websites of RESOLVE or the Cade Foundation, and lasted approximately 30 to 60 minutes. This wave of interviews focused more specifically on patients’ experiences with early symptoms of their infertility, and

how and when they sought medical attention, arrived at a formal diagnosis, and initiated treatment. Interviews also explored how infertility was discussed in early sexual and reproductive health education in their communities—with educators, clinicians, friends, and family members— and what barriers or obstacles ever impeded conversations about fertility-related topics. For this wave, all interviews were conducted over the phone. A total of 38 patients were interviewed in this wave.

In all interviews, the exact wording of each question and the sequence of questions were adapted to the interview setting to ensure that questions were relevant, tactful, and appropriate for the situation. Interviews were transcribed verbatim, and in-depth content analysis was conducted to identify common themes, and relationships between themes. Core themes that repeatedly appeared in the transcripts were identified, and compared with emergent ones as further interviews were conducted; identification of themes was thus an ongoing and iterative process. Once all interviews had been conducted, a list of themes was finalized and all interview transcripts were re-examined and coded for the presence of each theme. From this, a final tally of the percentage of participants endorsing each theme was obtained.

For patients, based on comparison of emergent themes in the transcript, the primary category of analysis was chosen to be patient diagnosis. However, analyses also included how responses tended to vary according to respondents' age, race, geographic location, with comments being placed in these demographic contexts on a case-by-case basis. Additionally, the analysis took into consideration how viewpoints of patients, clinicians, and policymakers both agreed and conflicted, revealing disconnects in the health care system and highlighting the need for better communication.

Verbal informed consent was obtained for all interviews. This study was reviewed and approved by the Harvard Committee on the Use of Human Subjects for protocol #IRB13-1322 on August 19, 2013.

Results:

Table 2.1. Descriptive statistics: Interviewees (n =54)

Characteristic	Point estimate (St dev)
Mean age	35.3 (4.8)
Mean income (combined household)	99.7 (50.1)
Mean education (years post-HS)	5.6 (2.0)

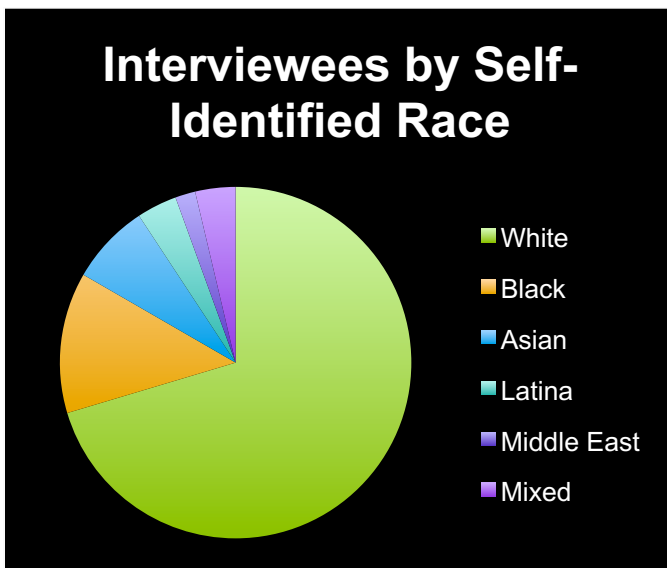


Figure 2.1. Interviewees by self-identified race

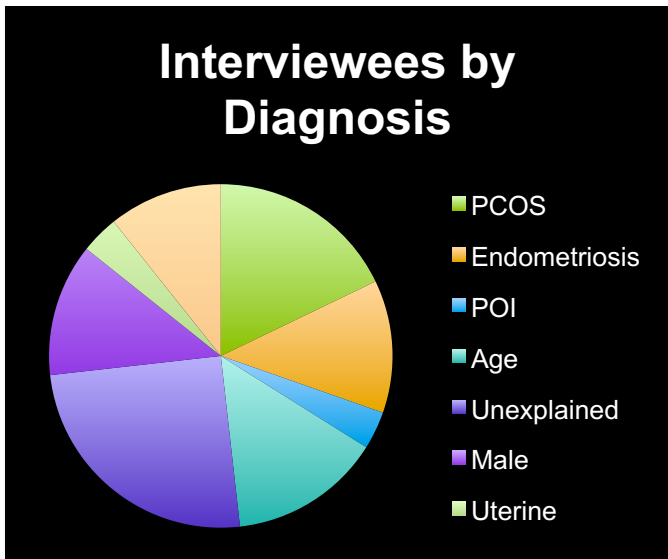


Figure 2.2. Interviewees' infertility diagnoses

A. Early education and awareness:

Aggregate demographic characteristics of the patients from both waves of interviews (54 patients total) are presented in Table 2.1 and Figures 2.1-2.2. As anticipated, age was one of the leading causes of infertility in this sample; and in accordance with the literature by Friese et al, many interviewees expressed regret and disappointment that they had not been adequately aware of the decline in fertility with age. Excerpts were selected for inclusion in the tables based on whether they were articulate, illustrative, and represented a variety of viewpoints; however, a total tally of the number of women of each demographic who endorsed each theme is presented in Table 2.2.

Table 2.2. Key themes endorsed by participants

Theme	Total # endorsed	White	Black/Latina	Asian/Other	Older (35+)	Younger (<35)
Total	21	14	5	2	12	9
1A (Age-related Infertility)	7	6	0	1	7	0
1B (PCOS)	6	3	3	0	3	3
1C (Endometriosis)	5	2	2	1	1	4
1D (POI)	2	2	0	0	0	2
2 (Sex ed)	15	13	1	1	6	9
3 (Stigma)	4	2	2	0	2	2

Selected quotations about age-related infertility are presented in Table 2.3. First, many of the older participants stated that they felt falsely led to believe that having children would be possible, or even easy, for them into their late 30s and 40s (see case Nora). Participants especially pointed out that they had been unaware of the tension between their plans to build a family and those to pursue education and a career (see cases Isabella, Leah). Several stated that if someone had informed them about the risks of age-related fertility decline, they would have begun trying to have families significantly earlier (see case Kaylee). This theme was endorsed by 7 of the 8 participants in the study who had age-related infertility (see Table 2.2).

Importantly, though, it was evident from the interviews that participants were also highly aware of other clinical and financial options for balancing a family with a career. In particular, several women stated that rather than simply having children earlier, they would have spent time preparing mentally and financially for measures like egg freezing (see cases Nora, Grace, Kylie). These women also stated that they now readily spread the

advice to take such measures to their friends and younger family members.

Our interviews additionally revealed some tension concerning *who* was responsible for informing the public about this relationship between fertility and aging. Clinicians agreed about that this lack of information was leading many patients to delay childbearing past the time when it is reasonable to expect natural conception. Dr A, an REI physician at a tertiary care hospital in New England, stated, “Advancing age... is the most important problem that we deal with. Often the regret [among patients] is that they waited too long. I have heard, ‘Nobody told me I should try to get pregnant in my twenties’... So more public education about that is really really important.” At the same time, somewhat at odds with her comments, patients voiced the wish that their clinicians had been more proactive, both in terms of fertility counseling and running baseline fertility tests (see case Kaylee).

Table 2.3. Selected excerpts of participants re: Age-related Infertility

	Participant pseudonym	Demographic (Age and Self-reported ethnicity)	Location	Excerpt
Theme 1A. Age-related infertility	Nora	38 White	NY	<p>This is what drives me insane right now[...] I had this idea that I could wait as long as I wanted to have kids, when not everybody can do that. Everyone I know in NYC is super career-oriented, and all my friends are neurotic New Yorkers like me, we don't have kids in our twenties. I feel like nobody ever told me that having a family was something I should think about earlier[...] This wasn't presented to me, I feel like I missed the information. There was a biological arrogance that I had, I just had no idea.</p> <p>I tell my friends now, the ones who are single[...] 'Someone should tell you this! If you don't want to have a family for a long time, you should freeze your eggs.</p>
	Isabella	44 White	MA	[Girls were] "socialized to be utterly devoted to having a career and consider family-building as an afterthought. So they actually weren't fully informed about the risk of infertility."
	Leah	37 White	CA	I went to [a private liberal arts college], and it was never ever talked about. I wish at women's schools it would be something they would talk about in the health department. Like[...] if you're going to have a career, and you'll be in school till 30, and you plan to have student loans, how do you do all that together.
	Grace	40 Asian	CO	If I'm lucky enough to have a child, and it's a girl, I'm going to tell her—or my friend's kids, I'd tell them—don't sacrifice your career for a family, but also[...] I would have frozen my eggs at 32, if I'd known.
	Kaylee	39 White	PA	I really believe that if you're in your 30s, AMH [Anti-Mullerian Hormone] is a 100-dollar test[...] I think that's one of the most crucial tests that could be done, because then you can make informed choices. My husband often says that if we'd known, we wouldn't have waited so long before trying to conceive.
	Kylie	39 White	FL	I think the hardest part is you really don't know until you start trying... [looking back, if i could do anything differently] I would have frozen my eggs, I would have spent money to do that when I was in my 30s, but I didn't have any idea.

Considering fertility as a relevant concern for younger women—and initiating

fertility counseling and testing at earlier ages— could not only help prevent cases of infertility due to advanced maternal age; it could actually identify individuals in the general population who are at high risk for infertility due to an underlying pathology. Medical conditions like endometriosis and PCOS were actually even more common in the sample than cases of age-related infertility: PCOS was the leading cause of infertility among the interviewees, while endometriosis was tied for third (see Figure 2.2). These patients' infertility narratives were quite different than those who experienced age-related fertility decline. Rather than feeling “blindsided” by a diagnosis of infertility after decades of being given a clean bill of health, many participants reported noticing symptoms of their conditions as early as their teens. However, these symptoms were often not recognized until years or even decades later, when the women first began trying to conceive.

Many of the participants suffering infertility secondary to PCOS expressed regret that they had not recognized their warning signs of infertility earlier, and undergone potentially fertility-preserving treatment (see selected excerpts in Table 2.4). This theme was endorsed by 6 of the 10 women diagnosed with PCOS in the study. They described clear-cut presentations of classic symptoms, and recounted how their doctors either did not diagnose them (see cases Sophia, Elizabeth), or diagnosed PCOS without electing to counsel them about its potential impact on their future fertility (see case Zoe). Significantly, they point out that such late or missed diagnoses meant a lost opportunity not only to start treatment, but also to form accurate and realistic fertility expectations, and become educated about both the condition and family-building options. Knowledge of this loss led to much frustration and anger during the infertility journey.

Notably, at least two participants also stated that they felt valuable information about fertility had been withheld from them in the past because of doctors' assumptions that they were not yet at the right stage of life to be concerned with childbearing (see case Elizabeth). This could occur even when patients actively sought out information; one patient felt that her doctor was outright dismissive of her fertility concerns, as she had "no husband and no childbearing opportunities in sight" (see case Abigail). These experiences importantly reveal how fertility counseling can be withheld not only from women who are deemed too young to be raising families, but also to those who are deemed to be in the wrong social position, in terms of marriage and stability. The requirement to be (heterosexually) married in order to be perceived as a "fit mothers" is another axis of stratified reproduction; furthermore, it is reinforced even beyond the clinic setting by insurance policies. For example, in Maryland, Arkansas, Hawaii, Rhode Island, and Texas, the mandate for insurance companies to cover or offer fertility treatments only applies to married couples. In Maryland, leading health insurer CareFirst declares that they are "unable to cover any procedure, unless it is carried out with the spouse's sperm" [55]. This axis of stratification of reproduction, and the ways in which it intersects those of class and race/ethnicity, is a crucial topic for future study.

Table 2.4. Selected excerpts of participants re: PCOS

	Participant pseudonym	Demographic (Age and Self-reported ethnicity)	Location	Excerpt
Theme 1B. PCOS	Sophia	37 Black	PA	My cycles were irregular, I had facial hair popping up everywhere, weight gain, all the symptoms of PCOS in my mid twenties, [and doctors] were just pooh-poohing it away like, ‘Oh, just get on the treadmill, push away from the table, you’ll be fine.’ Now here I am hitting my 30s and it’s like, ‘oh, what’s PCOS?’ It’s textbook, I fit the criteria perfectly, and I’ve fit them all my life[...] If I [had] been diagnosed before college, I could have been armed with information.
	Elizabeth	30 Black	CO	It made me quite frustrated and really angry that I wasn’t told about what PCOS was until I was 24. Even though I’d been to the same OB/GYN for years, but I wasn’t told I had signs of PCOS until I said I was engaged. I don’t know if that sparked ideas of, ‘oh she must be trying for a family,’ but I was really angry that nothing was told to me prior to that, in high school, nothing was said then[...] I could have been thinking about my future a different way.
	Zoe	28 White	NJ	At that time nobody went into the details of what the repercussions would be[...] No one said you’re going to have trouble getting pregnant, and at 16 that’s not really where your mind’s at anyway, so they kind of brushed over it. It wasn’t presented as a serious thing.
	Abigail	42 Mixed	VA	I even told a doctor that I was worried [about fertility complications] and I wanted to know more about it. The doctor at that time, which was when I was about 23, wrote me a prescription for birth control pills and walked out of the room[...] Up until my thirties doctor's acted like I was overreacting with no husband and no childbearing opportunities in sight.

Endometriosis narratives bore a striking resemblance to those of PCOS patients in many ways. Again, interviews found that women had not received a formal diagnosis until much later than optimal, despite experiencing symptoms from an early age (see Table 2.5). 5 participants out of the 7 in the sample diagnosed with endometriosis endorsed this theme. Again, participants consistently reported that their doctors focused only on controlling their painful symptoms, rather than seeking an underlying cause for the pain (see cases Avery, Mackenzie). Moreover, similar to patient narratives of PCOS,

interviewees related a tendency among clinicians to ignore or avoid discussions about possible fertility implications of this condition, revealing an assumption that young women must not yet be concerned with childbearing. This lack of information made many patients wait to seek treatment, possibly damaging their chances of treatment success (see case Madelyn).

Table 2.5. Selected excerpts of participants re: Endometriosis

	Participant pseudonym	Demographic (Age and Self-reported ethnicity)	Location	Excerpt
Theme 1C. Endometriosis	Mackenzie	34 Asian	CA	I went to the doctor because I thought they were so painful, something had to be wrong. But I was just prescribed like 800 mg ibuprofen or something.
	Avery	30 Black	MI	I didn't know anything about endometriosis until I went to see the doctor about it three years ago. I saw my old doctor's notes and all they said were painful periods and irregular bleeding and that's all, she didn't test me for anything.
	Madelyn	29 White	MI	[My periods] didn't feel normal... [but] at the time I didn't know that such a thing existed. So I didn't know there was some diagnosable thing. I wish I'd found out earlier[...] I feel like I have a textbook case of endometriosis. If [my doctor] had been observant enough to pick up on that I might have endo, [my treatment] could have been covered, but[...] there's not much I can do about that at this point.

Finally, a third cause of infertility present in this sample was premature ovarian insufficiency (POI). This condition causes ovaries to stop functioning before the age of 40 (and often much earlier). These participants also reported that their early indications of infertility, such as oligomenorrhea and menopausal symptoms, were not adequately recognized and investigated by doctors, damaging their fertility prospects later in life (see Table 2.6). 2 out of 2 participants with POI endorsed this theme, expressing frustration that doctors would be so “ridiculous” as to not run a simple blood test. Both stated that

had they been better informed about their condition, they would likely have started trying to have children years earlier, and might not be in their current situation at all (see case Julie).

Table 2.6. Selected excerpts of participants re: POI

	Participant pseudonym	Demographic (Age and Self-reported ethnicity)	Location	Excerpt
Theme 1D. POI	Aubrey	31 White	AZ	the university doctors... [didn't] take a blood sample and check my hormones. Looking back, it seems obvious[...] it's just ridiculous to me that they didn't do that." She states that if she'd known about her condition and the ways her fertility would most likely rapidly decline, "my husband I would have started trying a lot earlier.
	Julie	32 White	PA	I wish that my GYN would have ran a few tests... to test my ovarian reserve. Because of my age she probably though it wouldn't be a problem. But if I'd known two years ago, I might not be in this predicament and already had a child.

These interviews showed that there is tremendous room for improvement in the areas of awareness, prevention, and early management of risk factors for infertility. In total, the related themes of lack of awareness, late diagnosis, and regret were endorsed by 21 of the 54 respondents, or 38% of the study sample. The demographic breakdown of participants who endorsed this theme is examined further in the discussion section.

Regarding the lack of information provided by doctors, Isabella reflected, "I think it's very easy for women to be very reticent in asking questions about their sexual health and fertility. When you're sitting in stirrups and your GYN comes into the room and comes at you with the speculum, it's not a good time to ask what's on your mind, or does this symptom matter. So I think we need to train doctors to create the moment when a patient can say what is on their mind, if there's anything unusual." Thus, health care providers can play an essential role in the effort to grow and facilitate communication

about this topic, as well as doing the clinical work of recognizing early symptoms, and counseling young women with infertility-causing conditions about the potential ramifications of their diagnoses for future family-building.

At the same time, these conversations need not necessarily be confined to clinical settings. Perhaps the most natural way in which to provide information about infertility to youth would be to tie it in with conversations about sexual and reproductive health already occurring in schools or community centers. While clinicians may be best positioned to diagnose infertility-causing conditions and initiate treatment, having patients who are informed about infertility risks, aware of the potential significance of early symptoms, and armed with questions for their doctors, can make a tremendous difference in achieving timely diagnosis and appropriate management. At the moment, however, conversations about reproductive health and fertility are conspicuously absent from sexual health curricula, as I will examine in the following section.

Links between Fertility and Safe Sex Conversations

A common theme across many interviews was the problematic inadequacy of sexual health education in the US, especially in regards to its lack of engagement with infertility as a relevant topic for youth (see Table 2.7). This theme was endorsed by 15 participants, or 26% of the study sample; 13 of these participants self-identified as White, 1 was Asian, and 1 was Black. These participants reported feeling shocked by the binary switch they encountered from being told to avoid pregnancy at all costs in adolescence and early adulthood, to trying to become pregnant at all costs after a certain age (see cases Kaitlyn, Hailey). They felt blindsided by the realization that when it came time to

conceive, they could actually have serious difficulties.

Dr. B, an REI clinician at a teaching hospital in MA highlighted how, rather than being presented together as a holistic package, messages about safe sex and infertility can be seen as conflicting, coming from separate and even competing agendas. He stated, “From a public health POV, you’re thinking about teen pregnancy risk and protecting them from getting pregnant...that might be the large public health problem you’re seeing but there still may be individuals or couples out there who are on the other end of the spectrum, who are not getting pregnant, but that might not light up on your radar.” The interviewees affirmed Dr. B’s points from the patient perspective; they felt that educators had actually been “scared” to tell them the truth about how difficult it is to get pregnant, for fear of driving teenagers to riskier behaviors (see case Adalyn). These participants felt that they would certainly have been willing to listen, if the subject of infertility had been broached when they were younger. But when clinicians and educators are overly focused on spreading messages about contraception and preventing unwanted pregnancies, the topic of future fertility can get pushed to the background.

Table 2.7. Selected excerpts of participants re: Sexual Education

	Participant pseudonym	Demographic (Age and Self-reported ethnicity)	Location	Excerpt
Theme 2. Overshadowing of Infertility By Safe Sex	Kaitlyn	40 White	CA	Starting high school it's all about protection. It's always 'don't get pregnant, don't get pregnant.' I spent until my early 30s trying not to get pregnant, and I had no education about how maybe I couldn't get pregnant. I was completely ignorant, oblivious to it, and I was shocked how uneducated I was. That you can only get pregnant for like 2-5 days per cycle.
	Hailey	34 White	MA	I had no idea we had this issue, because I wasn't really paying attention, because you're always trying to <i>prevent</i> pregnancy.
	Adalyn	30 White	TX	If someone had talked to me [about fertility] back then, I would have listened for sure, 100%. I think at that age they're scared to tell you it's hard, you don't just have sex once and get pregnant... They don't tell you people have trouble all the time. I think it would have been really great to have some knowledge of it
	Brooklyn	34 White	AZ	I don't remember anything about infertility at all, endometriosis, blocked tubes, PCOS. But I went to a Catholic school, so there wasn't even contraception, it was basically abstinence.

Interviews also revealed how fertility issues could be overshadowed by conversations about safe sex and preventing STDs (see Table 8). Participants remembered that in sex ed classes, infertility was never discussed *except* as a consequence of STDs (see case Ellie). In this way, fertility issues were presented as a largely irrelevant concern, as long as individuals are making responsible choices.

At the same time, interviews revealed how the association between unsafe sex and infertility may actively prevent open conversations about fertility (see Table 2.8). This theme was endorsed by 4 participants, 2 of whom were white, and 2 of whom were black. By presenting infertility *only* as a concern of those who have risky sex, a stigma can arise that prevents young women from asking about their fertility or reproductive health in

general. Several participants reported that when they were younger, this stigma posed a serious barrier to gaining the necessary information to have their conditions diagnosed (see case Sophia). Family and community members who assumed that reproductive health concerns and pelvic pain were signs of irresponsible sexual activity posed an obstacle to seeking treatment, getting an official diagnosis, and beginning appropriate medical management.

Furthermore, while it may begin with conversations for youth, this stigma around infertility appears to continue into womanhood. Older participants described how all their lives, they had only heard of infertility as an affliction of women who had unsafe sex; thus, they felt defensive and uncomfortable seeking medical attention when they began having concerns about their fertility as adults (see cases Mia, Natalie). Their comments revealed how the link between infertility and STDs, while established at a young age, can persist in women's minds, causing an infertility diagnosis at any age to carry a concomitant burden of embarrassment and shame.

Table 2.8. Selected excerpts of participants re: STDs

	Participant pseudonym	Demographic (Age and Self-reported ethnicity)	Location	Excerpt
Theme 3. Link between Infertility and Sexual Activity/STDs.	Ellie	27 White	CA	The only thing I really remember [about sex ed] was how STD's can sometimes screw up your fertility- but that was it. I even actually had this talk with some of the girls in support group and none of us could remember anything about it being talked about. The biggest thing was how NOT to get pregnant and STD's.
	Sophia	37 Black	PA	[My family saw it as] not a medical issue, they saw it as, 'Sophia's sexually active.' When I wasn't, I didn't even like boys then! There was a sexual stigma about it.
	Mia	37 Black	FL	[I had only heard of one person in my family] "who never had children, and it was one of those things [people said] like, you know, 'she had an abortion in college, maybe that's why..."
	Natalie	46 Black	TX	When I found out I had blocked tubes I was like, " 'how could that have happened?' Because you have to have had some kind of pelvic inflammatory disease or infection to cause that. And I was negative for everything. So that was embarrassing, I was thinking, I live pretty decent, I take care of myself, there shouldn't be something going on wrong.

This conflation of infertility with irresponsible, and even immoral, sexuality places a heavy burden on women who, for any reason, have questions about their future fertility. For women with a potentially infertility-causing condition, interviews showed how this significantly affected their experience of symptoms, whether and how they seek treatment, and the timing of diagnosis. In addition, the stigma can crucially impact women's decisions upon receiving the diagnosis, including whether and how they pursue medical management, and whether they feel able to be open with friends and family. Now, having researched her condition and begun IVF, Mia states, "I think the biggest problem with infertility is that people assume that it's something we bring on ourselves. I think that's the biggest thing, we have to educate people, that it's not an STD, it's a

disease. And it [can] affect all women.” De-conflating these two conversations can allow discussions of both safe sex and fertility concerns to take place in an accurate, complete, and judgment-free way.

Discussion:

Our interviews revealed a troubling lack of information and support resources overall for young women with reproductive health concerns, on subjects ranging from optimal timing of childbearing and work/family balance, to the diagnosis and treatment of infertility-causing medical conditions. Interviews confirmed Friese’s narrative that a significant proportion of the infertility population comprises older, highly educated, professional women. These women expressed regret, disappointment, and even anger at the lack of information they were given about how fertility declines, and spoke about how having those conversations earlier could have helped them plan better to balance childbearing with education and career goals. Importantly, it was clear from interviews that increasing education about age-related fertility decline clearly does not equate to a simple prescription to hasten childbearing; rather, it can mean making women aware of multiple ways of having the families they envision, as several of our participants indicated their desire to have pursued egg freezing when they were younger. At the same time, it points to the importance of not only increasing education and awareness about infertility, but also practical support for such endeavors, since elective egg freezing is

currently prohibitively expensive for most women without insurance from their employer.³

At the same time, this study also clearly heard the voices of another subgroup of patients, whose infertility stemmed from medical conditions such as PCOS or endometriosis. These conversations indicated that often, while symptoms presented very early on, education and counseling about the fertility implications of the conditions were not provided until the women were actively trying to conceive. As a result, initiation of fertility management and treatment was delayed, and its efficacy was lowered. Even patients who received formal diagnoses relatively early were often treated only symptomatically, and never counseled about options for preserving fertility.

This lack of information and counseling certainly impacted women in all of the socioeconomic strata represented within the sample. The theme of lack of awareness leading to late diagnoses was endorsed by 39% of the study sample, breaking down to 14 of the 38 white participants (37%), and 5 of 11 Black and Latina participants (46%). However, it was notable that in the case of PCOS, all three of the black women in the study who had been diagnosed with PCOS spoke about lack of awareness and late diagnosis. Similarly, both of the 2 Black women with endometriosis in the study endorsed this theme. While the ability to draw conclusions about the distribution of infertility awareness was obviously limited due to small sample size, this provided some preliminary indication that Black women may be more likely to be affected by lack of information regarding the medical conditions PCOS and endometriosis. Whether this is due to an increased burden of these conditions in the black population, or whether the

³ Notably, the recent decision of the social media giant, Facebook, to pay for egg freezing for its female employees shows some shift in this area; however, this choice currently remains limited for women in highly skilled jobs.

problem lies specifically in barriers to infertility education and awareness in this community, is an important direction for future study.

The second major finding of this paper is the problematic nature of current messages and understandings about sexual and reproductive health in our communities. Interviewees recalled that in their sexual education curricula, the topic of infertility was either ignored, overshadowed by more “immediate” adolescent health concerns like pregnancy, or inexorably tied to conversations about unsafe sex and STIs. Stigmatization of STIs is pervasive in American society, with current cultural understanding essentially equating infection with a “blemish of character” [45]. Nack writes, “STDs have been socially constructed as symbols of moral corruption”; as a result, the diagnosis of an STD carries with it an inescapable assignment to the category or “tribe” of the “bad girl” or the fallen woman” [46]. This fact persists despite the fact that many of these STIs are eminently curable in the early stages, and even those with chronic infections can live with virtually no symptoms with appropriate care and management.

While this fact undoubtedly disadvantages all women by impeding open conversations about reproductive health and fertility concerns, the stigma attached to STIs may also contribute to *disparities* in patterns of infertility diagnosis, management, and treatment. Given the staggeringly uneven distribution of STDs in US society [56], minorities are more likely to experience this stigmatization as a community, and to be negatively stereotyped as being sexually promiscuous or irresponsible. Thus, while both minority and non-minority women may be hesitant to raise reproductive health concerns, for fear of calling their sexual history into question, minority individuals may feel especially burdened with disproving or contradicting negative stereotypes in their own

lives. At least in this set of interviews, the concern about an infertility diagnosis leading to social judgment and criticism was endorsed by 2 of the 9 Black and Latina participants (22%), and only 2 of the 38 White participants (5%). Moreover, the Black participants spoke in more detail about the impact this stigma had had on their personal lives, in terms of interactions with family members and clinical decisions, rather than about general conceptions they had formed about STDs and infertility during their education. Thus, this obstacle to infertility education and diagnosis appeared to be more common and potentially more serious among women of color.

This study had several limitations. First, it was limited by the small sample size, as well as the predominance of white participants who responded to the recruiting script. Thus, conclusions about the distribution of infertility awareness, and any appearance that a phenomenon was concentrated in minority communities, could easily have been skewed by the experiences of just one or two minority participants. However, the richness and complexity of the narratives gave ample evidence that the themes endorsed by this participant are real and worthy of further investigation, even if the prevalence of the phenomena they describe was uncertain.

The study was also limited by the lack of a second coder for analysis. All hypotheses and conclusions were therefore subjective, formulated by the author in discussion with a team of mentors and colleagues. Secondly, experiences of these women were reported from their adolescence and early adulthood, which occurred 10-20 years ago for most study participants. Therefore, the experiences discussed here might not be entirely representative of sexual and reproductive health education today. Nevertheless, ongoing battles over abstinence-only education indicate that conversations about

reproductive health are still severely lacking, not least in its inclusion of fertility [40]. The adequacy and quality of publicly available Internet educational materials about reproductive and sexual health, especially in regards to fertility, are further explored in Lee [57].

Despite these limitations, this study also had multiple strengths. To the author's knowledge, it is the first paper that undertakes an in-depth, narrative-based exploration of infertility awareness in the US, characterizing its gaps and shortcomings, and describing the effects of those gaps on the infertility journeys of patients across the socioeconomic spectrum. Moreover, it is the first to specifically investigate the complex association between the topics of infertility and unsafe sex, both in American sexual education and in popular understanding, and to explore how this linkage can influence patient experiences of infertility as well as inform socioeconomic disparities in infertility.

Policy Implications:

These data provide evidence of a great need for policies to improve awareness, education, and early preventive care for infertility. First, we can seek to expand education and open avenues for communication about infertility in the general population. Currently, reproductive health education for women exists in unrealistically discrete modules: young girls and women are told only about avoiding unplanned pregnancy; then, once they are married and settled, are expected to become fully informed about how to get pregnant. We must seek to change what I term this "binary switch" approach to female reproduction, incorporating messages about safe sex, protection against pregnancy, and preservation of fertility into an integrated whole. This would allow for

conversations about the timing of childbearing to begin much earlier in young women's lives, allowing them to prepare both mentally and financially to negotiate the balance between a family and a career.

Second, we must seek to improve targeted counseling for women with proven infertility risk factors, such as endometriosis and polycystic ovarian syndrome. This can create space for young women experiencing early symptoms of these conditions to ask questions, and to be counseled about their fertility potential and steps that can be taken to preserve it while their chances of success are highest. These conversations should occur *alongside* the reproductive health messages that already appear to be relatively well disseminated, including those about contraception and safe sex. This would help to convey the notion that these conditions are not uncommon, and not a source of embarrassment and shame; moreover, it would help spread the message that it is natural and even responsible for young women to begin thinking about their fertility early. Given the prevalence of endometriosis and PCOS in the population, incorporating messages about these conditions into the general reproductive health curriculum is only logical and sensible.

Thirdly, conversations about fertility should be decoupled from those about high-risk and “irresponsible” sexuality. As such, young women who may be at risk for infertility can be empowered to seek earlier evaluation, diagnosis, and management of their conditions, without fear of stigmatization or judgment. At the same time, this recommendation to de-conflate conversations about infertility and STIs does *not* mean that the fertility implications of the latter should be less often discussed. Rather, this work can occur while maintaining and even improving efforts at secondary prevention of

infertility through increasing awareness about STIs, their fertility implications, and their treatments in sexual education curricula. In this way, we can seek to de-stigmatize all sources of infertility, emphasizing instead the strength and resilience it takes to undergo an infertility journey, and beginning to equip young women with the broad array of information and tools necessary to manage fertility optimally.

Don't Give Up!: A Cyber-ethnography and Discourse Analysis of an Online Infertility Patient Forum

Abstract:

Infertility affects women across the socioeconomic spectrum; however, it is by no means egalitarian in its distribution, nor uniform in its lived experience. Evidence shows striking disparities by income, race, and education in infertility prevalence, access to infertility services, and success rates after receiving infertility treatments. However, few studies so far have investigated disparities in patients' access to psychological support during the infertility journey.

This paper undertakes a cyber-ethnography of the online patient forum, "Finding a Resolution for Infertility," hosted by RESOLVE: The National Infertility Association. It also draws from interviews with 54 infertility patients recruited from the forum. The aim was to examine how social support operates within this virtual realm, by examining how the forum's language, norms, and values create and enforce categories of deserving and belonging among site users.

I find that the forum's discourse privileges an infertility narrative I term the "persistent patient," in which a patient exhaustively researches treatment options, undergoes multiple cycles of treatment despite repeated failures, and ultimately achieves success (a healthy baby). Meanwhile, there is little to no discursive space for discussion of the financial and social resources necessary to act in accordance with this script. Thus, women without such resources can be alienated, silenced, and denied mental health support by this online community.

In the context of what we know about disparities in patient experiences of infertility, it is reasonable to expect that socioeconomic disparities would also exist in emotional experiences of infertility. According to RESOLVE, the National Infertility Association, the inability to start families when desired can be as a "major life crisis," accompanied by losses of "feelings of self-worth, work productivity, and hope for the future" [24]. In this crisis setting, having a strong social support system can be a critical form of coping assistance [58], allowing individuals to manage the stress of the infertility experience and maintain their mental and emotional well-being. Moreover, such support is also an important determinant of clinical outcomes, as a patients' emotional state can inform whether patients persevere through the disappointments and setbacks of the

treatment process. So far, very few studies have explored whether there are socioeconomic disparities in how patients seek and receive social support during their infertility journey, and the implications of these disparities for emotional and mental health, as well as clinical outcomes.

In recent years, the Internet has become a major source of social support for patients experiencing various health conditions and illnesses [59]. Online patient networks and communities aim to provide their members with emotional and moral support, as well as discussion spaces, health information and advice, and other patient tools. Infertility is no exception to this online trend: the online patient forum “Finding A Resolution for Infertility,” created by RESOLVE: The National Infertility Association, and hosted on the patient network website Inspire.com, currently 25,030 members, with hundreds of new threads and thousands of posts per day. Patient communities like this one are a critical focus of ongoing study in medical sociology, as a space in which society’s current discourse and cultural understandings surrounding illness are revealed, reaffirmed, and—potentially—renegotiated. They can indicate how patients are expected and constrained to behave, what experiences and feelings are validated and reassured, and which are disdained, or dismissed.

This paper undertakes a cyber-ethnography and discourse analysis of the online patient community, “Finding a Resolution for Infertility,” in order to investigate how social support operates within this virtual realm. I first characterize the discourse of this forum, investigating the language and norms of this emerging space created specifically by and for infertility patients. I then examine how this discourse creates dominant and counter narratives, creating and enforcing categories of deserving and belonging that then

impact how emotional support is differentially offered to and withheld from users of the site. In this way, I seek to explore how disparities in infertility can be formed not only in the course of infertility prevention, diagnosis, and care, but also in the ways in which patients find and receive social support during their treatment course. Finally, I consider whether this discourse offers a window into the infertility discourse in our society more generally, and how this may inform further policy reform.

Background:

Gottlieb defined social support as “interaction in relationships which improves coping, esteem, belonging, and competence through actual or perceived exchanges of physical or psychosocial resources” [60]. Cohen and Wills [61] hypothesized that social support can importantly modulate illness experiences, and thereby improve health, by “buffering” individuals from the negative effects of stressful life events. Cohen and Wills categorized social support into four main types: emotional support, informational support, social companionship, and instrumental aid. Each of these can provide protective and positive effects in the face of stress, both by attenuating individuals’ perceptions of the stressful event, as well as by providing direct solutions or aid in overcoming the problem. In this way, social support can crucially impact both patients’ emotional experiences and their health status during and after an illness experience.

But to investigate where and how patients receive social support, we must first ask where patients themselves seek it. As the Internet revolutionizes communication and connection in almost every sector, experts in patient counseling report that a growing number of patients are turning to online communities for social support about various

health conditions and illnesses. Access to the Internet has now become virtually universal; in the US, penetration has increased from less than 50% in 2001 to 87% in 2014 [62]. Thus, online communities provide a way for patients to instantly and conveniently “plug into” a support community, finding hundreds and thousands of users like themselves who can offer reassurance and encouragement.

Swan [59] reported that online communities provided a multitude of services for their users, ranging from emotional support and information sharing, to Q&A with physicians, to quantified self-tracking, to clinical trials access. Moreover, in these spaces, the “collective learning and experience of others can be leveraged and shared to help individuals make decisions,” making patients feel more empowered [59]. Very few studies so far have focused specifically on infertility communities. In general, those that did so reported findings consistent with observations about more general health-oriented online patient networks. That is, while infertility forums serve a variety of functions for their users, empathy and emotional support are consistently mentioned foremost [63]. These forums provide safe spaces in which to find sympathy and support, with the comfort of having supporters only “a click away.”

For infertility patients in particular, online communities also provide special benefits that are not relevant to all health conditions, particular in regards to privacy and anonymity. This is because infertility still carries a social stigma in many cultural understandings, which makes many women hesitant to speak openly about their infertility journeys. *Stigma* is defined as “a distinguishing mark of social disgrace,” and constitutes a group judgment about what is accepted or not [64, 65]. Greil, characterizing the burden of stigma that comes with infertility, wrote: “The heart of the experience of infertility

appears to lie in the inability to proceed with one's life according to life course norms, that are both reinforced by others and accepted as valid by the affected individual" [66]. Thus, infertility is associated with notions of a women's incompetence or defectiveness, and the belief that infertile women must "fix the broken part" [64, 67].

While stigma is the group's judgment about acceptance vs. ostracism, *shame* is the emotion felt by persons who are not accepted [64]. Lombardo writes, "Many women in that situation may feel ashamed, as if they are fundamentally different from other women"[68]. Psychology studies have found that infertile women score higher on measures of both external and internal shame and self-judgment than fertile women [69]. Thus, many women experiencing infertility choose to remain silent and try to hide their condition, to spare the pain of being stigmatized. As a result, women often do not find social support in the usual channels, such as close friends and family, who might have buffered them from other stressful life events,

In this context, online forums provide a "safe space" in which users can share experiences and support each other, with complete privacy and anonymity [70]. At the same time, these online communities are a potentially powerful space in which patients can feel empowered and validated in their experiences, and such shame can be contested and overcome. In this way, the infertility forums thus hold real promise for re-negotiating cultural and societal understandings of infertility, and dramatically changing its lived experiences. While recognizing this potential, I also seek to identify and challenge a possibly problematic aspect of the online patient forums: I question whether they are a space in which women from all backgrounds, and pursuing all treatment courses, feel welcomed, validated, and supported. I hypothesize that there could be a potential harmful

effect from the normatization of a particular discourse in these online spaces, which privileges certain patient narratives while silencing or excluding alternative or counter narratives.

Discourse is the integration of language and nonlanguage (ideology, beliefs, thinking, feeling, behaving, etc) to produce meaning [71]. Discourse analysis operates on the assumption that language is a social action and that language is performative [72]. Foucault [73] described the dominant discourse as the way in which those who have power in society directly or indirectly assert that power on others, by compelling them to adopt their actions and language. In this process, the behaviors and ideologies of the powerful eventually becomes the social norm. Moreover, within this dominant discourse, a dominant or master narrative emerges, to which subjects must conform in order to receive social approval and rewards. Thus, “dominant narratives... define our reality and guide our lives like an invisible hand. And when the dominant culture is oppressive, so, too, are its narratives” [74].

In the case of infertility, Becker and Nachtigall describe what the dominant narrative may be. In their ethnography *Born to Be a Mother*, they describe a tremendous persistence and determination that is a commonality in, and celebrated feature of, many infertility narratives. They write:

A central theme of American values, persistence has been demonstrated for persons seeking medical solutions for a range of conditions. Doing ‘nothing’ is equated with the failure to take responsible action, whereas doing ‘something’ is viewed as leading to the betterment of a given situation... Americans consider risk-taking to be their prerogative. [75]

In this context, then, we can understand the dominant narrative of the American infertility patient: a woman who is extremely determined and desiring of a child. Yet such

determination is demonstrated by expending material resources—time, money, etc— to go “above and beyond” to achieve a final positive outcome. Thus, in this narrative, which I will call the “persistent patient,” the subject must be someone who is both well-educated and well-resourced, in order to continue treatment to a successful end in the face of many obstacles.

However, in reality, it is clear that such persistence is only available to patients with extensive financial resources—either wealthy private payers, or patients with particularly generous or flexible insurance. Moreover, persistence is a privilege reserved for those with *additional* resources in terms of education, social and occupational status, and social capital. It can entail taking measures to travel, change jobs, negotiate with insurance providers, and file appeals. It also means challenging the basic power dynamic between patients and doctors, and taking an active role in one’s own treatment course. Nachtigall describes that the “key ingredients” to this endeavor are “1) patients and physicians share similarities in social status, and 2) the patient learns medical information and portions of physicians’ perspectives and becomes an expert in her own right”[75]. Thus, the entire endeavor requires a great deal of education and expertise, as well as occupational status and social capital. The need for these resources, and the mechanisms by which their presence or absence is translated into disparities in infertility, is explored in Lee [76].

In this way, we can see that the dominant discourse of infertility may devalue and exclude the real-life experiences of many patients. The dominant narrative of the persistent patient, while it is often presented as a tale of determination and triumph, is truly only relevant or accessible to those of a high socioeconomic stratum—measured by

education, financial resources, and other types of social capital, among other indicators. Meanwhile, those without the financial and material resources, as well as social privilege, to conform to this narrative may feel that their own voices are marginalized or silenced in comparison. Users may be hesitant or wary of introducing topics into the discussion that don't fit into this narrative, such as financial constraints to getting medical services, and stopping treatment for both financial or emotional reasons. Patients may also feel alienated or excluded from the forum altogether, and leave it in search of other support in another online space. Given the limited number of patient forums available, especially those with a sizeable following, women who feel alienated or excluded from this online community may face serious difficulties finding emotional support at all.

This paper will undertake a discourse analysis of the online infertility forums, examining whether and how the community of users prefers to offer support and encouragement for the dominant “persistent patient” narrative of infertility, while withholding support and validation for other types of narratives. It will explore how this infertility discourse manifests itself, in what forms, and also how it is countered and challenged. Furthermore, it will specifically investigate the counter-narrative of taking a break from or discontinuing treatment, and consider how to provide support rather than judgment for this narrative—*while* simultaneously recognizing the pressing need to advocate for increasing access to further treatment options for those who wish to pursue them.

Methods:

These hypotheses were explored in three stages. First, a pilot wave of key informant interviews took place in the summer and fall of 2013. Patients were recruited for interviews in response to a posting on the websites of two major infertility advocacy organizations: RESOLVE, the National Infertility Association, and the Tinina Cade Foundation. RESOLVE was founded in 1974 as “the only established, nationwide network mandated to promote reproductive health and to ensure equal access to all family building options for men and women experiencing infertility or other reproductive disorders.” The Cade Foundation was relatively newer, founded in 2005, and holds as its mission to provide “information support and financial assistance to help needy infertile families overcome infertility.” Interviews lasted approximately 30 to 60 minutes, using a semi-structured interview guide with open-ended questions. The interview portion of the study was reviewed and approved by the Harvard Committee on the Use of Human Subjects, on August 19, 2013 for protocol #IRB13-1322.

Interviews sought to elicit detailed patient narratives and capture a broad range of different personal and professional views on infertility and disparities in infertility experiences. The exact wording of each question and the sequence of questions were adapted to the interview setting to ensure that questions are relevant, tactful, and appropriate for the situation. Interviews were transcribed verbatim, and in-depth content analysis was conducted to identify common themes, and the relationships between themes. Core themes that repeatedly appeared in the transcripts were identified, and compared with emergent categories as further interviews were conducted. Reading and analyzing transcripts was thus an ongoing and iterative process.

Second, I undertook a detailed “cyber-ethnography” [77] of an infertility online patient community to examine how the hypotheses about how patients gain or lose social support on the Internet might be confirmed in the online discourse. The online community analyzed was “Finding a Resolution for Infertility,” the infertility support group on the online patient network Inspire.com. This group is the only one endorsed and utilized by RESOLVE: The National Infertility Association. The cyber-ethnography portion of the study was determined to be not human subjects research and therefore exempt from IRB review by the same committee, and an exemption letter was issued on 1/16/2015 for protocol IRB14-4581.

Cyber-ethnography is a new and growing field, with its methodology constantly being introduced and refined. Data were collected and analyzed for this cyber-ethnography using two methods: deep reading and quantitative sorting. While these methods were inspired and adapted from reading other similar studies [78, 79] [80], the exact procedures and the combination of these two methods was a novel approach defined by this study. In deep reading, all new threads were viewed in real time, up to three days prior to the day of viewing. This allowed comments to the threads to generally cease, so that conversations could be viewed in full. Both the original post and all of the comments/replies were part of the analysis. Data were collected at three different time points, approximately four months apart; the first wave of data collection occurred in July 2014, the second in November 2014, and the third in March 2015. Each time, data was reviewed for the entire month. The posts were then sorted into topic-based piles, as follows; each post was given a brief (two to five word) topic, staying as close as possible to words used in the post itself, and then grouped together based on similarities. From

this list, similar conversations were grouped together and overarching themes were identified. For example, posts coded as “Advice on symptoms,” “Advice on medications” and “Comparison of doctors” were grouped together under the theme “Clinical Concerns and Advice.” A table giving the different types of themes and topics is given in Table 3.1.

Table 3.1. Investigator-defined topics and themes

Topic and Description	Subtopics
Clinical concerns/advice	Advice on symptoms Advice on medications and treatments Comparison of doctors and clinics
Comparing statistics	Test results Dates
Community	“Just looking to relate” (similar patient characteristics, timing) “Roll calls”
Emotional Support & Solidarity	Expressing depression, anxiety, exhaustion “Vents” (about medical staff, family, etc) Looking specifically for success stories* Complaints about family and friends
Financial concerns/advice	Insurance coverage ACA Overall Cost Tallies
Considering Alternative Options	Questioning/Debating whether to continue Adoption Living childfree

From the above categorization, I did not seek to compare or quantify the frequency of different kinds of conversations, because the categories I defined were fluid, and many threads fell into two or three categories (especially including the comments). Thus, the main focus of this analysis was on the language used in the posts, and whether and how it may serve to create and/or reinforce a privileged “dominant” discourse of infertility. From deep reading of the content, tone, form, and diction of the posts, paired with analysis of the back-and-forth dialogue between the original posts and the following comment threads, I sought to evaluate how language made certain kinds of discursive

space available within the forums, privileging and celebrating certain types of patient narratives, while suppressing and silencing others.

On the other hand, in quantitative sorting, I quantified the relative frequency of different types of discussions, using the 18 categories that Inspire itself provides for users to “tag” their discussion threads for the archives. The advantage to this approach is that it categorized threads using the tags that their authors themselves chose, which can be seen as an indication of their intention for the discussion. I tallied the number of new threads in each category at a single time point, for the past day, week, month, and year. This tally is presented in Table 3.2.

Table 3.2. Quantitative sorting of Inspire threads by user-defined tags

Tag	Number of threads active within past...			
	Day	Week	Month	Year
Newly diagnosed	4	12	32	433
High-tech	17	70	177	1799
High FSH	1	2	7	77
Secondary	0	4	16	121
40+	4	11	28	257
Vets	1	7	23	197
Third party	1	3	28	228
Adoption	0	1	5	175
Living childfree	2	3	4	24
Break	0	1	1	44
Research	3	4	8	97
Male perspective	2	2	4	39
Loss	2	6	16	161
Financial	2	4	7	63
Insurance	0	1	3	47
Outside US	1	3	7	33
Friends	0	3	6	121

Finally, findings from the forum analysis informed and refined questions asked in a second wave of key informant interviews, conducted between May and September of

2015. Again, study participants were recruited from RESOLVE and the Cade Foundation, and the interviews followed a semi-structured guide with open-ended questions that were adapted from the first wave. The final data analysis sought to synthesize findings from both methodologies (interviews and cyber-ethnography). Moreover, it sought to include how participants' experiences tended to vary according to their age, race, income level, and infertility diagnosis.

By “sandwiching” the cyber-ethnography data collection between the two waves of interviews, and analyzing the final data concurrently, insights gained from the interviews could inform the cyber-ethnography deep reading process, and vice versa. In this way, I sought to have the two methodologies complement and resonate with each other, in order to create a deeper and more multifaceted understanding of the discourse of the infertility forums, and its impact on its users. While this approach may have led to less representative results, I sought instead here to elicit and characterize a diverse set of experiences with infertility, and especially to call attention to and problematize the experiences of a marginalized minority, rather than make statements about their generalizability.

Results:

Interviews:

A total of 54 patients were interviewed. Summary demographics of the study population are given in Table 3.3 and Figures 3.1-3.2.

Table 3.3. Descriptive statistics: interviewees

Interviewee demographics	
N	54
Mean age	35.3
Mean income (combined household)	99.7 k
Mean education (years post-HS)	5.6

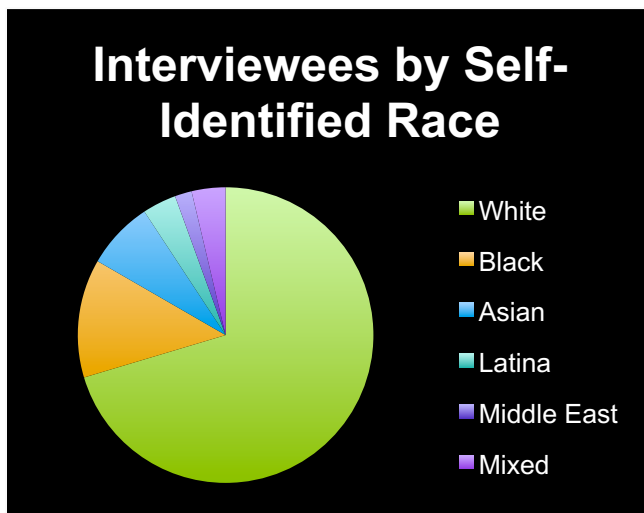


Figure 3.1. Interviewees by self-identified race

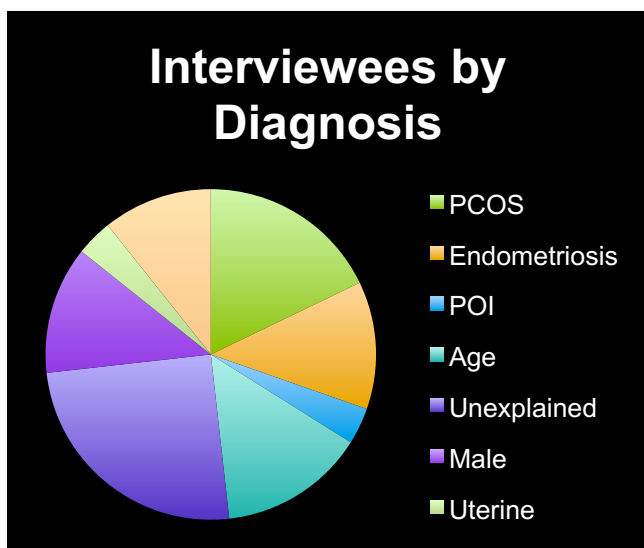


Figure 3.2. Interviewees' infertility diagnoses

Many of the narratives gathered from these interviews pointed to how deeply their emotions affected them throughout the treatment course. Evelyn⁴ stated, “It was way more emotionally and physically demanding than I imagined. I felt like a crazy person.” Moreover, many interviewees told how they felt that the experience of infertility was stigmatized and seen as abnormal. Anna said, “For me, the hardest part has been not feeling like I’m human, like I’m not having the full human experience. I just wish it was normalized that there may be some bumps in the road.” Similarly, Brooklyn stated, “It was really hard to make that step, like admitting you can’t do this basic human function.” In this way, they described infertility as an extremely isolating experience, feeling like they were set apart from the rest of the world.

In this emotionally fraught situation, many women stated that they kept their infertility extremely private, and did not find solace in the friends and family members who were their usual sources of support. Aria said, “I was having a really tough time admitting yes, we have infertility... My husband and I don’t talk to our families, because they’re really annoying with the “are you pregnant yet,” ‘just do this,’ ‘just do that.’” Similarly, Isabelle said, “I come from a very fertile family, so no one really understands the problem.” Many women, in echoing these feelings, said that these were in large part what led them to the Inspire community. For example, Ella stated, “It’s nice to hear that other people [on Inspire] are dealing with the same thing. I haven’t even been open with my family and friends.”

⁴ Names have been changed to protect privacy.

Cyber-ethnography:

The conversations on RESOLVE's forum affirmed how devastating infertility was emotionally, with countless posts recounting users' breakdowns, crying jags, periods of depression, and crippling anxiety attacks. One illustrative post described the emotional aspect of the journey as "like a knife to my heart... I don't know how to survive. I feel so weak and numb and like the only thing I'm good for is to be a emotional hot mess. I just need help...I just feel like a broken shell of a person barely hanging on." Another said: "I am having what I believe to be panic attacks triggered by my infertility. I begin to get really anxious like the walls are closing in around me and I feel like I can't breathe."

Many threads also described how this pain of infertility could be actually exacerbated by friends and family, who were largely ignorant of the struggles they were experiencing. "Fertiles have no idea how lucky they are," one user lamented. Another stated angrily, "I am beyond worn down by the clueless advice ('just stop thinking about it and you'll become pregnant') and insensitive remarks. The biggest mistake I ever made was telling anyone that we're trying." A third said, "I'm so ridiculously tired of not feeling 'safe' when talking with my friends about anything; especially my struggle with infertility!" By sharing and commiserating over these feelings of frustration and isolation, these threads created a strong sense of a community. As women described their inability to communicate and gain understanding from their usual sources of support, comments always assured that the Inspire community would be there to understand and to relate. As one representative comment put it: "You can always come here to vent."

At the same time, posts emphasized not only the solidarity of the community, but also its apartness; members often spoke about how they intentionally distance themselves

from other types of social media. A woman wrote that since she joined Inspire, “being on this website really helps me in feeling not alone... I don't even really feel the need to tell friends anymore since I don't feel alone at all.” These expressions of gratitude, relief, and solidarity showed how the Inspire community was an important alternative source of emotional and social support for its members— a safe space open only to “women who truly get it.”

Despite all of these positive features of the infertility forum, there was also evidence that only certain narratives were really validated, and that some women felt dissatisfied and silenced. Upon closer content analysis of the threads, it was evident also that this community could be selective and even exclusive, its borders policed and enforced by a number of norms and assumptions about its members’ age, demographic, education, and mindset. This was apparent mostly in the ways the discourse assumed access to a level of financial, material, social, and time resources, which were necessary to optimize the chances of a subject’s infertility journey ending in a successful pregnancy. These assumptions underlay and infused discussions of financing medical treatments, as well as important and poignant discussions about taking a break from or stopping treatments.

The Dominant Discourse

Many of the posts gave accounts of women who received multiple cycles of treatment. This was evident in, firstly, the “roll calls,” which were one of the most common types of threads (see Table 3.1). Roll calls were an opportunity for all patients starting a certain type of treatment on a certain month to connect with one another, so

they could post and read updates from patients in similar situations as themselves. Many users announced their presence with a short snapshot of their patient history, and many detailed long, protracted courses including multiple failed cycles. For example, an “IUI/IVF Roll Call” from March 2014, one of the most recent roll calls included in the study period, the first few responses elicited included a sixth-time IVF “veteran”, a third-timer, and a newcomer.

The trend of women receiving lots of treatment was also consistently in other discussion threads. For example, one user began a thread asking whether it was better to do cycles “back-to-back,” or to take a month or two off in between. Some of the discussants who posted comments described treatment courses of up to 8 cycles, with very few months taken off except when absolutely medically necessary. Another thread, relating to infertility specifically secondary to endometriosis, was replete with comments like, “For me, IVF #1 and #5 resulted in healthy pregnancies with live births,” “It took me 3 tries at two different clinics,” “I’m approaching my 6th IVF transfer with my last 2 remaining embryos.” One newcomer to the forum asked members directly how many cycles everyone had been through until they had success. Of the 21 replies, the number of cycles the users had attempted ranged from 1 to 9, with a mode of 3.

Particularly common on these forums were the voices of older women, who were experiencing age-related infertility. Many had already undergone multiple rounds of treatment, and described their plans to undergo more. For example, one woman, calling herself “Crazy & Determined,” wrote: “You all are going to think I’m crazy but I’m 45yrs. Old and tomorrow will be my 1st IVF!!!!... Before this I went through 3 failed

IUIs.” Her comment drew 41 replies, almost all from users of similar ages who were still actively pursuing treatment, to a one expressing sympathy and offering encouragements. Many threads also talked about the pain of failed cycles, from negative pregnancy tests, to chemical pregnancies, to miscarriages, to stillbirths. Still, amid the expressions of disappointment, anger, and frustration, almost every post was punctuated with a statement of determination, and wishing the same to all other readers: “Don’t give up hope. Good luck!!!!!!” “It is worth it if you get pregnant. It is worth it even if you don't get pregnant - at least you tried!” “Good luck. Hang in there!” “I am sure you will have success!” In this way, members encouraged one another to have multiple cycles of treatment, and created the impression that this was the experience of the majority of users on this site.

Furthermore, many patients were obviously extremely well-informed and had exhaustively researched their diagnosis and treatment options; this expertise was welcomed and celebrated by those in the forum. For example, one woman with “unexplained infertility” described her dissatisfaction with the diagnosis, and her active search for a doctor who would be more aggressive about pinning down a reason her treatments kept failing: “After 5 failed IUI's and a failed IVF I began to really dig on my own - saw different doctors who would order labs for me. My naturopathic Dr. found I have MTHFR gene mutation, another found my T3 was not optimal. The more digging I did, [the more] I found that I wanted (and needed for my piece [sic] of mind...” Comments on her thread admired her resolve for taking matters into her own hands, and encouraged her to keep going in order to find an appropriate and efficacious treatment plan.

Many women with a specific diagnosis also did extensive research about new or cutting-edge treatments for their particular case. The posts showed that many women had acquired a facility with technical and medical terms in the process that quite literally challenged their health care providers. For example, one woman wrote:

As an over 40 with "0 – 0.5% chance" of conceiving, I've spent the past 2 years researching new technologies that may give hope to my aged eggs... I began reading research journals and found specifically three techniques that would eventually help: in vitro maturation of primordial follicles (even over-40's still have 100s if not 1000s of PFs), eggs from "egg stem cells," (whose existence is still hotly debated despite the formation of OvaScience), and eggs from induced pluripotent stem cells.

The numerous comments on this thread, mostly by other women with age-related infertility, discussed these options in detail, with a high degree of technical and clinical sophistication. In this way, researching their condition and pursuing targeted treatments with all of their resources, allowed patients to exhibit the extreme determination, resolution, and energy that characterizes the “persistent patient.” Conformity to that script, with minor variations, appeared necessary in order to be embraced into that community.

The infertility forum occupies a unique position as a first-line support mechanism; that is, as evidenced both from literature and earlier pilot interviews, many patients who receive an infertility diagnosis described looking online for emotional support from the very outset of their journey. Examining these posts sheds valuable light on the kinds of support offered on this site, and thus who is likely or not feel welcomed and supported in this space. The women who are most common, and—more importantly—most vocal, on

the Inspire boards, appear to consistently undergo multiple cycles of treatment⁵, and put great effort and energy into researching different protocols and treatment options, continuing in the face of repeated failures. And yet, there was relatively little conversation about the financial and other resources—time, education, and social capital, to name a few—that would be necessary to act in accordance with this “persistent patient” script.

Discursive Silences and Tensions

In contrast to the dominant narrative above, few posts talked about the obstacles—financial, material, and social—that could prevent a woman from conforming to this normative script. However, interviews indicated that these were actually foremost concerns in many women’s minds. Evelyn acknowledged how crippling financial shortage can be when undergoing infertility treatments. She described asking herself, “where is this money coming from? Do I empty out my 401k? Spend all my savings? I don’t want to bring a baby into a world when I have a mountain of debt, is that even worth it?” Ava, a 31-year-old patient from Ohio, described her situation similarly: “there’s so many of us out there who don’t have the money, I’m kind of right on that cusp where we barely make enough that if we really scrape we might be able to afford 1 round, and that’s going to be it.” Aubrey also pointed out how “out of her depth” she felt by not being an expert on all the terminology and clinical knowledge surrounding infertility, saying, “I’m just endlessly amazed at how much these women know about all of this medical stuff... You’d think they were doctors themselves, it’s craziness.”

⁵ See *Limitations* at the end of the discussion section for a note on selection bias in this study.

When looking for where and how patients with fewer financial and educational resources might seek support and validation on the forums, the answer was not apparent. To be sure, many posts expressed frustration and even outrage about the exorbitant costs of infertility treatments.⁶ Many threads were devoted to sympathizing over the costs of treatment, and sharing strategies and tips for saving costs. For example, one user wrote: “Price is becoming a real deal breaker in all of this... I can't believe we paid almost \$1,000 for the last vial that had 2.5M and 15% motility! ☹️” Another woman described her struggle over whether to pursue IVF with her own or a donor’s eggs, saying: “I hate that this all comes down to money!!!... I would love to have a baby with my genes but am I prepared to risk \$33,000.00, on my body????... Uuigh! How do I make this decision??” Still another wrote: “I am 41 years old and going on my third IVF cycle this year. 5th IVF. Ughh... do we suck it up and pay \$2,600 [for ICSI], putting us further into debt?” Posts also discussed various creative solutions to fund treatments, including crowdfunding through websites like Gofundme, taking out home equity loans, applying for grants, and traveling to clinics overseas.

Yet while women did thus often express concerns about money—what one poster termed aptly, “financial infertility”—most of the financial discussion centers around relatively “upper price range” financial constraints. These are either patients with insurance for infertility treatments, or patients paying very high out-of-pocket costs (as the patient contemplating spending 33k on IVF seemed to be).⁷ Thus, at least among the

⁶ N.B. I am not focusing here on actual health treatment costs and flaws in the system, but how financial barriers are discussed in these forums and how it affects the kinds of social support provided therein.

⁷ Most of the women on the forum seemed to be insured for infertility treatments, under plans that offered coverage with varying degrees of generosity. One post asking how much women paid for their treatments, generated answers clustering around 5k for those with insurance, and in the 35k and 50k range for those funding their own treatments.

vocal discussants, these patients did have the means to pursue costly infertility treatments—as also evidenced by the predominance of narratives describing multiple cycles described above.

This also appeared true in many interviews. Even though infertility treatments strained the finances of many or even most patients interviewed, having some “cushion” or disposable income was crucial to making treatment work. Isabelle, from Texas earning 225k annually, said, “The thing about being 35, we’ve worked really hard, we can move investments, we can sell a little stock, and drop down my contributions to my 401k.” Similarly, Ella, with an annual income of 105k from CA, stated, “We both have good jobs where we feel comfortable and confident in being able to afford treatment so it’s not really—it’s gonna be a huge dent, but we’re willing to pay the money.” Thus, when these women spoke of finding comfort in the community of people “going through the same thing,” it was somewhat questionable whether all the users reading their posts felt the same.

Furthermore, as most discussants appeared to be in situations where at least some disposable income was available, discussions about the financial aspects of treatment were most commonly tied to statements of determination to *overcome* such hurdles. For example, in the above discussion about whether to spend money for ICSI, the very first reply was: “I say if your [sic] gonna do it, do it all the way. 😊” Of the 18 more replies on the thread, no one disagreed; another wrote: “if you are going all in - do not forego the one thing that may help. You may always ask yourself why you did not do it versus the contrary.” In this way, talk about financial constraints seemed mainly to re-affirm the

importance of staying the course and pursuing treatment—the optimal treatment—regardless of monetary burden.

In another illustrative post of this prevailing attitude, a woman wrote: “The amount we are spending on treatments is ridiculous and it stresses me out! We are going to have to start thinking of creative ways to fund this... We are about at the point where if we want to continue we'll have to start living in a box or something. Even knowing this I'm not ready to give up.” Thus, even in these purportedly extreme and desperate cases, this dominant discourse, with its rhetoric of perseverance, persists and re-asserts itself. Another woman echoed the same sentiment: “I know all too well how ridiculously expensive it is. It's unfair what we have to go through to make our families happen. But the outcome is so *worth it* (emphasis mine).” Implicit in this statement is that these treatment decisions are a judgment call about worth—and one that should always, then, be decided in favor of a baby (or even a chance of a baby).

Very few posts described situations of being completely uninsured and/or low income—what I am terming, “dire financial infertility,” in the sense that the cost of fertility treatments might render a couple’s goal of having a baby completely inaccessible. Yet, as noted above, this is exactly the situation in which many, or even the majority, of American women find themselves: more than half of states do not have mandated insurance coverage for infertility treatments, and even individuals in mandated states can find themselves without coverage due to loopholes for certain employers. A recent study conducted by RESOLVE found that only about 20% of 931 employers surveyed covered ARTs such as IVF [81]. Despite this, there appeared to be very few

posts describing situations when costs of treatment become completely prohibitive, exploring options like taking a break from treatment to rally finances, or living childfree altogether.

While this may suggest that this lower-income, uninsured demographic is not present on the site, it may also mean that the demographic is simply not vocal, or even actively silenced. During the period of analysis, posts about taking a break from treatment arose from time to time; yet when they did, the usually plentiful stream of comments appeared to dwindle, and the posts were met with a striking, uncharacteristic silence. In one thread, a woman described her financial struggles and asked, “When do we stop trying to get pregnant? when do we stop putting our money into something that today I feel like will never happen?” This comment drew no replies—a very rare occurrence, when almost every thread was met with at least an expression of sympathy or encouragement. Another, titled “how to reduce costs- uninsured,” also generated no replies.

Troublingly, the silence was even more striking when posters appeared to be from an underprivileged, under-literate, or limited English proficient demographic, as shown from the form and style of the writing. One post that read, “i am trying to find ivf medication it cost alot so where do i go to get help”. This post also drew only one substantive reply (suggesting that the poster go to EMD Serrono) and no offers to share relevant personal experiences. Another: “I’m in dilemma of doing one more round or not. Already gone thru 5 cycles all negative. Heart broken empty Bank and nobody to look up to.” Again, this post drew zero replies.

In other instances, rather than falling silent, the dominant narrative appeared to reassert itself, imposing the narrative of persistence and determination over that of realism and dire financial infertility. For example, one woman who felt she had exhausted all financial options wrote: “I am trying to decide and make myself understand that I should not try for anything and just live childfree.” The replies were not unsupportive, but offered little validation for the choice, instead appearing to equivocate and suggest that she think twice. One wrote: “Maybe you need to take some time to grieve and heal before making any decisions.” Another: “If you're someone who thinks even once a day about having a baby, then child free life may be challenging for you.” This was not an unusual response to women who appeared to be “on the fence” about continuing treatment; another post asked “When do I just say enough is enough and quit?” Of the replies, none shared experiences or thoughts validating the childfree option. Instead, they read: “Would you feel better just taking your records to another clinic for a consult?” “I just wanted to chime in that I would also suggest you look into another clinic.”

In still other cases, comments appeared to disregard the reality of financial constraints altogether, sometimes crossing the fine line from encouraging to obtuse. One woman wrote: “We have all of our credit cards max'd out, no savings left, watched my credit score plummet 100 points in 5 months, and seems like everything is breaking down around us...” The responses read, similar to many other statements of frustration or concern about finances throughout the forum: “You know that old saying ‘where there's a will there's a way’? It's true. You'll figure it out. Don't panic.” “Just remember: the debt isn't impossible - you will be able to pay it off.” Another patient, 30 years old with a new infertility diagnosis, wrote, “I'm now faced with the reality that we can't afford these

treatments. How far into debt are we willing to go?... I'm so depressed I can't see straight... How can I afford any treatment at all?" In response, one poster wrote, "The best thing you can do for now is find the right doctor and not worry about the cost if the meds..... Don't be overwhelmed, you'll figure it out!!!!!"

It was difficult to know, from the posts alone, whether these responses were received as encouraging, irrelevant, or even condescending, suggesting that women did not know their own financial options adequately. However, several interviews shed some light on this topic. Aubrey, of AZ, described how, when she had exhausted her financial resources and was looking for support in living childfree, she was exhorted not to give up and told "encouraging" stories of successful cycles after multiple failures. She said, "I get angry a lot reading [the discussion boards]... [I felt] that other users' responses implied that I must not really want a baby. That's how I feel people view me, and I resent the hell out of it. Because I do really want a baby, but I don't feel like I should have to do whatever it fucking takes, you know?"

Aubrey went on to relate how she has seen this happen many more times on the forum to users who are considering taking a break from treatment. She says, "There was a woman who posted yesterday, she was ready to give up, and she wanted to know people who resolved in this way have gotten through it. And you've got these women writing, DON'T GIVE UP! It took me this many tries, this many years to get my miracle bundle. And it pissed me off, that's not what this woman wants to hear, she wants freaking peace, she wants to move on with her life. So I had to give my two cents, and she actually messaged me back and said thank you." Aubrey's narrative indicates how women from certain backgrounds or who adopt an unconventional treatment course (such as taking a

break or living childfree) found it particularly difficult to find social support for their decisions.

Leah recounted a similar sentiment, when she spoke of the financial obstacles she faces: “The financial aspect is the only aspect, that’s the part that makes me feel really really isolated from the whole process...And that causes more anxiety. It just feels like added stress.” Yet when they turned to the online forum, the source of support that patients extolled for its warmth, constancy, and ability to relieve stress, there was little evidence that there was much support or relief to be found there. Instead, the tone of the online forums could turn oppressive and exhausting.

Our interview also indicated that such an attitude, which was present on the forums, may be found frequently in the offline world as well. Ava told us how, when she expressed a desire to take a break from her treatment in order to gather financial resources, her doctor was judgmental and condescending. She said, “My last RE’s bedside manner left a lot to be desired, like he said, ‘if you wait to have treatment you might not have any eggs left.’” Thus, Ava was made to feel irresponsible for not doing everything possible to give herself the best chance for fertility. In this way, the online discourse noted here appears to reflect and reinforce the infertility discourse emerging in larger society, which can also appear in the actual clinical setting.

While the comments on the forum often are given in a positive tone, their ultimate effect is to re-assert the dominant narrative of perseverance, determination, and continuing to work for a baby at all costs. However, such perseverance and determination are not equally available courses of action for all patients. There appears to be limited sympathy for those who stop working towards a baby— at least for material reasons, that

is due to dire financial infertility. In this situation, without a discursive space in which these concerns could be made legible, the forum tended to either fall silent, or into patterns of rather irrelevant platitudes. This analysis suggests that the dominant discourse, which privileges the narrative of the perseverant, determined—read: well-resourced—infertility patient, could serve to alienate and silence women who did not have the financial means to take the risks, get the loans, and “figure it out.”

On the other hand, the forum’s discourse inscribed a very specific space within which taking a break from treatment was an acceptable, and discursively legible, option: that is, taking a break due to age and realism. This was a quite commonly discussed topic; for example, one thread, titled “at what age will you stop?” included many women discussing ages, usually between 40 and 45, at which they had decided they would walk away from treatments. Thus, the discursive space appeared to more readily accommodate discussions of taking a break due to age and realism, rather than finances.

In one exchange, a poster wrote that, “I am at a point in which I really do not know what to do and I am struggling with the thought of giving up on having a child... we financially are not able to afford any artificial treatments. And im not responding as well to meds as i would have liked.” In a revealing juxtaposition of counter-discourse to dominant discourse, the reply came, “I did something that, for some, may be unheard of for a woman my age fighting against the biological clock: I let go and took a break at age 41... For one year I didn't do a damn thing but prepare myself for the ultimate decision to move on... During that time I invested in acupuncture, traditional Chinese herbal medicine, and therapy.” In this particular case, one women appeared to ask for support

for taking a break from or even giving up on treatment due to financial roadblocks; however, the comments she received flipped the discussion back to the dominant discourse of persistence. She was validated and encouraged in taking a break only as a way to demonstrate even greater resolve, to boost fertility in additional (and expensive) ways before returning to the quest.

In addition, the above comment described a break for a finite, pre-determined length of time. This was another consistent feature of these discussions, echoed by other replies on the same thread: “I always imagined "breaks" but could never really take them. I always have to feel like I am doing SOMETHING towards this dream.” Another read: “I say take time off until you get itchy to start again. For me 2 months does it, but... I could see taking longer.” Some posts specifically assured: “[taking a break] is not giving up” and “check back in when you’re ready.” In this way, the dominant discourse inscribes a space in which such “breaks” are acceptable and valid, and merit sympathy and encouragement. That is, a break is acceptable for a finite length of time; to gather energy and resources for the next try; and when tied to a statement of resolution to return to the quest. In this way, the discussion enforces conformity to the dominant narrative of perseverance and resolution.

The Counter-Discourse

While rare, there were some exceptions observed to the dominant discourse in the forum discussions. One woman asked:

Anyone out there decide to move on and live childfree without doing IVF? For whatever reason - cost, religious beliefs, personal beliefs, fears?? I don't know why but I just cannot bring myself to commit to IVF. The cost makes me so angry and hesitant... It's always the money. Everyone

says that shouldn't matter. You do what you have to do, but it does matter to me. We've struggled for so long to get on our feet financially I'm afraid to jeopardize it.

The responses were varied, and there was still the undertone of doubt, and the association of giving up with a tone of failure. One woman wrote, "I'm wondering if I will regret 20 years down the road not going with all my options..." Another wrote "I'm slowly excepting[sic] that we may be child free forever. We are not preventing pregnancy but I can no longer focus on treatment, charting, or timing and we are truly heartbroken."

However, as a rare occurrence, the responses also contained affirmations: "I think your feelings are 1,000% rational. Of course the money matters!! People who say it doesn't matter likely have a lot of it." Some chimed in with personal experiences: "On these more difficult days I try to focus on the two of us and how happy we are with our decision and our lives. A few years ago I never thought the day would come when I would be living a 'happy child free life' but I can honestly say that we are!" Another: "I live my life. I actually ENJOY my life! I am now a school crossing guard, I love it. It feels like I have HUNDREDS of children!!"

The presence of this counter-discourse shows the opportunity that the online forum can have, potentially, to offer support and validation for a range of experiences. This could be a space in which users are encouraged to evaluate and pursue whatever actions make the most sense for themselves and their families. This is certainly not to say that people should give up and accept financial infertility if they are less affluent; rather, those who are constrained by such circumstances are also entitled to social support rather than judgment. At this moment, the forum appears to be missing this opportunity to provide such broad and inclusive support, instead privileging the voices of a more privileged demographic of patients. In selectively validating and offering support for

actions that are in accordance with the “persistent patient” script, the forum’s discourse reinforces and upholds the power of this dominant narrative over others.⁸

Discussion:

For many patients, the Inspire forums served as a crucial part of their support system while receiving infertility treatments. Hannah said, “[The Inspire boards] been really, really wonderful, really supportive... I really really like it, the posts are really positive.” As Arianna stated, and was echoed often throughout the forum, “I find it beneficial being around people going through the same thing.” However, this analysis raises serious questions as to whether patients on Inspire were really so similar—and furthermore, whether patients whose experiences did not resemble the dominant narrative within Inspire’s forum could still find solace and support within its discursive space.

In the forum’s discussions, there was repeated recognition that the perseverance and determination celebrated in this infertility script is not a guarantee of success. As one user wrote on the forum, “[I was] told my whole life that if I work hard enough for something then I'll get it. Well, fertility definitely doesn't work that way, that's for sure!!” But while this uncertainty of success is openly and often acknowledged on the forums, *perseverance* is still celebrated and even valorized above all. Audrey, a 32-year-old from PA, described the predominant attitude well in the words, “Sometimes you feel very alone, and sometimes you feel very determined. I think, in the end...it’s something that people don’t stop at. You hit a roadblock, you find a way to go around it. And that’s what we’re trying to do now.” Her comment illustrates the pervasiveness of the dominant

⁸ See Limitations, below.

narrative on Inspire’s forum—that persevering in the face of obstacles is what all infertility patients do. It seemed that for patients without the resources to act with such determination, the social support that online patient forums afford was limited, and their attempts to find it in these communities were met with silence. In this way, the forum selective encourages and validates only certain actions and decisions, and exerts pressure on its members to conform to the dominant infertility narrative of the “persistent patient.”

What is more troubling, being able to expend resources in this way appears to be often discursively equated to effort, which is in turn equated to loving and *deserving* a child. Thus, one woman wrote: “It is so awesome and amazing to me that the women on this forum want their child so much and are willing to go to the ends of the earth and make great sacrifices for them. Those babies are *so loved and wanted* (emphasis mine).” While this on the surface appears to be a warm and affirmative statement, it also asserts that having such material assets to sacrifice somehow makes one more worthy of having a child. By contrast, the forum’s discourse very rarely acknowledged or addressed how factors like income level, career or occupation, education, and insurance coverage can all limit patients’ ability to “work for” and “sacrifice for” a baby. When such topics were introduced, discursive tensions were evident, as the dominant discourse appeared to ignore, misunderstand, or re-appropriate these threads.

This study inevitably had several limitations. First, it was limited by the lack of a second coder for analysis; all hypotheses and conclusions were therefore subjective, formulated by the author in discussion with a team of mentors and colleagues. Secondly, the study was limited by potential selection bias in assessments of the types of patients present on the forum, and how much treatment was the “norm” within the community to

receive. Users who were vocal in commenting on this forum were a self-selected set who were more likely to have had failed cycles than is representative of the entire population of patients diagnosed with infertility; this is because those who had successes would likely leave the forum, or become active on a different forum about pregnancy or parenting. Finally, in the analysis of the kinds of discourse and encouragement offered, it should be noted that many users seemed specifically to ask for encouragement and advice in tough situations. In this light, it seems natural that posts don't often address giving up.

Despite these limitations, this study had multiple strengths. It is the first study to undertake a detailed analysis of the social and emotional support offered by an online infertility patient community. Whether or not the users quoted are representative of the larger infertility patient population, they do shape the discourse and community norms that first-time comers to the website encounter, and which in turn impact and shape their experiences of emotional and social support. Moreover, regardless of what some users ask for, the overall impact of multiple requests for "positive only" comments appears to be that there isn't space for a conversation about discontinuing treatment on the online forum, even if some users do seek to discuss alternatives.

Conclusion:

The infertility journey is widely understood to be both emotionally and physically exhausting, ridden with anxiety, disappointment, and frustration; social and emotional support during this journey is agreed to be paramount by patients and doctors alike. Yet while online forums and support groups like RESOLVE appear as an exciting new resource for patients, it is clear that much work needs to be done before this discursive

space can be truly inclusive, welcoming, and in line with ideals of social equality and reproductive justice. The “persistent patient” script privileged here is only accessible to a particular and limited demographic; namely, those who are middle- or upper-class, educated, professional and able to afford at least several cycles of treatment without fear of financial ruin. On the other hand, women who lack the financial and social resources to conform to this script may feel alienated, silenced, and judged.

What is more, to extend the original hypothesis, the patients who feel thus excluded from the forum may, ironically, be those who could benefit from it most. These could be patients who navigate to these sites seeking emotional support because they lack other support resources—for example, they may not have the disposable income or insurance coverage for therapy or other mental health treatment. Moreover, grappling with the decision to discontinue treatment and live childfree, especially due to funds running out, may arguably be even more emotionally taxing than the process of continuing with treatments. For these women, an important and potentially powerful source of support can turn alienating, discouraging, and even into another form of oppression. This is an important direction for future study.

This situation illustrates how experiences of infertility may be multiply stratified, with disparities arising not only in terms of who can access treatment, but also in terms of who is offered emotional support and validation for their decisions during the infertility journey. While infertility is a bitter emotional struggle for all, patients with fewer resources can feel isolated and even blamed for their lack of determination. This withholding of emotional support for infertility patients with limited resources is one more way in which their struggle is deemed less worthwhile, their success less deserved,

and their reproduction overall less valuable. In this light, we see the extremely problematic nature of a status quo that restricts access to infertility treatment for low-income and minority women on the one hand, yet judges and withholds emotional support from women for being subject to those forces on the other.

Recently, a CDC working group on infertility reported, patients “cannot easily find objective information on... alternatives to infertility treatment, such as surrogacy, adoption, and childfree living... and the same racial and social disparities that affect access to treatment also affect access to information on alternatives to treatment”[38]. The insights gained from this study may highlight the need to not only make such information available, but also to begin open conversations and provide appropriate counseling about these topics as part of the management of infertility. While doing everything possible to expand access to and delivery of infertility services on the one hand—including the financial and non-financial resources that make pursuit of these treatments possible—we must also remember that treatment is not always the best or only option. We must ensure that emotional support is available for the wide range of choices patients may make at all stages of their infertility journeys.

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