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### #IVFgotyou: Instagram IVF Influencers as Social (Media) Support Systems

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#IVFgotyou: Instagram IVF Influencers as Social (Media) Support Systems

An Honors Paper for the Department of Anthropology

By Susu Gharib

Bowdoin College, 2023

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## **Abstract**

This paper details the ways in which IVF and infertility influencers on Instagram use their platforms to resist the silence surrounding reproductive difficulties. The analysis draws upon a thematic analysis of posts tagged with IVF-related hashtags and a semi-structured ethnographic interview with one influencer. Through these methods, I found that influencers build intimate publics through their platforms by sharing their journeys, interacting with followers, and reciprocal support. Within the context of the intimate publics, influencers are able to connect with others who understand their experiences, allowing them to break through the silence they may feel in their offline social groups.

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## Introduction

“We have never been more anxious about anything in our lives. We are terrified I am losing this pregnancy. Please flood me with similar stories that have ended in a baby in your arms. Give us hope” (Sabrina [@ivf\_baby\_d] 2022). This quote is taken from the caption of an infertility influencer’s post. The comment section is filled with over 460 comments of support and encouragement.

At some point in the fall of 2021, I liked a post on Instagram with the hashtag #IVF. Almost instantly, my Instagram explore page became flooded with infographics and influencers posting about infertility and in vitro fertilization (IVF). These posts covered a wide range of topics: awareness, advice, support, physician recommendations. Most notably, the posts that I came across were often of women sharing their own experiences with infertility and reproductive uncertainty. As I continued to click on these posts, I quickly became immersed in the digital world of IVF influencers.

I became interested in the concept of IVF influencers and how they work to build support networks through their social media presence. Comment sections on these posts garner hundreds of supporters and people sharing their own stories. As such, each influencer produces a virtual community of their own within their Instagram page. Through the process of “lurking” within these communities, I developed a series of questions about IVF influencers and their communities that ultimately served as the foundation for this research project. Through a combination of thematic analysis and interviews with influencers, I sought to answer the following questions: (I) what draws people using IVF to build platforms on Instagram? (II) how do IVF influencers view their role as influencer? And (III) how do these influencers use their platforms to navigate their experiences with infertility?

## Instagram as the Field

In conducting this research, my field of study was Instagram, a photo and video sharing social media platform. Navigating the virtual community of IVF influencers on Instagram was a challenging feat. The lack of borders between the “real world” and the virtual world I was studying proved to be a personal challenge. As someone who always has their phone in their hand, it was easy to fall into a trap of spending countless hours scrolling through comment section conversations and watching endless reels. Eventually, I created an Instagram account dedicated to my research which I only accessed on my laptop. This allowed me to create a line between Instagram as a field site and Instagram as an app on my phone.

Beyond this, conducting traditional ethnographic research on a vulnerable community was difficult. The ethnographic study of virtual communities is a relatively new practice as the internet went mainstream only three decades ago (Hart 2017, 2). The process of online ethnography is similar to that of in-person ethnography; both consist of observation and participant observation (Hart 2017, 4). Postill and Pink describe online ethnography as a practice that involves “keeping up-to-date with and participating and collaborating in social media discussions” (Postill and Pink 2012, 6).

As a 22-year-old with no known fertility issues, being an active participant in the community felt unethical. Instead, I chose to passively research the IVF influencer community by only observing. Instagram is a complex and fluid site with its own set of rules. I knew from my own personal experience that following someone on Instagram and never engaging with their posts is considered rude. I made sure not to participate in any way by not following any accounts and not liking or commenting on posts during observation to avoid breaking the unspoken rules of Instagram.

## Theory:

In this thesis, I draw on Lauren Berlant's notion of intimate publics to unravel the modes of sociality created by digital infertility communities. Berlant uses films and literature in "The Female Complaint: The Unfinished Business of Sentimentality in American Culture" to explore the intimate public of "women's culture" (Berlant 2008, 2). Intimate publics, Berlant argues, legitimate ways of existing that are otherwise deemed out of order or unsatisfactory by mainstream society (Berlant 2008, 3). As part of mass political culture, Berlant theorizes that icons and their image contribute to the creation of a "collective sense of social belonging" within an intimate public (Berlant 2008, 162). Moreover, collective attachment to icons indicates transpersonal intimacy (Berlant 2008, 162). While Berlant focuses on political icons such as Princess Diana and John F. Kennedy, her observations hold true for Instagram infertility communities wherein the influencer is the icon whose image creates a space for social belonging.

Berlant's theory of intimate publics is a popular framework for understanding digital community building among women. Petrychyn et al. (2020) analyzed how women build intimate publics through hook up apps. They found that queer and straight women's experiences on hook up apps differed in that queer women used the apps to find friendship and community in addition to romantic encounters (Petrychyn et al. 2020, 10). For queer women in Petrychyn et al.'s study, hook up apps provided a space for building a community that was more fitting than "physical queer spaces" (Petrychyn et al. 2020, 10). In contrast, straight women used hook up apps to create intimate publics in person with groups of women by using hook up apps together and sharing their experiences (Petrychyn et al. 2020, 10). Evans and Riley (2017) use intimate publics to explore the website TubeCrush, a site where women share photographs of men they find attractive on the London Underground metro system without their consent. They describe TubeCrush as an intimate public based on a shared culture of attraction to and "desire towards



masculinities that are conventionally normative” (Evans and Riley 2017, 11, 19). Kaisa Tiusanen examines the intimate public of women’s wellness culture on Instagram. Tiusanen argues that “feeling rules” and the act of feeling drive the operation of this digital intimate public (Tiusanen 2022, 4,15). These examples highlight the way intimate publics are formed by women online as a community-building practice.

The theory of intimate publics is a useful framework for understanding the popularity and purpose of infertility communities on Instagram as it emphasizes the desire for belonging that triggers formation of flocks based on shared experiences. Berlant stipulates that intimate publics provide their members with comfort and reassurance—they are a place where members can “breathe and thrive” (Berlant 2008, 3). Within the intimate publics of Instagram infertility communities, participants feel connected to others through their similarities, but also find solace from their struggles. Influencers create these communities by authoring posts that make the personal general; others then interact with and circulate these posts as a result of the affective pull of shared understandings of what it means to live with infertility.

Intertwined with the intimate publics of Instagram infertility communities are expectations of silence about infertility. In chapter five, I explore how the pronatalist norms of the United States contribute to the condition of silence about reproductive issues. I draw on anthropologist Jill Allison’s work on the reproduction of silence about infertility in Ireland’s profamily society to argue that intimate publics of infertility communities on Instagram have emerged as a form of resistance to social expectations of silence about infertility. Allison’s research foregrounds the embracement of silence in Ireland (Allison 2011, 1). Expectations of fertility are embedded in Irish society through the constitution which outlines the importance of the nuclear family to society and the influence of the Catholic Church on discussions of sexuality and procreation (Allison 2011, 4-5). As a result of the emphasis on reproduction and family as

critical to the national identity, childless couples are rejected as anomalies in Irish society (Allison 2011, 6). Allison notes that for most of her informants, “there was an element of isolation, loneliness, and lack of understanding” stemming from the silence about infertility (Allison 2011, 2). The United States shares a similar pronatalist culture, with fertility and reproduction as the established norm for women. Intimate publics on Instagram serve as a way for women to shatter the expectation of silence about reproductive struggles.

#### Chapter Outline:

The thesis is organized into five more chapters. In chapter two, I provide a literature review of scholarship on infertility and IVF. I focus on how society came to conflate femininity with reproduction and the social support options women have through infertility and IVF. In chapter three, I outline the methodology used to conduct the thematic analysis of Instagram posts tagged with IVF-related hashtags and the ethnographic interview. The thematic analysis is presented in chapter four, and an analysis of the interview with an IVF and infertility influencer is in chapter five.

As our world becomes more digitized, entirely new modes of sociality and connection are emerging. The traditional assumption that face to face communication is necessary to form deep connections is beginning to lose traction. Digital intimate publics allow people to break the silence they face in their offline worlds and provide them the courage to be vulnerable with their emotions and experiences. I argue that IVF and infertility influencers have emerged on Instagram as a result of the unique ability it provides to foster close-knit communities based on shared experiences. Influencers build platforms on Instagram that result in intimate publics. The platforms of influencers are a form of resistance as they contest the expectation of silence around reproductive difficulties. The extent to which infertility influencers are able to create these sites

where bare, candid emotions can be shared is incredibly important, and the following research illuminates how and why these digital communities have emerged.

## Chapter Two

### *Literature Review*

#### The History of IVF:

While Louise Brown marked the first live IVF birth, several discoveries during the first half of the 20th century laid the foundation for the development of IVF. First, Stockard and Papanicolaou discovered the oestrus (estrogen) cycle in female guinea pigs and found that ovulation was not spontaneous as had been previously accepted and was under hormonal control (Stockard and Papanicolaou 1917, 228, 260-262). This finding led to increased interest in the field of endocrinology. The next two decades were marked by a rapid succession of discoveries in reproductive endocrinology. Gynecologist Bernhard Zondek was at the forefront of most discoveries related to the pituitary-gonadal relationship. In 1928, Ascheim and Zondek noticed that the pregnant women had a gonad stimulating substance in their blood and urine called human chorionic gonadotropin (hCG) (Zondek 1929, 157). One year later, Zondek proposed that the gonads are stimulated by two hormones which he named Prolan A and Prolan B (Zondek 1929, 157). Zondek later found that secretion of Prolan A stimulated follicular growth while Prolan B induced ovulation (Zondek 1935, 158). Today, these hormones are referred to as follicle stimulating hormone (FSH) and luteinizing hormone (LH). The discovery of FSH and LH allowed researchers to understand the reproductive-pituitary axis, paving the way for the development of new reproductive technologies using these hormones.

These hormonal findings allowed researchers to begin exploring human fertilization by providing them with a timeline of expected gonadal events. Researchers Miriam Menkin and John Rock performed an in vitro fertilization experiment using a human egg and spermatozoa (Menkin and Rock 1948, 441). Their experiment demonstrated that when exposed to sperm

suspensions in human blood serum, eggs can develop to the two cell and three cell stages (Menkin and Rock 1948, 442, 447). The two proved that human eggs could in fact be fertilized outside of the body. While this was an important accomplishment, it wasn't until 1959 that it was proven that mammalian eggs fertilized by sperm in vitro can be transplanted into the mammal and result in pregnancy and the birth of normal young (Yanagimachi 2016, 847). This finding opened the door for researchers to begin investigating IVF techniques on humans.

In the following years, researchers across the globe raced to produce the first human IVF pregnancy. In 1965, Robert Edwards, a researcher from the United Kingdom, was invited to join Dr. Georganna Jones and Dr. Howard Jones at Johns Hopkins hospital to assist them with experiments in retrieving human oocytes, maturing them in vitro, and fertilizing the eggs (Zhao et al. 2011, 844). Edwards had previously focused his research on in vitro maturation of oocytes, making him an important addition to the work of Drs. Jones and Jones (Zhao et al. 2011, 844). While not recognized at the time, images from this collaboration reveal that the fertilization of in vitro matured oocytes was successful (Zhao et al. 2011, 844). Edwards went on to work with Patrick Steptoe, a pioneer in laparoscopic oocyte retrieval, to attempt IVF by 1968 (Zhao et al. 2011, 844). Together, the two sought to build a team of IVF researchers in the United Kingdom.

Edwards and Steptoe's research was a contentious undertaking. They were denied financial support from the Medical Research Council in the United Kingdom, which was a massive blow to their plans (Pfeffer 1993, 165). The political climate surrounding their work is important to note. At the time, the position of the United Kingdom on infertility was bleak. Anxieties about population growth placed infertility on the back-burner (Pfeffer 1993, 22). In fact, the British government actively sought to reduce its population growth by removing restrictions on contraceptives which limited their availability to married women (Pfeffer 1993, 24). The government's focus was completely placed on investigating and limiting population

growth, and infertility research threatened that mission. At best, proponents of infertility research were ignored, and at worst, they were publicly rejected, as in the case of Edwards and Steptoe.

Despite the setback, Edwards and Steptoe continued their research with private funding. The pair developed a system of hormonal injections to trigger ovarian stimulation. During the follicular phase, HMG would be administered to stimulate the growth of follicles every 2-3 days in addition to hCG on days 10-12 of the menstrual cycle to induce oocyte maturation (Zhao et al. 2011, 845). Laparoscopic surgery was performed 30 to 36 hours following the hCG injection to confirm follicle stimulation was successful (Zhao et al. 2011, 845). Once oocytes were removed, they were quickly fertilized and later transferred into the uterus at the eight cell stage (Zhao et al. 2011, 845). Edwards and Steptoe's IVF method was carefully and strictly regimented. Despite the seemingly precise nature of their method, they faced low rates of success, prompting them to begin investigating the use of natural menstrual cycle IVF. With this method, they could detect the naturally occurring LH surge during ovulation through the patient's urine to time oocyte retrieval (Zhao et al. 2011, 846). The duo's second patient to use this method was Lesley Brown (Zhao et al. 2011, 845-846). Nine months later, Lesley Brown gave birth to a baby girl, Louis Joy Brown, the first human born from IVF. Despite the incredible sacrifices Lesley Brown had to make to have her baby, her contribution to IVF research is often a mere footnote or passive acknowledgment in writings of the history of IVF.

In contrast, IVF development in the United States occurred at a much slower pace, owing in large part to a highly promulgated court case. IVF research was already a contested topic in the United States, with moral and legal arguments tearing through the scientific community (Thompson 2016). In 1977, the director of a hospital where IVF research was taking place decided to execute a secret raid in which he discarded fertilized embryos found in the laboratory

(Leeton and Trounson 2013, 29). The couple whose eggs and sperm were used to create these embryos in vitro sued the hospital, and the court sided in their favor (Leeton and Trounson 2013, 29). As a result, in 1978, preceding the birth of Louise Brown, federal funding for IVF research was frozen (Leeton and Trounson 2013, 29). This move placed the United States at the back of the race towards the world's first IVF birth.

When IVF proved to be a success in England, the Joneses who had collaborated with Edwards decided to move their research practice to Virginia where they obtained private funding and were able to set up a dedicated IVF clinic (Leeton and Trounson 2013, 29). In collaboration with researchers in Australia and the United Kingdom, they were able to produce the United States' first IVF baby in 1981, Elizabeth Carr (Leeton and Trounson 2013, 29). Despite the rocky start, IVF in the United States proved to be a success. Similarly to Lesley Brown, Judith Carr, the mother of Elizabeth Carr, often does not receive sufficient acknowledgment in the history of IVF in the United States. Newspaper articles about the day of the birth mention that Carr is doing well after delivery, but center their stories around the experiences of the doctors in the room (Rountree 1981).

Indeed, a common theme in writings of the history of IVF is the erasure of the women who essentially donated their bodies to the pursuit of IVF success. Women like Lesley Brown and Judith Carr are often briefly mentioned, their contribution passively stated. The scientific inquiries and discoveries that led to the success of IVF would not have been possible without the support of these women. While researchers had to deal with methodological failures, their patients had to deal with medications, daily urine or blood hormone tests, potentially invasive ultrasounds, hormonal injections, and laparoscopic egg retrieval. Despite the phenomenal effort and struggle these women went through, their contributions are rarely highlighted. In the

following sections, I will explore the social factors contributing to the silence around the women who helped develop IVF which still shrouds women undergoing IVF today.

### Defining Womanhood and Fertility:

As described by Pfeffer, historically, sterility was viewed as the moral price to be paid by women who deviated from the norm—women who had depression, were sexually active, or had an idle lifestyle for example (Pfeffer, 1993). Sterility was constructed as a result of social shortcomings. In consequence, when a couple faced involuntary childlessness, the blame was placed on the woman. Today, infertility has become increasingly medicalized. While debates on whether or not infertility is a disease abound, both the World Health Organization and the American Society for Reproductive Medicine define it as a disease of the reproductive system (“Infertility” n.d. and “Infertility” 2020). These two organizations have overwhelming authority in the fields of public health and medicine. By defining infertility as a disease, it has come to be denoted as a condition *requiring treatment*.

Although definitions of infertility have transformed over time, a salient characteristic of infertility both in the past and present is that it is viewed as a deviation from the societal expectations of women. Infertility is a departure from the image of womanhood, one that ties the female identity and existence to reproductive capacity. Marcia Inhorn expands this idea by noting that the medical field of women’s health is focused on two disciplines—obstetrics and gynecology and maternal and child health—both of which focus exclusively on women as reproducers (Inhorn 2007, 8). In this manner, the medical world defines womanhood as an identity based on reproductive capability. This bioessentialism manifests itself in the framing of infertility as a biomedical issue requiring treatment.



Central to the reproductive essentialism placed on women by the institution of medicine are Michel Foucault's ideas of biopolitics and biopower. Foucault describes biopolitics as a political mode of supervision and control over the body as a means of life specifically focused on "propagation, births and mortality, the level of health, life expectancy and longevity" (Foucault 1978, 139). Biopower explains how biopolitics functionally works in society through the "subjugation of bodies and the control of populations" by institutions of power (Foucault 1978, 140). Biopolitics and biopower manifest in society through the focus on the reproductive capacity of women. By establishing women's health as inseparable from reproduction, the medical field has granted itself authority over the reproductive systems of women. In engaging with the institution of biomedicine, women's bodies as sites of reproduction become subjects of medical surveillance, constantly monitored to ensure reproductive success. Biomedicine therefore has jurisdiction over defining what constitutes a normal or abnormal reproductive system and in turn, what makes a body normal or abnormal.

Through medicine's framing of reproductive bodies as normal versus abnormal, society has further classed them as natural or unnatural. The natural woman is fertile and capable of reproduction; the unnatural woman is infertile and incapable of reproduction. In terms of treatment for infertility, methods of assisted reproduction are then also categorized as unnatural as they are the antithesis of natural reproduction through sexual intercourse. Helena Michie and Naomi R. Cahn explore the paradoxical "nature of infertility," adding that the end goal of infertility treatment is to induce "the natural state of pregnancy" (Michie and Cahn 1997, 121). In effect, the purpose of infertility treatment is to move the unnatural body into a state of natural existence (i.e. a state of reproductive capability). Furthermore, Michie and Cahn observed that treatments for infertility rely heavily on illogical distinctions between artificial and natural, as in the case of artificial insemination (Michie and Cahn 1997, 122). This observation demonstrates

that even within the sphere of infertility treatments, a separation is made between the natural and unnatural. These distinctions demonstrate a preference towards aligning with the natural body.

Where then do men lie in the equation of infertility? Inhorn emphasizes that the reproductive essentialism placed on women is not the same for men (Inhorn 2007, 9). A 2015 study found that male factor infertility accounts for 50% of infertility cases in the United States (Agarwal et al. 2015, 3). Despite this, men's reproductive capabilities are largely excluded from infertility discourse. Liberty Walther Barnes conceptualizes this divide as the result of prevailing cultural notions of masculinity (Barnes 2014). Barnes details how much of our vernacular centers around the male reproductive system as a symbol of power and strength (Barnes 2014, 4). Phrases such as “grow a pair...that takes balls” demonstrate the societal notion that a potent and virile male reproductive system defines masculinity (Barnes 2014, 4). It is likely that as a result of this socialization, men may have a harder time discussing issues with infertility.

While male and female reproductive systems have both been subject to social scrutiny, women have historically faced the burden of infertility, owing to the patriarchal roots described at the beginning of this section. Karen Throsby links this chasm to the effects of the enlightenment, namely the societal shift towards the scientific paradigm (Throsby 2004, 24). Throsby notes that the scientific paradigm positioned men and women as opposites with distinct biological differences, leading to the overwhelming view of reproduction as the natural fate for a woman (Throsby 2004, 25). This biology based fate was then used to exclude women from public life (Throsby 2004, 25). More recently, the idea of the biological clock has come to symbolize infertility in terms of a woman's responsibility to adhere to the “innate, hormonally fueled drive to reproduce” (Throsby 2004, 28). Granted that both men and women's roles in society are socially constructed around their reproductive functions, it is clear that women face a

more callous view in comparison to men. Male reproduction is seen as a sign of brawn and vigor while female reproduction is seen as the execution of biological duties.

In sum, the framing of fertility as womanhood is the consequence of a number of factors. Historical trends of placing the burden of infertility on women as a repercussion for leading socially unacceptable lives derived from the view that women should be excluded from public life have greatly contributed to notions of fertility and infertility today. Most notably, these ideas manifest in the institution of biomedicine and its establishment of reproduction as women's health. This has given biomedicine control and supervision over the reproductive facets of women's bodies, allowing it to define what is normal and what is abnormal. In addition, men have been vastly excluded from discussions of infertility despite accounting for 50% of all infertility cases in the United States as a result of cultural notions linking male reproductivity to strength. Through a combination of these elements, fertility and infertility have been inextricably linked to womanhood.

#### IVF Dilemmas:

Infertility can be traumatizing and have devastating effects. The desire to have a child and form a normative family is central to the experience of infertility. Descriptive literature provides a rich understanding of the emotional weight of an infertility diagnosis. Women who are infertile express feeling socially isolated, envious of mothers, a sense of worthlessness, and resentment (Greil, Slauson-Blevins, and McQuillan 2010, 144). Quantitative studies have shown that women experiencing infertility suffer from higher levels of distress and more depression and anxiety than comparison groups (Greil, Slauson-Blevins, and McQuillan 2010, 147). Furthermore, when infertility treatments or interventions fail, women may face feelings of grief, disappointment, and anger. One of the dominant themes that arises from both qualitative and quantitative studies of infertility is a sense of loss of control over one's life (Mounce, Allan, and

Carey 2022, 319, Gourounti et al. 2012, Cousineau and Domar 2007, 295). Struggling to conceive can challenge a person's sense of control over their own body leading to feelings of confusion and anger. IVF treatment can exacerbate this sense of loss of control due to the demands it places on the patient. In seeking medical treatment, women have to reinterpret their bodies through the lens of illness despite not feeling sick in conventional terms (Mounce, Allan, and Carey 2022, 316-317). By receiving an infertility diagnosis and deciding to undergo treatment, women's daily status changes to patients, a transition that can be difficult to accept.

Apart from the general distress caused by infertility, IVF treatment poses unique obstacles that compound the all-consuming nature of an infertility diagnosis. IVF procedures are time consuming and, for many, a financial stressor. A single IVF cycle can range from \$15,000 to \$30,000 in the United States, and many women require multiple IVF cycles to achieve a successful pregnancy (Conrad 2022). To aid with the cost of treatment, IVF clinics often offer financing or loan options for people seeking treatment (Aspire Fertility n.d., Shelton 2021). However, treatment seekers must then factor in interest costs and grapple with the very real possibility that they may go into debt and end treatment without a baby. On top of the direct financial commitment, IVF requires patients to sacrifice a large amount of time. This time lost can present another financial burden in terms of travel time or lost wages while undergoing treatment. A time-cost study found that IVF patients spend 125 hours on average pursuing treatment per cycle (Wu et al. 2013, 2028). IVF demands significant lifestyle sacrifices that come in the form of time and money. As such, the choice to pursue IVF treatment often requires women to renegotiate their social roles in daily life. Due to a loss of time, women have reported no longer engaging with leisure activities and quitting their jobs or leaving educational programs (Collins 2019, 27-30). Consequently, when using IVF, treatment frequently takes the forefront in women's lives, excluding them from parts of their prior social lives.

Additionally, IVF frequently affects relationships between partners. Research has shown that in general, prior to beginning IVF treatment, couples score similarly to normative groups in terms of psychological well being (Malina and Pooley 2017, 555). However, upon receiving an infertility diagnosis and beginning treatment, relationships seem to falter. The emotions brought forth by infertility and IVF treatment negatively affect communication, bond strength, and satisfaction with sexual life (Malina and Pooley 2017, 555). Partners may struggle to discuss their emotions leading to feelings of a lack of support within the relationship (Holley, Pasch, and Domar 2021, 679-680). Furthermore, sexual satisfaction is reported to be significantly worse in couples undergoing ART treatments than in couples who achieved spontaneous pregnancy (Shoji et al. 2014, 3-4). The pressure of IVF on relationships also affects treatment and goal attainment. A systematic review found that almost 17% of patients who discontinue ART treatments cite marital or relational issues as the primary reason (Gameiro et al. 2012, 660). Overall, IVF causes a considerable strain on relationships. When the support of a relationship is under tension, women undergoing IVF are left to seek out alternative sources of support.

### Modes of Social Support

One of the many dilemmas women undergoing IVF treatment face is finding support. With all of the emotional consequences of IVF and infertility, support systems are an important way to manage stress. It has previously been shown that social support can help to alleviate the emotional burden of infertility (Steuber and High 2015, 1639). A study by Saleem et al. found an inverse relationship between perceived social support and mental health issues (Saleem et al. 2019, 2535-2536). Malina, Głogiewicz, and Piotrowski found that supportive social interactions during infertility treatment lead to a significant decrease in stress levels (Malina, Głogiewicz, and Piotrowski 2019, 5-6). Despite the clear benefits of social support, women frequently report not finding enough support throughout the IVF process.

In general, most people find emotional support from their friends and family. However, finding support through IVF and infertility poses a unique conundrum in that infertility is relatively stigmatized. As a result, sharing information about treatment with others may feel embarrassing or isolating. Berger, Paul, and Henshaw found that infertile women report their social environment as painful due to casual stigmatization and exclusion (Berger, Paul, and Henshaw 2013, 4). Additionally, women feel expected to keep their feelings and experience hidden to prevent others from feeling discomfort (Berger, Paul, and Henshaw 2013, 4). Similarly, McBain and Reeves explored disenfranchised grief among infertile women and identified a series of common themes including: hurtful comments or solutions; being excluded or ignored; lack of empathy and compassion; the grief is concealed; difficult to rely on previous supports; seeking to be understood (McBain and Reeves 2019, 159). These themes demonstrate the trials women go through when attempting to share the grief of their infertility with others in their lives.

One of the overarching issues that arises from these themes is a lack of support through the grief associated with infertility. In these situations, the help of a traditional support system may make women experiencing infertility feel worse. This finding is supported by the data from Berger, Paul, and Henshaw in which women reported feeling IVF failures as the death of a child and sought societal validation of their loss as being a loss of human life (Berger, Paul, and Henshaw 2013, 4). Moreover, Born, Carotta, and Ramsey-Seaner found that women report experiencing “constrained communication patterns” with people in their lives due to unshared infertility struggles which generate a sense of isolation (Born, Carotta, and Ramsey-Seaner 2018, 2999). In all, while traditional support systems have been shown to reduce distress associated with IVF and infertility, oftentimes these support systems fail to provide adequate aid. These

factors may contribute to why women turn to social media for support through their IVF journeys.

Social media has become an increasingly important source of health-related support. Rosen et al. investigated social media use of adults in Spain during the COVID-19 pandemic and concluded that social media was used as a form of emotional support due to isolation and health uncertainty (Rosen et al. 2022, 16-17). As previously discussed, women experiencing infertility and IVF report feeling social isolation due to their health status. Likewise, Lin and Kishor found that social media use in health allows users to create communities based on shared values and affords users the opportunity to develop social relationships through those communities and the experiential support they provide (Lin and Kishor 2021, 5-6). The desire to build relationships with people who understand the unique challenges one is going through is a strong factor for the prevalence of health related social media use.

Studies of social media use by people who are infertile have consistently supported these ideas. Sormunen et al. found that social media dedicated to infertility provided an outlet for women to share and receive both informational and emotional support (Sormunen et al. 2021, 390). Osadchiy, Mills, and Eleswarapu discovered that men facing infertility use social media to anonymously share stigmatized feelings of emasculation and isolation that they may not feel comfortable sharing with people in person with others online experiencing the same thing (Osadchiy, Mills, and Eleswarapu 2020, 5). Johnson, Quinlan, and Pope analyzed social support in the comments of Instagram posts tagged with IVF-related hashtags (Johnson, Quinlan, and Pope 2020, 327). They found that comments are used for emotional and belonging support, informational support, and tangible support through material aid (Johnson, Quinlan, and Pope 2020, 331-332, 336). The findings of these studies demonstrate that social media support is used in the sphere of infertility to generate community support that may not be found in person.

## Chapter Three

### *Methodology*

#### Data Analysis Methodology

All data for this study was collected using an open-source scraper provided by the web scraping platform Apify (Alexey, Apify). I chose to use data scraping over manual data collection in order to avoid any bias from the Instagram algorithm that would arise from collecting data using my personal account or research account. The data scraper allowed me to collect a dataset without logging into an Instagram account which circumvented potential bias from the algorithm. First, the data scraper was used to identify a pool of IVF influencers. After obtaining a pool of influencers, the scraper was used to collect recent posts by these influencers for thematic analysis. Thematic analysis was conducted using the MAXQDA software and Braun and Clarke's thematic analysis process (Braun and Clarke 2006).

#### Ethical Considerations:

Data scraping has gained traction as a valuable tool in health research, particularly for investigations of the role of social media in health. In particular, data scraped from Instagram has been used for studies on lymphedema (Tuğral et al. 2021), infant safe sleep practices (Chin et al. 2021), and vaping (Ketonen and Malik 2020). Despite the growing use of social media data scraping in research, the ethics of this method are not well defined. Instagram posts are, by technical considerations, publicly available data (Ravn, Barnwell, and Neves 2020). However, the boundaries of public and private are often blurred on Instagram, especially when posts contain sensitive information that could be used to identify the account owner. A review of the ethics of mining data from social media sites for health research by Ford et al. suggests that consent for data use is not required when collecting data without the use of log-in details (Ford et



al. 2021, 10). Data collection without the use of log-in information is considered more ethical as it restricts collection to data that can be accessed by anyone (Ford et al. 2021, 10). Ford et al. also identified a consensus that researchers should protect the privacy of posters by maintaining their anonymity during analysis and publication of results (Ford et al. 2021, 11).

To establish a set of ethical considerations for my research, I examined the ethical guidelines used by others who have published social media research on sensitive topics. Content analysis studies of infertility and IVF social media posts have used different methods for reporting their findings. In two different articles, Johnson, Qunilan, and Pope chose to publish Instagram images from their data set with usernames blurred (Johnson, Qunilan, and Pope 2019, 2, 8, 10, Johnson, Qunilan, and Pope 2020, 330, 333, 339). In contrast, Perone et al. and Blakemore et al. chose not to include Instagram images (Perone et al. 2021, Blakemore et al. 2020). To minimize harm and protect the identities of posters, I decided not to report any images or usernames associated with the data set in this project. This protection will prevent the possibility of misuse of the data beyond my control. I also considered the use of direct quotations from posts. In a thematic analysis of eating disorder recovery posts on Instagram, LaMarre and Rice sparsely included block quotations of post captions (LaMarre and Rice 2017, 6-11). Harding, Whittingham, and McGannon published a thematic analysis of Instagram posts related to motherhood and alcohol use that presented aggregated data and single word quotations as opposed to lengthy direct quotations taken from posts (Harding, Whittingham, and McGannon 2021, 4-7). Most studies of social media based infertility thematic analysis used block quotations taken from posts (Hanna and Gough 2016, Sormunen et al. 2021, Perone et al. 2021). Curious about the differences in quotation use by researchers, I decided to investigate whether lengthy quotations used in these articles could be traced back to the original post through Google. I could not find the original posts of the quotations when I searched them alone or with the name of the

relevant social media site included at the end of the quotation. Based on the lack of agreement among researchers on whether or not direct quotations should be used in thematic analyses of social media posts related to sensitive topics, I chose to include quotations taken from posts in congruence with other Instagram-based infertility research. Where necessary, I removed any names or identifying information included in quotations used.

Based on information provided by the Bowdoin Institutional Review Board (IRB), this study was not considered human subjects research, therefore, IRB approval was not sought. After establishing these ethical considerations, I began collecting the data.

#### Data Collection:

In my preliminary investigation, I became familiar with the ways in which IVF influencers spread their content. Posts are often tagged with a plethora of hashtags related to IVF, infertility, or trying to conceive. I noticed that IVF influencers often used the following hashtags: #IVF, #IVFsupport, #IVFjourney, #IVFcommunity, #IVFsuccess, #IVFfailure. On October 31st, 2022, I used the data scraper to retrieve the top nine and up to 100 latest posts for each of these hashtags. This data also included the usernames and follower counts of the account owner of each post. From this information, I identified accounts that post content primarily related to IVF and generated a pool of IVF influencers based on follower count.

Influencer status is typically determined by follower count. However, there is no clear definition of influencer status. For this study, accounts with greater than 25 thousand followers were classified as influencers. This number was selected based on categories of influencer status tiers. Based on the number of followers, users can be assigned as either mega, macro, mid-tier, micro, or nano influencers (Keenan 2021). Accounts with 25 thousand followers would be classified as micro influencers according to this categorization (Keenan 2021). While classified as micro influencers, it is important to note that the IVF sphere on Instagram is a lower-traffic

subsection in comparison to other topics. For example, the hashtag #IVF has been used by approximately 2.5 million posts compared to #fitness or #beauty which have both been used by approximately 500 million posts each. Accounts that were unrelated to IVF or whose content was not primarily in English were excluded from the study.

A total of 23 IVF-influencer accounts were included in the study. On November 1st, 2022, the 20 most recent posts by these accounts were retrieved using the data scraper. The 20 most recent posts included posts that were pinned to a user's profile as Instagram provides users with the option of pinning up to three posts on their account. Videos and reels were excluded from the study. A total of 240 posts were collected. For posts that were a set of images, only the first image in the series was included in the data set.

#### Data Analysis:

In order to analyze the content of the images and their associated captions, I followed the thematic analysis methodology of Braun and Clarke (Braun and Clarke 2006). Braun and Clarke's (2006) methodology focuses on six core steps for analyzing qualitative data. Phase one involves familiarizing yourself with the data (Braun and Clarke 2006, 16). To familiarize myself with the data sample, I thoroughly and interactively read all of the posts in the data set twice. I took notes on repeated patterns and post types. Repeated reading of the content allowed me to identify preliminary codes to be used in the next phase of analysis.

In phase two, I formally coded the data using a set of initial codes (Braun and Clarke 2006). I first coded each post as being related to IVF, infertility (not IVF specifically), or other. Coding and analysis during phase two was conducted using Microsoft Excel. Posts were coded with IVF if they were tagged with an IVF-related hashtag, the image or caption contained text that said IVF, or the account owner became pregnant through IVF and the post is related to the pregnancy. Determining IVF pregnancies required that I looked at other posts from the account

owner to discern the context of their pregnancy. Similarly, posts were coded with infertility if they were tagged with an infertility-related hashtag or if the image or caption contained text related to infertility but not IVF. Posts were coded as other if they did not meet the criteria to be coded with IVF or infertility. Based on the preliminary coding, 147 posts were related to IVF, 21 posts were related to infertility, and 72 posts were not related to IVF or infertility. All posts coded with IVF or infertility were coded a second time to ensure they were coded correctly. The inter-coding reliability was 100% as determined by the Holsti method.

Next, posts coded as IVF were coded for their overall content. This step involved looking at the image and caption content as a whole and identifying an overarching category to describe the content. These codes included: question and answer, emotional spectrum, experience update, journey, political, advertisement, success, humor, medical experience, and personal. Posts coded as personal during this step were posts whose content was unrelated to IVF but used an IVF hashtag. Many of the posts could be coded with multiple codes, but they were assigned the code that fit with the majority of the post content. The majority of posts focused on the emotional spectrum of IVF or provided updates about the account owner's IVF journey (Figure 1). This step further immersed me in the data and provided a deeper understanding of the content of IVF influencers' posts.

## Post Category

n=147

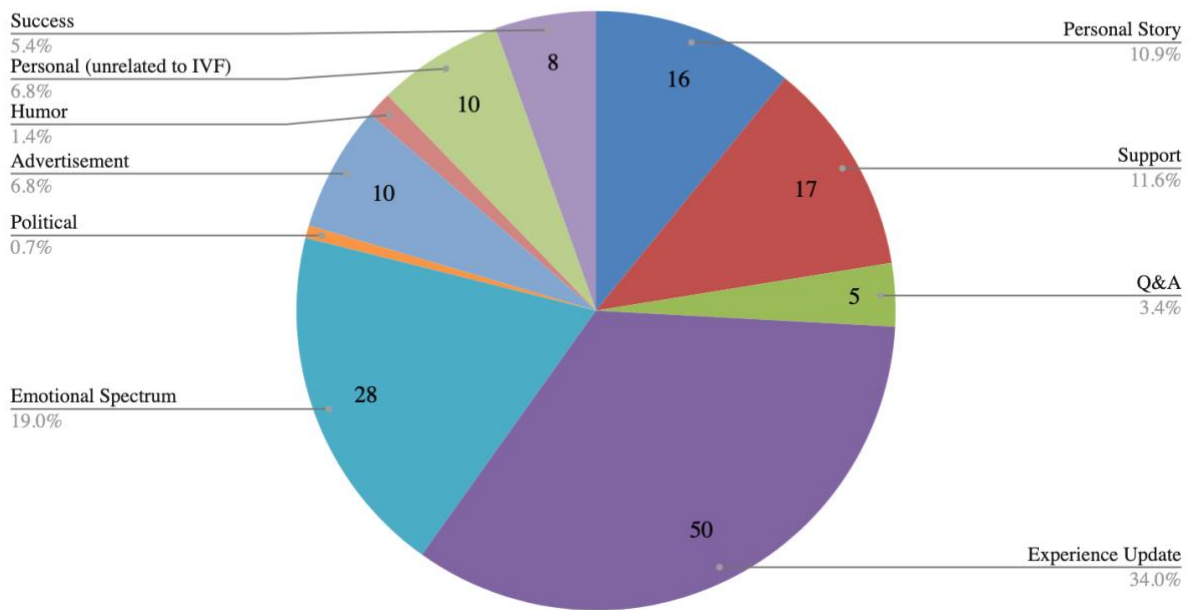


Figure 1. Distribution of IVF post categories, n=147.

After initially coding all posts, phase three of Braun and Clarke's method began. In the first coding phase (step two), posts were categorized as whole groupings. In contrast, during step three, thematic coding, extracts of data from posts were coded with themes. During this phase, coding was performed using MAXQDA, a software program for qualitative analysis. In step two, as I coded images and captions of posts as a whole, I discovered that the heart of the post content is often in the caption. Posts were typically captioned with long narratives more similar to what one might expect of a blog post. Images contributed to the overall tone of the post, but captions were central to communication of the post content and often contained a spectrum of topics. As such, in phase three, multiple themes were extracted from the captions despite each post only being coded into one content category. Coding was done organically and inductively. Data extracts were assigned themes that emerged as the coding process went on as opposed to being

labeled with themes derived from previous research on the subject. Overarching themes and subthemes were identified during this coding process.

Once the candidate themes were identified, they were then refined in phase four (Braun and Clarke 2006). In this step, I carefully analyzed the data extracts and generated a thematic map (Figure 2). Candidate themes and the data extracts were reworked until a coherent pattern was identified. This process involved meticulously reading and rereading data extracts to ensure that the candidate themes captured the core of the data. Next, I considered the individual themes and whether or not they accurately reflected the data set by rereading the entire data set, as suggested by Braun and Clarke. I continued refining my thematic map during this step until I exhausted the limits of the data.

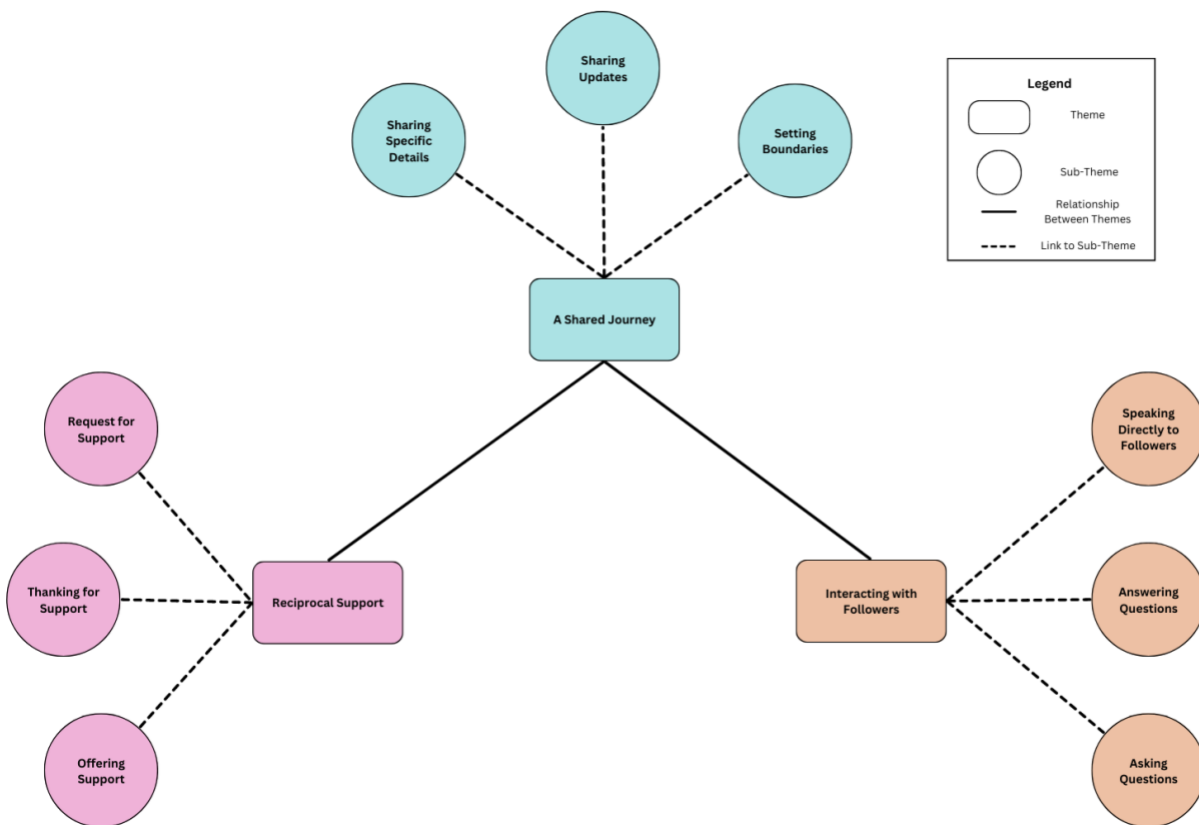


Figure 2. Final thematic analysis map.

In phase five, I named and defined the extracted themes (Braun and Clarke 2006). At this stage, I analyzed the data extracts together to identify the story they convey about what it means to be an IVF influencer and how IVF influencers interact with their followers. Table one provides an example of the thematic analysis process, inspired by Sormunen (Sormunen 2021, 29). Phase six involved generating a final analysis and report of the data (Braun and Clarke 2006). The final thematic analysis produced using Braun and Clarke’s methodology is presented in chapter four.

<b>Data</b>	<b>Code</b>	<b>Subtheme</b>	<b>Theme</b>
Once we get that done, and if all is ok, we will reveal the sex to you all with a fun reveal next week. Fingers crossed	Waiting to share	Boundary Setting	A Shared Journey with Boundaries
We got good news This morning I had my baseline ultrasound and bloodwork to start IVF. I have more follicles than we were expecting, my hormone levels were right where they need to be, so I will be starting shots now.	IVF Update Medical Update	Sharing Updates	

Table 1. Example of the thematic analysis process.

### Interview Methodology

Throughout January 2023, I contacted Instagram IVF influencers to conduct semi-structured interviews about their experiences as influencers. A semi-structured interview format was selected for several reasons. Due to the sensitive nature of IVF, I wanted to ensure the

majority of my questions were worded in a way that was trauma-informed to minimize the potential for upsetting interviewees. This excluded an unstructured interview from consideration. In contrast, I felt that a structured interview would be too rigid. Structured interviews seek to uphold a high level of standardization across interviews (O'Reilly 2009, 125-130). Experiences of infertility and IVF are personal, so a standardized interview on this topic would be illogical. Furthermore, I aimed to build a relationship with the interviewee as I was requesting that they divulge information about a vulnerable and intimate part of their life. Thus, I settled on using a semi-structured interview format. This format allowed me to generate a list of questions that were intentionally prepared and allowed interviews to occur more similarly to a conversation. Additionally, the semi-structured interview gave space for the participants to guide the conversation and share their stories on their own terms.

Initially, I planned to interview 5-10 influencers identified during the data analysis section of this project. During the month of December 2022, I contacted these accounts via Instagram direct message from my research account (Figure 3). My message included a brief description of the project, a copy of the informed consent form, and a request that they participate. Accounts were sent one follow-up message a week after the initial contact. By January 1st, 2023, I was unable to schedule interviews with anyone from the pool of influencers. Due to the short timeline of the project, I decided to lower the follower count required for study participation to 15,000 followers. To identify influencers who met this criterion, I used purposive sampling. I identified influencers as I scrolled through the hashtags used previously and messaged them as I came across them. In the end, I was able to conduct one interview with an influencer from the original pool.

The interview was conducted via Zoom. The interview guide consisted of a list of 10 questions addressing topics such as how the interviewee came to become an Instagram



influencer, what their relationship with their followers looks like, and how being an IVF influencer has altered their IVF experience. The interview lasted approximately 45 minutes, and the participant was given the option of whether or not the interview was audio recorded. For interviews that were audio recorded, I transcribed the recording immediately following the interview. The interviewee was given the option of having their camera on or off, but my camera remained on throughout the interview. A pseudonym was assigned to the interviewee to be used throughout the project. A case study analysis of the interview is presented in chapter five.

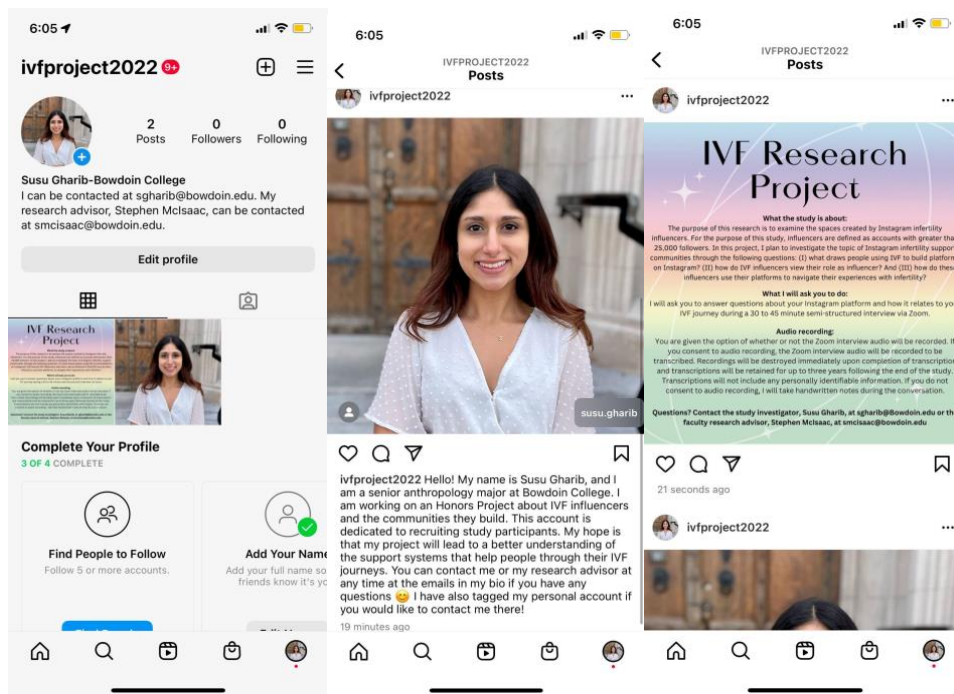


Figure 3. Research account used to contact IVF influencers.

## Chapter Four

### *Thematic Analysis*

In this analysis, I explore the themes of interacting with followers, reciprocal support, and a shared journey with boundaries through Lauren Berlant's concept of "intimate publics" (Berlant 2008, 5). Berlant describes intimate publics as sites that are "...porous, affective scene of identification among strangers that promises a certain experience of belonging and provides a complex of consolation, confirmation, discipline, and discussion about how to live as an *x*" (Berlant 2008, viii). The Instagram accounts of IVF influencers act as digital intimate publics. In this liminal space between public and private, influencers create communities by sharing their personal experiences, creating sites of identification and belonging for others. I argue that IVF influencers "do" intimacy to build intimate publics by sharing parts of their IVF journeys with their followers and forming relationships with them. With this, IVF influencers also negotiate the public nature of their private experiences by creating boundaries in their relationships with their followers.

#### Interacting with Followers:

Broadly, posts by IVF influencers tend to have an aspect of follower interaction embedded in them. Influencers address the reader directly by using the pronoun "you" to generate lines of communication with their followers. By addressing the reader, influencers generate a sense of reciprocity between them and their followers. This method of communication conveys closeness and intimacy, underscoring that their followers have a stake in their IVF journey.

"I'm not trying to make this depressing, but just trying to keep our expectations (and yours) realistic." (Influencer 1)

Beyond directly addressing their followers using second person pronouns, some influencers refer to their followers as their friends. These messages reflect the camaraderie that is formed by the influencers' platforms.

“Hi friends!! Omg I feel like it’s been forever!!” (Influencer 2)

“Realize we have a lot of new friends here and we haven’t done this in a while!!”  
(Influencer 3)

Conversational elements such as influencers asking their followers questions also appeared. These questions range in their scope, but all use the pronoun “you” to engage the reader and encourage them to share their responses.

“If this part of the “fight” is over for you, who are you now? How are you different?  
What are you like? How does your past shape you now?” (Influencer 4)

The engagement with followers built by the language of IVF influencers is not one-sided. IVF influencers also interact with their followers by answering their questions. Influencers often reference receiving multiple requests for their answer to a specific question in these posts, highlighting the engrossment of their followers in their IVF experiences.

“I’ve received so many questions about the egg donor process, I’m going to an IG live soon to answer all your questions!” (Influencer 2)

These methods of follower interaction lay the groundwork for the formation of intimate publics. By engaging their followers, IVF influencers facilitate a sense of shared belonging. Their language implies a relationship between the influencers and their followers. The linguistic style used by IVF influencers is not unique and is a widely used method of follower engagement used by influencers in all spheres. In a study on the language used by influencers on Youtube, Lee and Theokary identified interactivity and closeness as important tools used by influencers to form relationships with their followers (Lee and Theokary 2021, 865). While Lee and Theokary

focused on the use of first person pronouns to assess closeness, IVF influencers utilize both first and second person pronouns to demonstrate that their relationships with their followers are mutually close (Lee and Theokary 2021, 865). Thus, the foundation for intimacy in the building of intimate publics by IVF influencers stems from their interactions with their followers. The language used by IVF influencers conveys a shared closeness or intimacy with their followers, indicating a mutual relationship.

#### Reciprocal Support:

One of the overarching themes identified was reciprocal support between IVF influencers and their followers. This support can be categorized into three topics: requests for support from followers, offering support to followers, and gratitude for the support of followers.

#### Asking for Help:

Many of the posts assessed included a request for support. Asking for financial support for an IVF cycle was a common request.

“Over the years, many of you have asked me to start a GoFundMe or share my Venmo, but I’ve always declined for that very reason. I’ve pushed it off as long as I could, even with [redacted name] telling me we can’t afford it much longer. But after recently finding out how much IVIG is going to cost us I knew I finally needed to take people up on their offer and ask for help.” (Influencer 1)

In addition to asking for personal financial help, some posters advertised other’s requests for aid, demonstrating the community-based aspect of IVF influencer accounts.

“As so many of you will no doubt relate, [redacted name] can’t just sit back and accept that this is it... she has set up a Go Fund me page in the hope that she might raise enough money to support her with another round of IVF.” (Influencer 5)

Others asked for help in navigating social and emotional experiences. Friends and family not understanding infertility or IVF was a common struggle. These requests suggest that IVF influencers and their followers find a level of support through Instagram that they do not receive offline from other support systems.

“How do you stop sharing your journey with your family once you have started? I can’t do this again under such an enormous spotlight.

Can anyone relate to this? I love my family and I worship my sister, but this pressure is just too much. It’s not my fault that my IVF failed. I did my best. I really did.”

(Influencer 6)

*Offering Support to Followers:*

Influencers frequently included notes of support and inspiration in their captions. These supportive interactions included an acknowledgement of shared struggle.

“I know I’m not the only one who has had a hard year. I know some of you have had it harder. I know I’m not the only one who wakes up and wonders, how the f is this my life? Then silently breaks down in tears.” (Influencer 4)

When IVF influencers provide their followers with support, it is often framed around the notion of understanding one another’s feelings and encouraging others to feel things fully.

“...when life is kicking your ass 24-7, like it is for many of the women in this community, it’s okay to be honest about those negative feelings and work through them.”

(Influencer 4)

Furthermore, loneliness through infertility and IVF were referenced in these offers of support. Using phrases such as “we are not alone” (Influencer 5) and “you aren’t alone” (Influencer 7) contributed to the community-centered focus of these accounts.

“You do not need to suffer silently & I hope my page gives you some comfort through your journey” (Influencer 8)

Inspirational messages were also used as forms of support. These messages encouraged others to continue on their IVF journeys.

“It’s impossible to know if your next transfer may be the one to answer all of your prayers and dreams...But, if you’re just not ready to stop, then keep going with hope in your heart.” (Influencer 9)

Gratitude for support:

Many influencers expressed gratitude for the support they have received from their followers. Some posters referenced their followers as their “village” through the process of IVF.

“I’m so thankful to all of you who have supported us. Yes, it takes a village to raise a child, but in our case, it takes a village to have a child too. And you guys are definitely a part of our village. Thank you.” (Influencer 1)

Influencers identified drawing inspiration from interactions with their followers. These messages further reflect the reciprocity of support between IVF influencers and their followers.

“We’re so thankful for all of you who are following along, praying for us, and sharing your stories with us. It inspires us each and every day! We are just so grateful to have gotten this far.” (Influencer 10)

Many posts referenced years of ongoing support from followers. This support is described as being a reason why some have been able to continue with their IVF journeys despite the associated pain.

“Thank you to each and everyone one of you for your love and support throughout the years. I’m honestly not sure if we could have made it this far without you guys. Thank you” (Influencer 1)

In all, the supportive content of these posts is a factor in building communities. By offering support to their followers through inspiration and a shared understanding of the IVF experience, IVF influencers contribute to a reciprocal interaction in which they both give and receive support through their Instagram pages. Reciprocal support between IVF influencers and their followers illustrates how intimate publics function like economies (Berlant 2008, 20). Here, support is a commodity that is exchanged between influencers and their followers. Berlant argues that within intimate publics, participants wish to know and adapt how others have “survive[d] being oppressed by life” (Berlant 2008, 20). Through support exchanges, IVF influencers’ pages become sites of emotional continuity where followers can expect to gain support either directly or indirectly by involving themselves in the economy of the intimate public.

#### A Shared Journey with Boundaries

The third theme recognizes that IVF influencers share their journeys with their followers— with limits. Extracts that fall under this theme highlight the challenges IVF influencers face as they negotiate the public nature of their accounts while they undergo an emotionally and physically taxing process. Different influencers choose to engage in sharing their IVF experiences in different ways. Most IVF influencers share their journeys with their followers by posting updates on the IVF process. Some post updates containing specific post-transfer lab values to keep their followers in the know.

“I had my beta blood test on Friday and my fertility clinic called with the news that my hcg was 94 at 10 days post transfer. I know a lot of people have a higher beta than that, but I’m happy with that number.” (Influencer 1)

Updates range in emotional tone. IVF influencers often post updates related to their journey, good or bad. As figures whose journeys are public, these updates also include sharing failed IVF cycles.

“And just like that, the hope and the excitement is gone! Another cycle we were keeping a secret. In hope that we could say “SURPRISE! We are pregnant” Another cycles failed. Although this time we didn’t even get a chance to onboard a little baby.” (Influencer 8)

Challenging updates often take on a narrative form. These posts communicate the struggle the poster has had with IVF and infertility. By sharing their candid feelings, IVF influencers open a safe space for others to share their similar experiences.

“Infertility has eaten me alive. It has gobbled me up and spit me out over and over again. It has changed my identity, my outlook on life, my relationships and my life path. Infertility messes with your mind. It can cause self doubt, self loathing, blame, depression, fear, panic, and anxiety. It takes you to a dark place, and no one else, other than those who have experienced it, knows how lonely it feels.” (Influencer 4)

With how personal the stories IVF influencers share are, some influencers set boundaries with their followers. These boundaries are typically related to updates about the IVF process. Influencers set time frames on when they will share certain details or results, creating a line between what is public and private about their journeys.

“As far as transfer, I’m going to be waiting a little bit (couple months) but will keep you guys updated of course” (Influencer 2)

Some influencers express justifications and apologize for their boundaries, while others simply assert their limits.

“Sorry for making you guys wait for the results but was so nice privately celebrating these little wins just us two.” (Influencer 2)

“With that being said, [redacted name] and I have decided to preserve the outcome of this embryo transfer and keep the results private until we’re ready to share.” (Influencer 11)



In sum, while IVF influencers share intimate aspects of their experiences, they also impose limits on their relationships with their followers. This theme can be understood through the communication privacy management (CPM) theory (Petronio and Durham 2015). CPM theory deals with how people conceal and disclose private information about themselves with others (Petronio and Durham 2015, 465). Fundamentally, CPM argues that people draw boundaries between what is public and private about their lives in order to manage what information is shared with others (Petronio and Durham 2015, 469). Across this theme, influencers can be seen negotiating what is public and private about their experiences with IVF, or, in other words, managing their intimate publics. Berlant claims that intimate publics can mediate “what is hard to manage in the lived real—social antagonisms, exploitation, compromised intimacies, the attrition of life” (Berlant 2008, 5). IVF influencers navigate a delicate balance as they build intimate publics. While some updates make the intimate parts of IVF such as failed cycles and laboratory test values public, other updates serve as boundaries to establish privacy. Boundaries create a line between the lived real and the intimate public, that is, they grant IVF influencers autonomy and control over information exchange within the communities they build. These boundaries allow influencers to control what others know about their journeys, despite the significant exposure their IVF experiences receive.

#### Conclusion:

Overall, the posts included in this study convey the nuances and mechanisms of how Instagram IVF influencers navigate their roles as public figures who post intimate details of their lives. Through the process of creating intimate publics, IVF influencers form relationships with their followers. With these virtual relationships come hallmarks of traditional relationships such as sharing personal information, establishing boundaries, supporting one another, and interacting with each other. IVF influencers perform intimacy to build these relationships by sharing details

of their journeys and creating lines of communication with their followers. Doing intimacy creates a space where their followers can find shared identification and belonging. At the same time, influencers retain control over their privacy by creating boundaries with their followers to limit the release of information about some parts of their experiences.

## Chapter Five

### *Influencer Case Study*

In this chapter, I present a case study of one Instagram IVF influencer, Nancy, who uses her platform with the explicit intention of community building. Nancy's Instagram has between 50,000 and 75,000 followers, and her content primarily focuses on advocacy and support for women who are infertile. My interview with Nancy provides a greater understanding of why IVF and infertility influencers have risen to popularity on Instagram. I argue that IVF and infertility influencers build their platforms out of a lack of connection and support from others within their offline communities and ultimately use their platforms as a way to find others going through a similar experience and derive support from them. The theme of reciprocal support identified in the previous chapter continues here. Influencers view their role within the community on Instagram as supporters rather than decision influencers; gaining followers and becoming an influencer is secondary to the desire to find support and build a community.

#### Silence

Nancy was drawn to share her story with others online as a result of the years of isolation she went through dealing with infertility on her own. Silence and isolation were defining features of her experience with infertility in the years before beginning her Instagram account. Her isolation was compounded by social expectations for people her age:

“I've been going through infertility since 2010, about a year after I got married, and, literally, nobody I knew was going through it. I was only 26, when I was diagnosed. Unexplained infertility was my diagnosis, and I was also one of the first few of my friends that started wanting to start having a family. So none of that was like, even a thought [for Nancy's friends]. So I went on for years and didn't talk about it. My husband

didn't want to talk about it. And it just kind of became this really heavy, heavy, heavy weight, that at some point, I just knew I needed to get out because I didn't know how else to deal with it. And I was like, I'm not going to start calling every single one of my friends and tell them what's going on, nor do I feel like they have the time to like, listen to everything that had happened in the past. At that point, I think it was about eight years of like, not talking.”

Because they were in their mid-twentys, Nancy had a sense that people in her group of friends would not understand what she was going through or feeling after being diagnosed with unexplained infertility. Wanting to start a family at that age was not the norm within her social circle, so Nancy kept her diagnosis to herself. Beyond her friend group, Nancy and her husband did not discuss infertility. As a result, Nancy dealt with the diagnosis of unexplained infertility on her own in silence for almost a decade.

The sustained silence and isolation Nancy faced is not unusual among women diagnosed with infertility. Infertility threatens one's alignment with a normative identity within society and positions them as an outsider. In Nancy's case, talking about *wanting* to have children was not conventional for people her age. Others who were not yet thinking about having children likely would not understand the emotional weight of being diagnosed with infertility. Silence acted as a form of identity management for Nancy, allowing her to externally maintain the identity she had before being diagnosed with infertility. For many other women, silence surrounding infertility originates from the stigmatization of infertility and the expectation of childbearing for women (Taebi et al. 2021, Yao, Chan, and Chan 2017, 69, and Whiteford and Gonzalez 1995, 28). In both cases, silence is a response to social expectations of what one's reproductive life should look like. Silence acts as a protective factor for women diagnosed with infertility by allowing them to retain a normative identity within their social groups.

None of Nancy's friends knew what she was going through until she reached a point where the weight of the silence was unbearable, and she felt as though she needed to share her story. At that point, she still did not feel like she could talk about it with people in her life, so she decided to share her story online through a blog:

“Um, so I decided to write a blog and I wrote about like, 10 essays off the get go. Just like different topics: miscarriage, on what it does to marriage, on all this other stuff. Um, and then one of my friends was like, oh, you should, you know, put it on Instagram, because how else are people going to see it? And I was like, I don't know, because, I'm not, wasn't that into Instagram and everything. And anyway, so I said, sure. And I opened up a page, and just kind of started sharing, you know, one blog a week, and then I realized that there was a huge community and how much support I was feeling. So I thought if I could just continue to share, maybe there's other women like me, who, you know, don't feel comfortable talking and didn't want to, you know, open up yet, but still are looking for that support system. So that's kind of where I came in. And in turn, it kind of became very therapeutic for me, and it still is. And then I hope that I'm helping, you know, one or two people a day, if that.”

The lack of support in her offline world drove Nancy to begin sharing her story with others online after years of silence about being infertile. Nancy found an outlet through blogging about the impact infertility had on all dimensions of her life. Creating an Instagram account gave Nancy's writing more exposure and publicity. Through this exposure, Nancy became embedded into a community of people sharing their experiences with infertility and IVF on Instagram. The community on Instagram gave Nancy the support she needed and was unable to find offline. By posting her story on Instagram and finding a community of others going through a similar experience, Nancy was able to find her voice despite the years of silence she experienced.

Nancy used her platform to navigate her experience with infertility by forming connections with others who understood what she was going through. In terms of her personal journey through infertility and how impactful Instagram has been for her, Nancy said:

“Um, dramatically. I mean, I think it's been, like one of the most amazing things not and not necessarily like the numbers, you know what I mean, but just in general feeling connected. Because I thought I was like, one of the only ones out there my age, at that time, like trying to have a baby and couldn't and I felt ashamed and being able to see that there are so many women who feel the exact same way, and some men is pretty awesome. You know, it sucks. I mean, nobody wants to be in this situation. But it has really allowed for me to have an outlet.”

The way Nancy uses her platform to navigate infertility highlights the importance of social support. Posting on Instagram allowed her to break through the wall of silence around infertility in her life. Nancy references the shame and isolation she felt going through infertility alone. Discovering that others her age were speaking openly about infertility on Instagram allowed Nancy to find connection and support from others. Additionally, Nancy runs her platform with the mission of creating community rather than focusing on the numbers. For Nancy, Instagram acts as a positive coping mechanism in offering her an outlet for her feelings and social support.

Through the community she has created on Instagram, some of Nancy's relationships have transitioned to in-person friendships. Nancy described developing relationships with her followers that now exist offline:

“I've actually made a couple of really, really, really, really good friends. One that I've actually traveled, just traveled to [city] to see this past weekend. And I, you know, we've traveled to each other, probably like, four or five times in the past two years. So I've

definitely made a couple of very, very, very close friends. And I feel like you just kind of know, okay, this is like somebody that is going to be a good friend and I, there's just the universe connecting us... I find that a lot of women, you know, that have that are doing this also kind of do that too you know, they ended up finding like a couple of really close friends through here, which is really cool.”

By traveling to see friends she made through her platform on Instagram, Nancy’s engagement with her Instagram community extends offline. She notes that other women who post about their experiences with IVF and infertility have similar experiences with making close friends through their platforms. Meeting up with others allows Nancy to further resist the silence she went through by providing the opportunity to bring discussion about infertility and IVF offline.

In her work on the production and reproduction of silence around infertility in Ireland, anthropologist Jill Allison found that silence protects the privacy of individuals while simultaneously maintaining the status quo of fertility as the norm for women (Allison 2011). The silence around infertility in Ireland parallels its production in the United States. Allison makes the case that silence is maintained in Ireland as a result of heteronormative Catholic expressions of “traditional” families being directly inscribed into the Irish constitution (Allison 2011, 4-5). The Irish constitution places a firm emphasis on motherhood and the nuclear family, which effectively designates childless couples as incongruent with the fabric of society (Allison 2011, 6). Although the United States does not have a direct pronouncement of the nuclear family as an expectation, pronatalism is deeply embedded within legal and political discussions. Anna Gotlib, a philosopher of bioethics, asserts that pronatalist political rhetoric combined with laws that express “pro-family” and “traditional” values has led to the fetishization of motherhood within the United States (Gotlib 2016, 332-336). Moreover, Gotlib claims that the fetishization of

motherhood “valorizes a single aspect of a woman’s life as entirely constitutive of her personhood itself” and positions childless women as social deviants (Gotlib 2016, 332, 340). For infertile women in the United States, the legal and political mechanisms that ingrain childbearing as the norm for women cultivate a culture of silence about infertility comparable to the culture of silence identified by Allison in Ireland.

Furthermore, in both contexts, digital support is used as a medium for connecting with others. Allison argues that cyber infertility forums used by Irish women seeking support through infertility blur the line between private and public as women use these sites to anonymously share their experiences (Allison 2011, 15). However, within these sites of communication, silence is still reproduced as these forums create “private, closed, and secretive relationships” through their reliance on anonymity to maintain the privacy and confidentiality of posters’ lives (Allison 2011, 15-17). While the Instagram accounts of IVF influencers typically are not anonymous, their platforms share similarities with cyber forums researched by Allison. By virtue of attaching their real names and faces to their accounts, the dialogue that takes place through the accounts of IVF influencers is not silent as in the anonymous forums. Nonetheless, both sites of discussion provide participants with opportunities to engage in “communication, community, and sharing of information, experiences, and frustrations” (Allison 2011, 14). Similar to the experience of Nancy in finding close friends through her platform, Allison notes that despite the anonymity of infertility forums, sometimes people will discover that someone they regularly communicate with through the forums lives near them and they will connect with each other in real life (Allison 2011, 16). Allison uses this example as a way in which silence on the topic of infertility is challenged and broken (Allison 2011, 16). Akin to how Instagram is used by IVF influencers to make connections with others who are struggling with a similar experience, the



use of online forums among infertile Irish women allows them to defy the expectation of silence by providing them with a space to build meaningful relationships that may transition offline.

### Instagram Accounts as Intimate Publics

Nancy views her role within the infertility and IVF community on Instagram as a supporter of others rather than an influencer of their decisions. Nancy described consistent communication with her followers:

“...everybody always writes to me it's funny, because I'll get messages and then I'll write back and people are like, Oh, my God, thank you for writing back. I didn't think you would, and I'm like, why, you know, and I guess, I guess there's a lot of like, people are with, you know, a handful of followers that don't reply back. And you know, it's fine. It's, I get it. I've written to those people and never heard back and never thought twice about it. But it's, it's interesting to me that I always get that I get that at least once a day from somebody saying, well, thank you for getting back to me, and I'm just like, How can I not? You know, it's kind of my way of paying it forward for getting my kids earthside is kind of what I see it as.”

Nancy's Instagram account is an intimate public where she shares details about her life and journey through IVF and infertility. As such, she has built a community and network of followers who are going through similar experiences. The community itself provides support to her followers, but more directly, Nancy provides active support to her followers by maintaining an open line of communication via direct messages. The reciprocity between Nancy's followers' engagement with her life and vice versa suggests that the relationships Nancy's followers have with her are not one-sided. Her dedication to maintaining an open channel of one-on-one communication with her followers establishes the basis for the closeness she has with her followers. Nancy also describes a desire to get to know her followers on a deeper level while

acknowledging that it is unrealistic due to the size of her following. Her desire to not only share her life with her followers but to also learn about their lives further separates Nancy's relationship with her followers from the parasocial model.

The communication between Nancy and her followers has allowed her to create a social world. A social world is not defined by place or boundaries, but rather by "effective communication" (Strauss 1978, 217). Social worlds exist at various scales (Strauss 1978, 217). The Instagram app itself is not a social world. Although Instagram provides a means for effective communication, social worlds hinge on "regularized mutual response" (Strauss 1978, 217). Instagram users can create social worlds through communication with others. Nancy noted that her followers are often surprised when she responds to their messages, suggesting that other influencers they message do not respond to them. She describes personally having similar experiences attempting to establish a line of communication with other influencers and not receiving a response. Nancy's dedication to maintaining effective communication with her followers sets her platform apart from those of other influencers. By regularly responding to her followers messages and interacting with them, Nancy has built a social world through her platform.

In "The Female Complaint," Lauren Berlant describes "women's culture" in the United States and its production of intimate publics. Lauren Berlant's definition of intimate publics aptly captures the social world-making of Instagram IVF and infertility influencers: "...it flourishes as a porous, affective scene of identification among strangers that promises a certain experience of belonging and provides a complex of consolation, confirmation, discipline, and discussion about how to live as an *x*" (Berlant 2008, viii). Berlant's work focuses on the proliferation of "women's culture" through mass media and the intimate public of femininity it creates (Berlant 2008, 12). In chapter seven, Berlant analyzes the production of a women's intimate public through the

genre of romance. Berlant describes the romance genre as a “negotiation of desire and institution (marriage, reproduction, property, dynasty, nation)...intensively both with the fantastic unreal and the real that constitutes what “a life” should be, especially for women” (Berlant 2008, 259). Furthermore, Berlant highlights the role of “the plot of optimism for the iconic *thing*” within romance as a critical aspect of the women’s intimate public (Berlant 2008, 263).

The intimate publics created by IVF influencers on Instagram resemble the women’s intimate public created by mass media that Lauren Berlant chronicles. Moreover, the Instagram intimate publics bear a resemblance to Berlant’s analysis of the genre of romance. Through their Instagram platforms, influencers share vulnerable stories of their experiences with IVF and infertility, shattering the silence that is expected in the offline world. These accounts often detail the owner’s journey through negotiating their desire for a child with their marking as “other” by society for struggling to conceive. For these influencers, the iconic *thing* is having a child, with motherhood constituting what a life should be.

By sharing the intimate details of their stories, influencers create a site where complex networks of relationality are built. Berlant notes that insider conversations about “details of women’s situation and the strategies of survival and affect management emerging from it” are crucial to the formation of the women’s intimate public (Berlant 2008, 233). This sentiment is reflected in the ways influencers communicate with their followers. For Nancy, regular communication via direct messages allows her to build connections with her followers by providing them with support from her personal experience. Additionally, her public openness about infertility and IVF, the desire to obtain the iconic *thing*, may encourage others who are still covered by the shield of silence around infertility to speak out knowing that their experience is shared with others who understand what it means to live as someone who is infertile. These sites

then become marked by a shared identity, leading to a sense of belonging and understanding among strangers.

## **Conclusion**

In all, IVF and infertility Instagram influencers build their platforms out of a need for support and community. Finding support from offline social networks is difficult as infertility changes a person's identity and self-concept. Moreover, in a pronatalist society such as the United States, childbearing is often the assumed path for women, and women who deviate from the norm are stigmatized. Silence around infertility emerges as both strategic and debilitating. Women who are infertile may choose not to disclose this with their social groups as a form of identity-management. Additionally, silence can act as a shield which protects these women from potentially insensitive and triggering conversations about reproduction. Eventually, however, a need to speak out and find support from others who understand develops, as in the case of Nancy. IVF and infertility influencers create intimate publics through their platforms by sharing vulnerable details of their experiences. This act draws others who are going through similar situations to break their offline silence online. As a result, a collective identity is formed, and members of the community feel a sense of belonging and understanding. The support is reciprocal; influencers find support for their own journeys through others within the communities they have built while simultaneously providing support to their followers. Finally, Nancy provided interesting insight into the role of infertility influencers. Infertility and IVF influencers do not necessarily influence the decision-making of others. Instead, they are community leaders who provide support and encouragement to their followers. Although their accounts often have large numbers of followers, growing their platforms in terms of numbers is secondary to the act of supporting others going through a challenging time in their lives.

## Conclusion

At the beginning of this research, I embarked on a journey into the world of IVF and infertility influencers with the expectation that their role within their niche on Instagram would mimic that of the standard influencer. However, as chapter five demonstrates, the work of these influencers is unique and emerges from social, political, and cultural norms that silence the experience of infertility. IVF influencers on Instagram build their platforms out of a lack of understanding for their reproductive difficulties in their offline worlds. By sharing their stories on Instagram, influencers resist the expectation of silence that permeates their lives offline. Consequently, the accounts of influencers act as intimate publics, spaces where personal lives become public and commonalities between participants are present. Influencers' followers participate in the intimate publics by sharing their own stories and support in the comment sections of their posts. Moreover, influencers provide support to their followers through active communication over direct messages. These actions allow influencers and their followers to obtain support and understanding despite the silence surrounding infertility offline. Influencers form reciprocal friendships with their followers that sometimes move off of Instagram and into the brick-and-mortar world. As such, communities based on shared lived experience emerge out of the platforms of influencers.

Social media infertility communities are an uncharted field for ethnographic research. I hope that in the future, I can continue to uncover more about the importance of these communities. Several new lines of investigation have emerged for me. Do members of the communities feel that their relationships with the influencers are reciprocal? What draws participants to begin interacting with influencers? While I began to explore the history of IVF and the medicalization of infertility, I did not dive into the political nature of infertility and

ARTs. How do influencers navigate the politics of infertility? Why or why don't influencers post about reproductive politics? As Instagram continues to grow, understanding the modes of sociality that arise from the app becomes more important. The case of Instagram infertility influencers highlights the way Instagram allows people to be their fullest authentic selves in spite of social expectations of silence.

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