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# Where Trying to Conceive Becomes a Community Effort: A Digital Ethnography of Online Infertility Forums

Megan Burns

*Ursinus College*, [meganalexburns@gmail.com](mailto:meganalexburns@gmail.com)

Adviser: Lauren Wynne

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Where Trying to Conceive becomes a Community Effort: A Digital  
Ethnography of Online Infertility Forums

Megan Burns

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## Abstract:

Online forums for women using in vitro fertilization (IVF), or similar assisted reproductive technologies (ARTs), provide a useful setting to further evaluate and understand women's expectations of motherhood, the relationship infertile women have with physicians and biomedicine, and their interactions on the forums. Some critics of ARTs consider them a tool of oppression in a pronatalist state. The pressure and desire to become a biological mother leads the women with access to these technologies to use them regardless. Through digital ethnographic research on four online ART forums, this research examines the intersection of altruism and self-interest in the ways forum-users give and seek support, as well as how the structure of the forums allows for these interactions to occur. The forums still reflect society's pronatalist preference of biological motherhood, but they function as a space women can participate in to gain and provide knowledge and encouragement during this time in their lives.

## **Where Trying to Conceive becomes a Community Effort: A Digital Ethnography of Online Infertility Forums**

### Introduction

Assisted reproductive technologies and the occupation of online space are common topics of debate, study, and media coverage. An overlap in these two subjects occurs on online forums for women using fertility treatments, which provides an opportunity to further evaluate and understand women's expectations of motherhood, the relationship infertile women have with physicians and biomedicine, and their engagements with each other on the forums. Observations of such online forums reveal a tension between altruism and self-interest. This thesis analyzes how women balance this tension in the ways they give and seek support online, as well as how the structure of the forums allows for the interactions that occur. Due to pronatalist pressures and women's relationships with biomedicine, online forums provide space for women to vent, gain knowledge, disseminate knowledge, and attempt to relieve their anxieties. How they engage with each other on the forums is directly related to these functions, for while they may be coming to the forums out of self-interest, the community that is created requires caregiving and sensitivity. Far from being an online space that is removed from social order, the forums I study echo society's conceptions of women's connections to motherhood. By exploring how women undergoing fertility treatments engage with each other via online forums, we can develop a greater understanding of women's experiences with assisted reproductive technologies, as well as women's participation in online spaces.

Reproductive technologies are inescapable in the contemporary world of American middle-class pregnancy and childbirth. A reproductive technology could be anything from birth control pills, to a c-section, to an ultrasound. When women need help conceiving, they may turn to an assisted reproductive technology (ART). ARTs are the technologies used to specifically treat infertility, which could include donor eggs, donor sperm, surrogates, etc. (Medline Plus 2018). The most common ART is in vitro fertilization (IVF), which involves the sperm and egg mixing outside of the womb to create an embryo/s, and then the embryo/s are put inside the womb to grow (2018). A similar treatment frequently discussed on the forums is frozen embryo transfer (FET), which is a common procedure for women who have extra embryos after one cycle to freeze and use them in a future cycle (TheLaborofLove 2017). Another common high-tech ART is intrauterine insemination (IUI), a procedure in which a partner's or donor's sperm is washed and concentrated, then injected into the woman's uterus (2018). While ART is an umbrella term, three of the four online forums I study describe their forum as IVF forums, one of which more broadly labels itself "IVF and High Tech," and the fourth forum is dedicated to general fertility treatments. This paper focuses on high-tech ARTs, mainly IVF and FET.

## Background and Literature Review

To analyze how women using ARTs engage with one another via online forum, it is essential to understand the current climate of motherhood and infertility in our culture. Literature about women's expectations of motherhood in general and as it pertains to infertility

helps us to identify why a woman may choose to undergo fertility treatments, as well as what types of women have access to these technologies and feel compelled to use them. Not only that, but studies of women's relationships with biomedicine and their participation in online spaces inform us about their experiences using ARTs, including the function of participating on a forum. I analyze data collected from online forums to study the online community of these women. My study yields significant conclusions that increase our knowledge about women's desire to achieve biological motherhood, their engagement with biotechnology, and use of online medical forums.

### Expectations of Motherhood

Being a woman in the United States means that you are faced with strong pronatalist ideals. While pronatalism affects women differently along lines of race, class, sexuality, and other identities, motherhood as a key aspect of feminine identity is a hegemonic norm that all women face in some way or another (Showden 2011:95). Ideologically, motherhood has been constructed as a duty to one's nation for eugenic or patriotic reasons. Culturally, pronatalism naturalizes the motherhood identity as central to being a woman (95). For adults, motherhood is a rite of passage to become wholly woman (Whitehead 2013:ii). This conflation of woman with mother is ubiquitous enough that not being a mother is often perceived as unnatural (Showden 2011:99). Our pronatalist ideals may be one of the reasons why the U.S is one of two industrialized, Western countries with a fertility rate above the replacement rate (99-100). Due to this culture, remaining childless is fraught with tension.

Despite the strong pronatalism in our country, some women choose not to have children. For those whose childlessness is involuntary, however, it is often viewed as a failure (Showden 2011:103). The medical terminology surrounding infertility supports this, with terms such as “sterile,” “barren,” “hostile mucus,” “incompetent cervix,” and “failure to conceive” (103). Even the way doctors have described menstruation, whether you are infertile or not, paints it as a failure using terms such as “debris” of uterine lining (Martin 1991:486). Women are faced with language and perceptions that view their bodies as wasteful and worthless if they are not producing a baby. ARTs offer a way for people with access to the technology to continue trying to achieve the goal of parenthood (Showden 2011:113). In reviewing the engagements on the online forums, we see that failure is not an option. Every woman struggling with infertility on the forum communities empathizes with the need to succeed in this uphill battle.

As they relate to pronatalist pressures, a greater understanding of the context of ARTs in our society is necessary to analyze the structure and interactions on the forums. The treatments and technologies in place to fix the “failure” of infertility are almost exclusively accessible to white, middle-class women, which is the group of women least affected by infertility (Showden 2011:113). While ARTs can enhance freedom by allowing women to avoid any circumstance that restricts motherhood options, the women who would benefit the most from that freedom (minority, low socioeconomic status, etc.) are not the ones who have reasonable access to these technologies (93). The technology itself is not oppressive, but it can be used as a tool for oppression (127). Many scholars argue that ARTs inhibit autonomy because they reinforce the patriarchal norms that womanhood and motherhood must be

connected, specifically biological motherhood (93). On the other hand, ARTs provide options to women who were previously left out of biological motherhood (Rapp 2001:470). Women on the forums often display cautious hope that they would not otherwise have without the technology. They may describe it as their only option. ARTs do, in fact, provide an opportunity to take control over and fulfill one's reproductive desires.

All women in our society must confront the connection of biological motherhood to womanhood, but the identity of white, middle-class women with access to ARTs gives them different perceptions of this connection. These middle-class white women may have a sense of entitlement to motherhood because they feel they have consumer choice (Whitehead 2013:44). Consumerism and pronatalism work hand-in-hand, for if you do not pay for fertility treatments, then you are not trying hard enough to be a mother, and if you are not a mom, then anyone can blame you for not trying the technology (47). As such, the choice to pursue an ART or not exists, but the pressure to do anything to conceive makes ARTs the only option (47). While this further emphasizes motherhood as a part of one's gender identity, motherhood can also be a way for women to relate to one another (49-50). If motherhood connects us, then so can trying to conceive, which leads to the creation and participation on online forum communities. The need to become a mother and the feeling that ARTs are the best or only option to do it is a shared feeling of women on the forums, and it fuels the empathy which shapes their interactions.



## Doctors and Patients

Chance is a large component of the IVF process for both doctors and patients. Often, patients will describe IVF as their last chance (Modell 1989:128). Because of this, they believe gambling is better than doing nothing, and may view an ART as an opportunity to have a child rather than a desperate alternative (130). The odds of having a successful pregnancy after one cycle of IVF or FET varies based on the woman's age and other factors, and different clinics advertise different success rates. The rate of success could be between 20 and 40 percent, but after the age of 40 it dips below 20 percent (Centers for Disease Control and Prevention 2017). Despite these odds, it is unlikely that a patient would plan to stop after one attempt (Modell 1989:129). The determination to try all possible options and beat the odds can be seen as a struggle for control, where the sense of control comes from the patients' expert knowledge of their own bodies (130-131). The pronatalist ideals of our society can inform why the gamble of IVF, even after the doctor has made this gamble apparent, is better than doing nothing; thus, women often do IVF despite the odds.

The accessibility of ARTs may be a privilege for certain women, but the women who do undergo high tech fertility treatments do not usually have an easy experience. Most likely, both patients and doctors would agree that IVF is anything but easy. Still, perceptions of IVF differ between doctors and their patients, which in turn affects how both parties view each other and the technology. For instance, patients and doctors define success differently. An IVF patient defines success as having their own child (Modell 1989:129). The doctors are more likely to define success as the number of pregnancies in the average population. Both odds are defined by pregnancy, but the patient's definition is reliant on their individual experience, and the

doctors' definition is more statistical (129). The discrepancy in doctor and patient perceptions of IVF could explain why women feel the need to discuss their journey with other patients rather than just their doctors.

The position of the patient and the doctor is essential to understanding why women go to the forums in the first place. Patients are more likely to feel that a doctor is knowledgeable if the doctor is empathetic to the patient's experience (Modell 1989:131). On the other hand, doctors tend to feel that patients only have lay expertise, or non-expertise, and that they are naïve about their situation (132). A doctor's knowledge is authoritative in the sense that it is culturally and structurally superior and given more weight than alternative or patient knowledge (Jordan 1993:152). Patients do not see it this way; rather, they feel they have knowledge equivalent to their doctors because they know their own bodies best (Modell 1989:132). At the same time, the patients rely on doctors to actually do the IVF procedures and patients take the prescribed medicines, but they feel they are using technology rather than medicine (132). Ultimately, patients and doctors view the IVF technology and odds of success differently, and they also have particular views of each other. Neither party seems to trust the other, and there is discrepancy in how they view the IVF technology depending on their relation to it. The difference in the doctor and patient perceptions of the IVF journey can contextualize the experiences and feelings of the women who use the forums, including what they are looking for in terms of support.

In communities of people who share some kind of medical issue, such as infertility, lay-experts help spread information and influence. A layman is someone who is an outsider, or non-expert (Prior 2003:53). An expert is someone who is experienced or skilled. As such, the

term lay-expert is an oxymoron. It describes someone who has experience with a health issue or illness, but is not practiced in the management of that issue. Only by having experience with the health issue can someone be a lay-expert. Lay-experts have embodied knowledge to impart about their particular condition, often about their own bodies, pains, and reactions to medication. Lay-experts also often have knowledge about others' experiences in addition to their own that they may share. Some argue that having experience is not enough to understand the complexities of or best way to manage a condition or illness; that management is best left to the physician. This is partly because experiential knowledge is individualized and restricted, and it only generates knowledge about one particular instance. Lay-experts can simply be wrong, too (53). The interactions on the online IVF forums are not only full of lay-experts, but full of people who seek and value lay-knowledge.

Expertise and relationships with doctors have changed since the availability of medical information online. Looking up health information is one of the most common uses of the internet (Akerkar and Bichile 2004:120). It offers a quick and convenient way to get information, but now the doctor is not the only source of information (120-121). This creates a more empowered patient, one that is potentially more skeptical of their doctor (121). Most patients still trust their doctor's information more than what they read on the internet, but the doctor now may act more as a consultant on what to do with all of the available information the patient can access (121). As such, the patient seeking alternative knowledge may feel like more of an expert than they would if they were solely reliant on their doctor's word. What is more, the aforementioned empowerment and lack of trust for one's doctor could cause patients to seek alternatives to traditional biomedicine. Historically, the health care system has

made women passive participants in their treatments, and seeking alternatives to traditional biomedicine can improve well-being in that the alternatives may offer healing powers of friendship and other social relationships, as well as autonomy (Warriner, Bryan, and Brown:142). While this paper does not discuss alternative medical practices, the distrust of traditional biomedicine and desire to seek supplementary or alternative information is a potential reason for infertile women to participate in an online forum.

### Online Forums

To understand how women use the online IVF forums, we need to know more about how an online forum functions. There is speculation as to whether or not online forums can be labelled “communities,” or if they fit the requirements of interpersonal obligation, responsibility, and reciprocity (White and Dorman 2001:693). Despite the lack of physical proximity, forum users are able to share interests and experiences (693). Online support groups and forums have many benefits to the users. The forums are available 24 hours a day, seven days a week, so that users can participate whenever it is convenient for them, and they have time to carefully formulate their posts (694). There may even be hundreds or thousands of people on the forums who never post, but just read. Most online forums have no official administrative structure, but they may have a frequently asked questions page that goes over the guidelines of the forum. Some have moderators who make sure the interactions stay on-topic (703). On the online forums, there is no limit to the number of participants and observers, and the anonymity hides people’s identity, such as their race, ethnicity, age, socioeconomic

status, and more (694). Online forums may not seem like an official setting, but they have rules, whether explicitly stated or not, that develop a community.

There is a certain appeal to online medical forums that keeps them active. Sharing and gaining information with an online group can be empowering (White and Dorman 2001:693). Seeking support on forums is linked to stigmatized medical issues that are often overlooked by the public, sometimes even overlooked by a medical professional. This may be because those with a stigmatizing disorder find the internet a more welcoming platform due to the anonymity which allows users to more easily discuss embarrassing or taboo subjects. The resulting vulnerability promotes honesty and intimacy in the online space (694). Participation on a forum dedicated to a stigmatized group can yield high levels of trust among users, and lead to a “virtuous circle of caring” that improves a user’s feelings of emotional intelligence and social cohesion (Pendry and Salvatore 2015:217). As such, women who communicate via the internet may find it easier to cope with the stigma of infertility.

Although there may be an appeal to an online forum or support group, some people are skeptical of them. There is a potential that messages could be misunderstood without the audio-visual cues of face-to-face interaction (White and Dorman 2001:695). Online medical forums may even be sites of misinformation since there is little to no regulation of the information that is disseminated by the lay-experts. Studies show that most information given on an online medical forum is not by a medical professional, with one third of this information suggesting unconventional treatments. Online forums can be a place to share health knowledge, but no research to date has examined the effectiveness of the distributed information. White and Dorman argue that participation on a medical forum does not lead to a

person's desired health outcome (704). Pendry and Salvatore argue, though, that it is not a question of whether or not a forum improves someone's general health, but why, when, and how their health is improved (Pendry and Salvatore 2015:212). Someone may use a forum to improve their emotional well-being, but not necessarily improve the specific health issue they are dealing with. Similarly, this paper argues for the functions of online ART forums that encourage well-being.

### IVF Forums

Studying the online forums of women who use IVF helps us make sense of women's expectations of motherhood, and how people interact via the internet. Some research has already been done on the online infertile community. Krista Lee Whitehead's research offers a useful framework for the content and demographics of the online infertility forums. I agree with Whitehead that online life is real life, and that the online world does not exist separately from the physical world (2013:10). As such, the way people behave on the internet can tell us how they would behave in a physical space. For instance, Whitehead interviewed women in addition to reading online posts, and she found that the narratives in the face-to-face interviews reflected what was being said online (2013:15). She also found that, in the online space designated for those struggling with infertility, the communities are mostly made up of white, middle-class, heterosexual women, with most being in their 30s (14). Given the structure of the forums, though, people do not have to detail their identity, and in this paper I do not speculate about people's identities.

Mihan Lee has also done research on online infertility forums. She found that a support system helps to manage the stress of infertility, and that this support can in turn affect the clinical outcomes of the treatment because one's level of emotional well-being can affect whether they choose to continue the treatment or not (Lee 2017). Studies show that the internet is an important place for people struggling with infertility to get information, and infertility patients have confirmed this as true. Part of the reason for this is that patients who are dissatisfied with the information provided by their clinic and doctors are likely to turn to the internet to seek answers. What is more, it is quite common for women struggling with infertility issues to keep that aspect of their life private, and not talk to family and friends about it; hence, they turn to the internet for support. Mihan echoes what others have said by asserting that both in the offline and online world, women feel irresponsible for not pursuing anything and everything to try to have a child (2017). Either way, if a patient is unsatisfied, cannot talk to their friends and family, or both, then the internet provides a more likely environment to at least try to calm the stress of undergoing a fertility treatment.

The existing literature provides information about the pronatalism and consumerism that drive the need to be a biological mother among women in our society. Scholars also explain how patients who use an ART are different than the average medical patient, and may not feel their doctor has sufficient expertise while they themselves choose to produce medical knowledge. These details about our culture and infertility help to describe why infertile individuals likely experience stigma, and illuminate the potential appeal of an online platform to discuss issues and ask questions as they relate to IVF or similar treatments. My research adds to this by providing a detailed account of the forum cultures and structures. I discuss how women

interact with one another on the forums. My approach adds to our understanding of the use of assisted reproductive technologies, and the use of medical forums by women.

## Methods

To study how women undergoing infertility treatments interact online, I conducted digital ethnographic research on four public forums: Fertile Thoughts, Justmommies, What to Expect, and Two Week Wait. I took field notes and copied the posts and threads that I read into separate, private documents that I could easily access. Although the members of the forums already have a veil of anonymity due to their usernames, I give them pseudonyms to respect their online presence. These forums have thousands of posts, and some posts have thousands of replies. In order to narrow down the posts I took notes on, I only analyzed threads that started in 2017. This way, I recorded the most recent information. Older posts could still be relevant to my topic, but by narrowing my focus to 2017, I have ensured that I have recent data.

I took notes on roughly 10 posts for each of my forums. The number of posts I took notes on is arbitrary because each post has a different number of replies; thus, each produces a different amount of data. I decided to halt data collection and move on to analysis when I realized that I was not finding anything new in my data. In addition to taking the field notes, I made a reference sheet for myself. In the world of assisted reproductive technologies like IVF, there are numerous acronyms that stand for medical terminology I had never heard of until



doing this research. Not only that, but there are also acronyms and vocabulary specific to pregnancy forums that I made record of, such as baby dust, or TTC (trying to conceive).

Going into this research, I had intended to study bodily autonomy among IVF users, and as such I created an online interview which was meant to help me evaluate this. The interview got limited responses, and even got me banned from Justmommies. While I had to change the purpose of my research due to the lack of responses, this online interview helped me in other ways. It required me to create accounts on each of the forums I studied, which gave useful insight into the structure of the online forums. Also, the lack of responses to my online interview tells me that answering questions about bodily autonomy, or perhaps answering questions for any research, is not something many of the women on the forums are interested in doing. In this way, posting my failed interview was still a useful method because it forced me to create accounts on the forums, and it got me thinking about what types of posts and topics women engage with.

I used grounded theory to conduct my research because it allowed me to notice themes and patterns as I was collecting my data, and create more questions as a result of those findings. To analyze my data, I coded all of my posts in nVivo, which is a qualitative coding program. I drew many themes from my initial coding, and I continued to narrow these down until I found my main focus. As this is inductive research, I let my ideas of discussing bodily autonomy go, and I narrowed in on what the data wanted to show me. The data I collected provides useful insight into the ways in which women both ask for and provide support on the forums, as well as how the environment of the forums makes these interactions possible. There is potential bias in the fact that I am a woman who wants to have children, but as I have never

undergone a fertility treatment or been a member of the community I am studying, my identity has insignificant impact on my findings.

## Data and Analysis

### Forum Structures

The environment of the forums is the foundation for the interactions that take place, and their structure explains why women come to these online spaces in the first place. To start, in order to post on the forums, you must create an account. Some forums ask for more personal information; others simply require a username and password. Some start with a terms of service you must agree to before continuing; others do not. I created an account on all four of my forums initially to post the online interview, but I ended up learning more about the culture of the forums by creating these accounts. One of the forums I studied, What to Expect, specifically asks if you are trying to conceive or if you are a first time mom, as well as the due date of your baby. What to Expect may ask such personal questions because they send a newsletter of pregnancy updates. Fertile Thoughts requires similarly personal information, and requires forum users to have experience using a fertility treatment, or managing infertility:

Two Week Wait and Justmommies, on the other hand, do not ask as many personal questions, if any. Two Week Wait only requires a username and password. While Justmommies does not ask as many questions as What to Expect or Fertile Thoughts, they do ask how many children you currently have. The questions the forums ask are meant to keep the community restricted to those trying to conceive, those who are already moms, or those who have done

IVF or similar high tech treatments. Outsiders, like me, do not belong on the forum. Given the types of topics people discuss, the forums are a place where people are allowed to be vulnerable and explicit about their experience with those who have a greater chance of understanding what they are talking about.

The process of signing up for an account on the forums is actually one of the ways in which the forums gatekeep. Essentially, gatekeeping is a practice that filters information or access (Nahon 2009:1). Because registering is similar to a screening process, being able to understand the terminology and language surrounding ARTs is mandatory to participate on the forums. Since the forums are public, women may use language as a form of gatekeeping to filter who responds to their posts. Apparent in almost all examples I quote, the women use medical terminology, such as FET and stim, without taking the time to define these terms. There are also many acronyms unique to the forums, such as DH (darling husband) and AF (Aunt Flow, or menstrual period). Anyone can look up these terms and acronyms, but by using and understanding this language, the forum users are proving that they are members of the ART forum community. This creates an in-group of women who have used an ART or are trying to conceive, which lets the women feel they are able to discuss the intimate details of their IVF journey with others who understand rather than with random people. At the same time, the gatekeeping on the forums may also cause the users to feel like they have special knowledge if they understand everything that is being posted, and as such they feel they are knowledgeable enough to give advice and answer questions. In this way, the structure of the forums allows for the interactions that occur.

There is gatekeeping on the forums, which allows women to make detailed posts about their experiences, but there is also sensitivity in the topics they discuss. One forum, Fertile Thoughts, even implements trigger warnings in their forum rules:

“When posting about positive beta, BFP on HPT, pregnancy, u/s results or children, ALWAYS put (pg ment) in your subject line, as a courtesy to all members. While hearing positive results and success stories is ALWAYS welcome here, we need to remember that this is a "safe place" & someone might be having a hard day & might not want to read about pregnancy or children at that time. Please keep this in mind in your signatures too. If your signature or avitar mentions pregnancy or children, please change your settings to reflect that and your signature will automatically be turned off on the infertility boards. If you need help doing this, please PM one of the BC's.

Thanks!!” (Fertile Thoughts)

This forum explicitly states that it is meant to be a safe space, and proves this by not allowing users to discuss their successful pregnancies whenever they please. This shows us that not just any conversation can be had on the forum, and the concerns of women who are struggling to conceive are given precedence over those with success stories. Forum users do follow this rule, as seen in this quote: “I was overconfident after my last fresh cycle- ments we got our beautiful daughter end ments plus a frozen boy and girl!!” (Fertile Thoughts). I have also seen a user say “PREG MENTIONED, SUCCESS MENTIONED” (Fertile Thoughts). As we can see, the forum users may not say exactly “pg ment” as the forum rules state, but they will use a clear trigger warning of some kind. What is more, the only fight I have ever seen on a forum was on Fertile Thoughts about a trigger warning for a successful pregnancy. Whether trigger warnings are an explicit

rule or not, there is a general sensitivity around mentioning pregnancy on all of the forums. The only time women are allowed to mention their success is when they are currently struggling to conceive via ART even though they have had children from it in the past, or if someone asks for success stories. The use of the trigger warnings further solidifies the in-group of women who are trying to conceive.

Initially, it may seem that the structure of the forums creates a safe space online, outside of our culture, where women can communicate without fear of being questioned about why they do not have a child yet. However, the structure of the online forums actually reflects the structure of our society. The need to become a mother shapes both the interactions and the structure of the forums. Although public, participation on the forums is meant for those who use an ART, typically IVF, and for women who understand the language of the forums. Women may flock to the internet to relieve stress and seek answers because infertility is stigmatized; however, joining a forum does not eliminate the stigma. The online spaces these women use reflect the need to have a biological child in the way that women cheer each other on to continue trying to conceive, in the way they describe their own experiences, and in the way they must be careful about mentioning their successful pregnancies.

### Seeking Support

Women frequent the online IVF forums to seek support, which is expressed in the way they form cycle groups and ask for advice. A cycle group is a thread in which women who do an FET, or any transfer, around the same time check up on each other and share their experiences. They may even call each other “FET buddies.” Women may feel the need to form these cycle

groups if there is no one in their lives going through an IVF cycle at the same time, and they wish to talk about their experiences and learn more about IVF through others' experiences. The fact that these women form cycle groups at all tells us that some using high tech infertility treatments not only wish to connect with others who can empathize with their experience, but also seek smaller groups within the community to update and stay updated with women who are doing the same process at the same time. These cycle groups are not exclusive, though. Women may ask to join a cycle group, but I have never seen one turned down. Those with a stigmatizing medical issue may find online platforms more welcoming, but cycle groups also give women partners to wait with. Much of the IVF process involves waiting, and women on the forums often describe how they try to occupy themselves while they are waiting for transfers or results, or they may discuss how impatient they are. Users feel they are getting more out of the forum experience if they are interacting with those who are at a similar stage in the IVF process so that they can form tighter relationships by being a part of a cycle group, and cycle groups also provide company during an impatient time.

Women may ask each other about their experiences to better understand someone else's point of view, or to offer support, but most of the time they ask about others' experiences to relate them to their own. A person may present a scenario, and then ask if others have had success with it. One user asks: *"Had to do a freeze all due to my hormone levels. Started my first period yesterday and I am having a lot of blood clots and some big ones. Anyone else experience this?"* (What to Expect). Another user posts: *"Anyone experiencing success with round two after the embryos not making it to day 6 for testing? I was on 450 follistim, lupron and low dose hcg. I had 10 follicles and only 4 eggs retrieved. 3 were mature, 2*

*fertilized and stopped growing day 5*" (What to Expect). Here we see that these women are only showing interest in others' experiences to gauge whether they themselves are making the best decisions. Presumably, the women who ask these questions are worried about the uncertainty of IVF, and seek to feel more confident by hearing how others have handled a similar situation. Sharing and gaining information makes people feel more powerful. Knowing what others have gone through in regards to one's specific issue with IVF may also make women feel more in control if they can better understand what is happening to their body by learning from other women who have gone through a similar situation.

The forum users may ask others what they have gone through to help make sense of their own IVF experience, or they may seek help in a more straightforward manner. Here is what one user, Melissa, posted:

"Good morning ladies, as for me bad and good news i have 11 follicles all over 17mm waithing on the lab to know our next step. Mostlikely egg retrieval on sunday. Here is the bad news, my uterus lining from 10mm came down to none existing 5.3mm we will be cancelling the transfer to another day. what a low blow. What could have cause this? The only thing different i use was the ganirelix to keep me from ovulating. I know i was on extra stress at work and at home trying to make sure everything was set." (Two Week Wait)

In this post, Melissa is asking for more than advice; she is asking for an answer to why she had to cancel her transfer. You would think this would be question for a doctor. By posting this question on an online forum, she is assuming that someone may have experienced the same issue and can shed a light on this occurrence. Her post also suggests that she would prefer to

hear from other IVF patients rather than a doctor, or in addition to a doctor. Either way, it seems Melissa's RE (reproductive endocrinologist) is not giving her the information she needs to hear to make her feel comfortable in her IVF process. This could be because no amount of information could make you feel comfortable in this process given the uncertainty of success. At the same time, Melissa may have turned to the internet because of the discrepancies in attitudes of doctors and patients towards IVF. If patients do in fact feel that a doctor is more knowledgeable the more empathetic they are, then the empathetic space of the online forums may be a better place to ask questions if the patient feels a lack of understanding from her doctor. Melissa's post is not unique, for many use the forums to ask similar medical questions.

Forum user Lisa gives us insight into one possible reason why people come to the forums to ask advice rather than rely solely on their doctor:

"I have a consult with my RE on Friday to find out the details, but in the meantime I wanted to see what others experienced for their natural cycle FETs. How much monitoring did you have? What meds did you take and for how long? Anything else I should know?" (Two Week Wait)

It seems that Lisa is using the forum to figure out everything she can before she actually talks to her RE. She wants to be prepared rather than wait to hear what she should expect from her doctor in a few days. This may be because Lisa is nervous and wants to know as much as she can to alleviate her anxieties. In this case, it may not be that Lisa does not like or trust her doctor, but she simply does not want to wait to have her questions answered. One of the appeals of an online space is that Lisa can come to the forums to ask her questions whenever she wants rather than having to wait to ask her doctor. What is more, infertility patients' sense



of control come from their knowledge of their bodies. Because Lisa does not know how her body will handle the natural cycle transfer, she is trying to use the embodied knowledge of others so that she can feel more in control. Regardless, Lisa's post is an example of the empowered patient who collects information from the internet, and shows that women seek alternative knowledge in addition to what their doctors tell them.

Other posts ask for general support rather than answers to questions. One online forum user, Samantha, posts an example of this:

"Omg ladies im being started on the stim today no waiting for rf my follicle are nice and quite and my lining is just perfect. Was not expecting this to be so fast. My head is spinning. Ok ok they started me on 150 follistim and 75 menopur. No lupron on this cycle but will be on ganirelix started on day 6 of stim. Ladies please please keep me on your prayers. So i guess we are a week ahead of schedule." (Two Week Wait)

Samantha sounds exasperated in her post by describing how fast she feels her IVF process is going, and by using phrases such as "omg" and "ok ok." In her post, she is describing her current experience, and asking others to keep her in their prayers. It is hard to say what the purpose of this post is for Samantha other than to tell others of her situation. This post suggests a therapeutic function of the forums as a place for patients to calm their anxieties by writing all of their thoughts down and sharing them with others. Typing your concerns and feelings may help you to comprehend what you are going through so that you can better control and understand your situation. What is more, it may be encouraging to hear people are wishing you luck if you are in stressful situation. As Mihan Lee (2017) said, support on the forums can

improve the patients' emotional well-being. Like Melissa's and Lisa's post, Samantha's post is not unique, for many use the forums to describe their situation and ask for luck or prayers.

Although with the anonymity of a username it may be easier to describe personal experiences and ask personal questions, coming to the forums in the first place and being willing to share such information about one's life shows that the forum users trust others who have experience with IVF and similar ARTs. However, by trusting in the other forum users, those seeking advice and support are assuming that using IVF gives them enough in common to be able to understand and help one another. In reality, there are a plethora of doctors, nurses, and facilities with their own way of handling IVF, as well as different reasons for and physical responses to IVF. There is variation in their experiences, but the forum users are trying to find a commonality, or hear success stories, presumably because they want to know everything they can to help ensure a successful pregnancy. Women seek support on the forums to supplement any lack of information or support they receive elsewhere. While the responses they get may not improve their infertility issues, the support given on the forums can improve emotional well-being.

### Giving Support

If someone is seeking advice and support on the forums, then there is almost always someone on the other end giving advice and support. One common practice on the online IVF forums is to check on other forum users rather than or in addition to discussing one's own experience. *"Is your doctor changing anything this cycle?"* (What to Expect). *"Oh wow. How many embryos do you have??"* *"Are you doing anything different this round?"* *"Thank you! I will*

*probably give it one more try. I hope your cycles were successful?"* (What to Expect). These are all normal questions to ask on the forum regardless of the fact that none of these women have met in person. Notice how some questions are more general, merely asking whether or not someone's cycles were successful, while other people ask more probing questions about the decisions of someone else's doctor. Questions such as these tell us that some women are interested in what the other women are going through either to try to help them, or to better offer support. It seems as if nothing is taboo on these forums, but occasionally someone will apologize for asking for too much information (TMI), further hinting at the sensitive nature of the infertility experience. In one thread, someone posted *"Is there a particular reason they want three cycles? Just curious but understand if TMI,"* and someone replied with *"From my point of view more nothing is tmi anymore."* (Two Week Wait). By being a member of this forum, a person is opening themselves up to being interrogated about their IVF journey, but never punished for the choices they make on this journey.

Whether TMI or not, forums users do ask about others' IVF journey for reasons other than seeking medical knowledge. Those questions that women ask about how successful others' transfers were or how many embryos they have do not necessarily provide valuable medical knowledge that someone could relate to their own situation. Rather than using the forum to gain understanding of their own experience, the women asking these questions are doing so because they are either genuinely interested, or genuinely wish to provide support. I call these questions "compassion questions." As Pendry and Salvatore's analysis of online forums explains, online stigmatized communities tend to have high levels of trust that yield a "virtuous circle of caring" (2015:217). In addition to the aforementioned cycle groups, many

women on the forums participate in this circle of caring. The ability to discuss one's situation and ask about others' situations without the fear of prompting "too much information" certainly creates trusts among the users. This trust translates into the care people take and give on the forums- hence, the prevalence of compassion questions. This means that, whatever the reason for joining a forum in the first place, women participate not only to help themselves, but to support to others.

Perhaps the most common practice on the forums is to wish someone luck. *"I'm here if you have questions. I check forum occasionally so don't hesitate to ask anything. Best of luck!!! Stay strong and positive AND take one day at a time."* (Two Week Wait). *"Oh, I am so sorry. But stay positive, as IVF is like playing Russian Roulette, you might have the weakest start, but finally it will be you who have won. Keep my fingers crossed x."* (Two Week Wait). *"Good luck with your testing tomorrow!"* (What to Expect). Truly, luck, prayers, and positive thoughts are all over the IVF forums. Some women even try to reassure others that they will have a positive outcome, like a successful pregnancy, even though they could not possibly be certain, as seen in these two posts:

*"If your hormonal tests are fine and ur ovarian reserve is still good ur chances are pretty good!Good luck to you!"* (Two Week Wait)

*"Ahh I can only imagine how you feel after you had done so well and got 9 eggs.*

*Statistically I'm sure it's very likely more will thaw than won't and it will be the good ones that do thaw anyway so you still have a great chance. Fingers crossed for you, it*

must be very frustrating having to wait even longer. Very best of luck x." (Two Week Wait)

Despite the efforts of these users to reassure others of a potential successful pregnancy, they still feel a need to wish them luck, which suggests that they are not confident in their reassurance. They wish luck because they cannot predict the outcome of anyone's IVF journey. These women are not trying to claim that they know whether or not the other user will have a successful transfer, and it also does not seem that these women are trying to disseminate particular medical knowledge. While the user who posted the second quote does throw in the statistics about FETs, these quotes offer more reassurance and optimism than factual information. We know that the probability of getting a successful pregnancy out of a transfer is quite low, so by wishing each other luck and offering comfort, these forum users are trying to keep one another calm and feeling positive since there is nothing they can say that will ensure someone's successful pregnancy.

Women may also wish each other luck despite having struggles of their own. The comments of one woman, Rebecca, provides a perfect example of this:

"I have been trying to have a child for the past 4 years and I'm finally at the IVF stage and I don't know how much more of this I can take... I'm trying to figure out how to financially support one more IVF. I want to end this after I feel like I've given it my all, like I've tried everything. It's exhausting. I'm glad you took a break, it was obviously very restorative to do so. Keep us posted on how the embies develop, wishing you all the best for lots of healthy, beautiful 5-day blasts, fingers crossed, x." (Two Week Wait)

Rebecca is clearly frustrated with IVF, saying that she needs to try everything she can, but supports the other user's decision to take a break. Rather than simply say "good luck," she explains that she thinks the other user made the right decision, and even asks about her embryos and wishes for their health. She complains about her situation, but seems to genuinely wish the best for others. Rebecca's post simultaneously served as an outlet for her to express her feelings about IVF and as a way to wish luck and reflect on someone else's situation. In this way, there is not one type of forum user. There are not forum users who only vent, or forum users who only provide information and advice. Most women do a bit of both. Those who actively participate in the forum threads are asking questions or venting for their own gain, but also making posts to support others.

When forum users do not have an answer for those seeking advice, they may just wish them luck to provide support. Others, though, do attempt to answer questions. One user asked a question about IVF and endometriosis and another user, Laura, responded:

"I don't have endo but from what I have learned through years of participating in forums and listening to podcasts on the topic, my understanding is that doctors will want to try to remove as much of your endo as possible before IVF treatment to increase the chances of success. I think that removing endo also helps to manage pain (though it usually comes back over time, as does the endo). As for the period after IVF, I think it depends on if you have a fresh transfer or not. I didn't have a fresh transfer and I found the period after stims to be a little heavier than usual, but not a huge difference. If you have a fresh transfer and it fails, your period might be heavier because you'll also have been on hormonal treatment to increase the thickness of the lining. After a failed frozen

embryo transfer, my period was noticeably heavier and therefore more crampy. I hope that helps! Good luck!" (Two Week Wait)

Laura is one example of responding to a question that you would seemingly ask a doctor by explaining what they have had experience with or heard of. Laura also describes her own experience to help answer the question, even though she does not have endometriosis. While she may have helped the question asker, she is unsure and wishes her luck anyways. Laura is disseminating the information she understands, but most patients still tend to trust what their doctors say over what they read on the internet. If anything, Laura just gave the question asker something to think about before her RE gives her their personal take on the matter. In this way, this is less about giving advice, and more about appearing to be knowledgeable.

You may describe Laura as a lay-expert. She is using knowledge she has gained through her own research and embodied experiences, and others' experiences, and applying it to someone else's situation. Rather than only being a lay-expert on endometriosis, Laura is a lay-expert on IVF more generally. Laura is simply saying what she knows, probably to relieve her own anxieties. If she feels like she knows something about IVF well enough to talk about it on the forums, then perhaps she feels she understands IVF better for herself, which may make it seem like less of a daunting mystery. This type of "advice" is all over the forums. More than helping those who are seeking the advice, answering questions may be a way for the advice-givers to relieve their own anxieties.

Not all lay-experts on the forums are as confident in their answers as Laura was. The following quotes are more representative of the types of lay-expertise I see on the forums:

“The only reason we did the BC pills was we only had 3 blasts to send for testing, and my RE didn't want to medicate me in case we had no normals. We only are doing like 10 days of BC pills. If you need a break, do the pills, if not, power through.” (Fertile Thoughts)

In this quote, we see again a woman detailing her own experience as a way to answer whether or not someone should take birth control pills. When the women on the forums do this, they are essentially asserting that the knowledge they have of their own bodies is expertise that is valuable to other users. In the end, the woman who made this post just describes her own experiences and answers by listing the only two options: take the pills or do not take the pills. The remaining two quotes listed both give answers based off of something that they have heard or read:

“If it were me, I'd go for it. Every cycle is different. I hear acupuncture has worked for some in increasing their follicle count, as well as other supplements. Good luck!” (What to Expect)

“Hello, I have read a few stories where the women had the same problems and after the dilation method they had a successful transfer.

I don't know if resulted in a pregnancy or not.

Can they put you under for the transfer and have your cervix dilated a few minutes before?that would be great but i don't know if is duable.

Good luck!!” (Two Week Wait)



The second quote gives advice I often see on the forums, which is “if it were me, I’d go for it.” These women may not be able to tell others how to manage their infertility from a medical perspective, but they can share what they would do in others’ situations. By the mere fact that they, too, have experience with infertility, their opinions are taken as actual answers to questions.

The lay-expertise on the forums may be a way for the advice-giver to relieve her own anxieties about IVF or other ARTs, or it may be a way for her to feel she has a handle on her own treatment. Lay-experts on the forums give advice by explaining their own experience on what they would do in someone else’s situation, or by talking about what they have heard or read. As discussed in Modell’s research, doctors tend to view these patients as naïve, and it is likely that these doctors do not recommend seeking information on the forums because of this. I do not wish to argue that the lay-expertise I see on the forums is not helpful to the women who go to the forums for answers; however, I think that the reason such advice and answers are helpful may not be because of the content of the advice. Instead, the fact that there is a support system at all, a group of women who can at least offer their own experiences and knowledge whether it helps someone to have a successful pregnancy or not, may improve forum-users well-being. Mihan Lee’s study did show that online infertility forums help to relieve stress, which can affect whether or not someone continues treatment to achieve that successful pregnancy. In this way, regardless of the expertise on the forums potentially being naïve or objectively unhelpful, the forums can still help women through their IVF journey.

The community of the online forums does offer support, but it does not offer relief from the pressure to have a child. Take a look at the following quotes:

“I wanted to give you my take on IVF as I was fighting infertility for 5 yrs. Money is just money. Our IVF FET package cost us 20k without medication. I managed to save on meds getting it through various places with giant discounts including overseas. I'm not rich, but I wanted baby JUST LIKE YOU. I have loan to pay off, but it's called LIFE INVESTMENT called Miracle.

I know my clinic cares for the success rates not the money, and I felt assured they do all to get me what I want and pay for. PLEASE, DONT LET ANYONE FOOL YOU. You pay the money and expect the care you deserve. It's a long journey and truly emotional.” (Two Week Wait)

“Stay positive. I know it's hard. Supposedly lower counts of eggs are higher quality! My neighbor did IVF and got 7 eggs and 2 fert, and I got 18 and 10 fert and we both ended up with 2 normal blasts. It can happen and it does!!” (Fertile Thoughts)

“The waiting game sucks but hang in there it come faster then u know it and it ll be just the perfect timing.” (What to Expect)

“Hello - I agree, definitely go for it, it is my philosophy too. I am 43. I'm still going for it. I'll be your partner for cheerleading each other.” (What to Expect)

Women on the forums know better than anyone the need to use technology to conceive. These women interact with one another because they know they can rely on other women who use the forums to empathize with the struggles of IVF, but at the same time, they are all sharing

their ambition and desperation to get pregnant. When women offer advice and support, they may tell women to take care of their bodies first and foremost, but they mostly cheer each other on and tell each other to stop at nothing. As seen in the first quote above, no matter how expensive or how tough, there is almost always someone on the forums saying that it will be worth it in the end. The online forums offer better emotional well-being by being a place where women can relieve their anxieties about IVF, but the forums do not save any woman from the pressure to conceive. Because of the United States' pronatalist values, pursuing IVF and similar ARTs is not a choice, it is a necessary path to biological parenthood in which women can coach each other on via online spaces.

## Conclusion

This study does have limitations. I did not get enough responses from the online interview I posted to draw conclusions from them. The women's exact feelings and intentions are unknown, especially because they have time to craft their posts. All I have to work with are the posts, but what the women are trying to convey and what they actually convey could be different. What is more, this study focuses on women who have the privileged access to high tech ARTs. While white, middle-class, heterosexual women are the main users of such technologies, the imposed passivity of the female patient and our pronatalist culture causes women to pursue the technologies and rely on the forums. These limitations call for further questions. I would like to know how the women using the forums feel about the forums, whether they view the forums as a community, whether they would acknowledge their own

self-interest, and whether minority women participate differently on the forums. Future research could examine these things, as well as how the forums serve as a waiting room for women who are impatient to hear from their doctors. This study analyzed the interactions on the forums, but the posts express a plethora of themes. In this way, posts on the forums can be used to guide further research about ARTs and online medical forums.

The online IVF forums are real communities. Women interact by seeking and giving knowledge and support, and there are both spoken and unspoken rules that work in conjunction with the interactions to create a thriving space. Women make posts explaining their struggles, or simply where they are at in their process, and ask for support or specific advice. Women respond to give support or circulate knowledge in order to minimize their own anxieties or to help. The ART users are making connections with each other through an online space, even keeping track of one another through cycle groups or other means. White and Dorman describe a community as having obligation, responsibility, and reciprocity among members. Certainly there is obligation and responsibility in the threads where women are keeping track of one another's journeys, providing support, and following rules such as not mentioning successful pregnancies and using trigger warnings. Reciprocity is intertwined with this, for the women will also provide support if they are asking for it. Researching the interactions on the forums, and being able to label it a community, opens the door to evaluate online IVF forums as you would evaluate any community. Further, this is a community of women that most people have never considered unless they have a relationship with IVF. Yet, the existence of this community speaks volumes about infertility, women's relationships with biotechnology, and the dynamics of online spaces.

The forum-users' empathy toward one another's need to conceive a biological child serves as the foundation for their connection. The obligation aspect of White and Dorman's definition of community begs the question of whether women feel they need to participate on the forums because that is the culture, or whether they genuinely care for the other women on the forums. Some women display knowledge on the forums by answering medical questions about IVF to alleviate their own anxieties and reclaim control. Other women wish each other luck and send prayers because they mean it, or because they believe it is the right thing to do if they are going to continue participating on the forums. We can never know the true intentions behind someone's behavior; however, it does not matter if these women are totally altruistic, or participating for their own self-interest, because it is possible for both to be true. A woman may offer lay-expertise to someone because she believes it will help that woman, because that woman asked for it, and because it makes her feel better to discuss whatever she knows. A woman may share her story and ask people to wish her luck because talking about her experience alleviates anxieties, because it opens herself up to connect with others who can relate, or both. As in all communities, there is both self-interest and compassion in the online forums.

## References

Akerkar, SM and LS Bichile. 2004. "Doctor patient relationship: changing dynamics in the information age information age." *Journal of Postgraduate Medicine* 50(2):120-122.

Centers for Disease Control and Prevention. 2017. "Infertility FAQs." Retrieved April 11, 2018. (<https://www.cdc.gov/reproductivehealth/infertility/index.htm>).

Fertile Thoughts. 2018. "IVF and High Tech." Retrieved April 11, 2018. (<http://www.fertilethoughts.com/forums/ivf-and-high-tech/>).

Jordan, Brigitte. 1993. *Birth in Four Cultures: A Crosscultural Investigation of Childbirth in Yucatan, Holland, Sweden, and the United States*. Prospect Heights, IL: Waveland Press, Inc.

JustMommies. 2018. "TTC by IVF." Retrieved April 11, 2018. (<https://www.justmommies.com/forums/f562-ttc-ivf/>).

Lee, Mihan. 2017. "Don't Give Up! A Cyber-ethnography and Discourse Analysis of an Online Infertility Patient Forum." *Culture, Medicine, and Psychiatry* 41(3):341-367. doi 10.1007/s11013-016-9515-6.

Martin, Emily. 1991. "The Egg and The Sperm: How Science has Constructed a Romance Based on Stereotypical Male-Female Roles." *Journal of Women in Culture and Society* 16(3):485-501.

Medline Plus. 2018. "Assisted Reproductive Technology." Retrieved on April 11, 2018. (<https://medlineplus.gov/assistedreproductivetechnology.html>).

Modell, Judith. 1989. "Last Chance Babies: Interpretations of Parenthood in an in Vitro Fertilization Program." *Medical Anthropology Quarterly* 3(2):124-138.

Nahon, Karine. 2009. "Gatekeeping: A critical review." *Annual Review of Information Science and Technology* 43(1):1-79.

Pendry, Lousie F. and Jessica Salvatore. 2015. "Individual and social benefits of online discussion forums." *Computers in Human Behavior* 50:211–220.

Prior, Lindsey. 2003. "Belief, knowledge and expertise: the emergence of the lay expert in medical sociology." *Sociology of Health and Illness* 25(3):41-57.

Rapp, Rayna. 2001. "Gender, Body, Biomedicine: How Some Feminist Concerns Dragged Reproduction to the Center of Social Theory." *Medical Anthropology Quarterly* 15(4):466-477.

Showden, Carisa R. 2011. "Mum's the Word Assisted Reproduction and the Ideology of Motherhood." Pp. 93-133 in *Choices Women Make: Agency in Domestic Violence, Assisted Reproduction, and Sex Work*, edited by Carisa R. Showden. Minneapolis, MN: University of Minnesota Press.

TheLaborofLove. 2017. "What do IVF, IUI and FET Stand For in Fertility Treatments?" Retrieved April 11, 2018. (<http://www.thelaboroflove.com/articles/what-do-ivf-iui-and-fet-stand-for-in-fertility-treatments>).

Two Week Wait. 2013. "IVF." Retrieved April 11, 2018. (<http://www.twoweekwait.com/community/viewforum.php?f=50>).

Warriner, Sian, Karen Bryan, and Anna Maria Brown. 2014. "Women's attitude towards the use of complementary and alternative medicines (CAM) in pregnancy." *Midwifery* 30:138–143.

What to Expect. 2018. "Fertility Treatments." Retrieved April 11, 2018. (<https://www.whattoexpect.com/forums/fertility-treatments.html>).

White, Marsha and Steve M. Dorman. 2001. "Receiving Social Support Online: Implications for Health Education." *Health Education Research* 16(6):693-707.



Whitehead, Krista Lee. 2013. "Great Expectations: Maternal Ideation, Injustice and Entitlement in the Online Infertility Community." PhD dissertation, Department of Sociology, University of Toronto.