

#ttc on Instagram: a multimodal discourse analysis of the treatment experience of patients pursuing *in vitro* fertilization

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ABSTRACT

While searching the Internet for health information is now commonplace, giving and receiving medical expertise on social media platforms such as Instagram (IG) is underexplored. In order to investigate the ways in which social media platforms are a resource for seeking medical expertise, we employed a multimodal discourse analysis; specifically, we focused on the hashtag #ttc and the engagement of the IG community it comprised. We examined three main themes around medical expertise during treatment indexed by the hashtag: treatment protocol choices, treatment side effects and pregnancy diagnosis/confirmation. Our findings suggest that social media platforms provide a new arena in which patients can challenge medical expertise by circumventing it or adopting lay expertise instead of practitioner suggestions. We close with research implications and suggestions for further research.

Introduction

In October 2016, Instagram (IG) User 1 received an email from a nurse at the Reproductive Endocrinology and Infertility (REI) clinic where she underwent a suc-

cessful fertility treatment and was monitoring an early pregnancy (user names related to images have been anonymized as User 1, 2, 3, *etc.*). At 2:15 p.m., User 1 read this email, captured it with a smartphone and by 2:19 p.m. posted it on her IG account without any identifying information redacted. User 1's image caption responded to the nurse's comment, "sorry for the typo" with "Typo... that's a pretty big, can cause you to miscarry the baby, typo. Ack. This does not help my anxiety at all."

The comment section below the image (Figure 1) of the email and the caption included references to institutional health systems, encouraging messages about self-advocacy, individuals sharing their own treatment horror stories and a series of emoji. The hashtags used by User 1 made this post searchable by millions of IG followers, despite the nurse's full name and the user's full legal name (not the IG account name) listed in the image. It is not clear whether User 1 shared their concerns directly with the nurse and the REI practice in question, or isolated their reaction to their account on this social media platform. It is evident that a semiotic act occurred in this post, in that the discourse (*e.g.*, through images, texts), both symbolically and literally (re)created meaning. Here, the images, text and hypertext – individually and taken together – reflect the determined agency of a patient challenging the rhetoric of passivity, and signaling to the viewing audience that in the age of social media, medical mistakes or misinformation can be posted and enter the public record. The poster is raising awareness of medical errors that can and do occur; to blindly trust medical staff is unwise. The post operates as a kind of threat as well – the public airing of these errors could have professional and monetary consequences for REI practices.

Examining the post semiotically (through the study of signs and symbols and their meanings) offers ample material in the responses to this post (*e.g.*, hashtagging and

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dialogue). Multimodal discourses (textual, visual, inter-textual, hypertextual) confirm that account followers understood the aims of the post, promising to increase their own attentiveness to treatment protocol, calling out health systems where they supposed this type of error would occur and encouraging other readers to be aware, with one user concluding “now you’ll be questioning everything I bet.” Infertility remains a pressing concern for individuals struggling to create a family, just as it was over a century ago. Yet today, individuals can share their experiences with hundreds, thousands or millions of strangers in real time. The result is a unique type of intimacy, one that infertile individuals did not have access to previously.

Since 1878, estimates of infertility rates have hovered between 9%-11% for heterosexual couples, with outliers ranging from 6% to 20%.¹⁻³ Currently, the Centers for Disease Control (CDC) estimates that “12% of women aged 15-44 years”,⁴ will experience infertility, while the National Institute of Child Health and Human Development estimates “9% of men and 11% of women”,⁵ and the World Health Organization (WHO) project “10% of women” will experience this condition. The CDC and WHO define infertility as occurring after 12 months of

unprotected, heterosexual sex between two cis partners. Similar to the variety of percentages available infertility is described using a wide range of definitions, framing the issue as anatomical, physiological, or a reflection of demography.⁶ Infertility remains a persistent health challenge despite advances in treatment including *in vitro* fertilization (IVF), intra-cytoplasmic sperm injection (ICSI) and genetic testing for embryos, which emerged by the late 20th century.^{7,8} The Mayo Clinic defines IVF as “a complex series of procedures used to treat fertility or genetic problems and assist with the conception of a child” (n.p.). During IVF, mature eggs are retrieved from the ovaries and fertilized with sperm in the lab setting. Later (e.g., 3, 5, or 6 days), the embryos are placed into your uterus. As for ICSI (pronounced *icksy*), this procedure resulted from the successful experiments of Dr. Gianpiero Palermo, who manually fertilized one egg with one sperm in 1992.⁹

Regardless of availability, treatment (with or without medication) is expensive and many insurance companies do not offer sufficient coverage.^{7,10,11} Aside from the procedural cost, medicines can cause uncomfortable side effects, and treatment cycles dictate schedules, placing

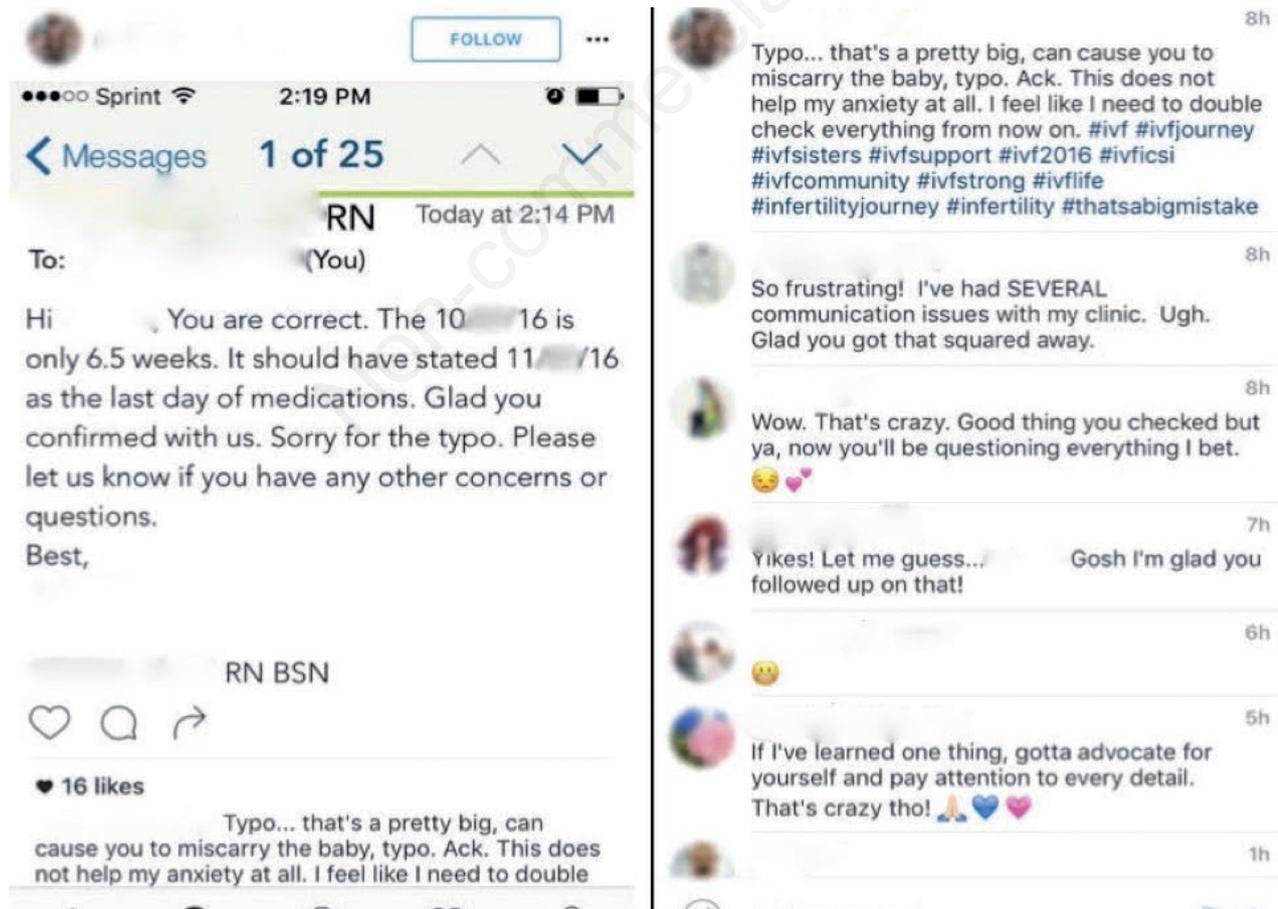


Figure 1. Reproductive endocrinology and infertility practice error.

social and emotional pressures on familial and other interpersonal relationships; patients often feel isolated, which can increase anxiety.^{8,11-17}

This isolation can result from the difficulty of the treatments (e.g., cost, side effects), but also from a lack of agreement among researchers, medical practitioners and patients on language framing and describing diagnosis and treatment. For example, physicians may reference *fertility treatments* for an infertility diagnosis, even when that diagnosis is *unexplained*. Inversely, some patients never self-identify as *infertile* or never receive a formal diagnosis yet undergo *fertility treatments*. Individuals may conceptualize infertility as a journey, a condition, a disease, or even a social construct and choose language that constitutes their perspective and experiences. Therefore, definitions of infertility are contextual: shaped by individual and social constructs, embedded in systems of oppression.^{7,10-12} For example, it is not necessary to link motherhood to any individual of any gender identity,¹² yet the inability to conceive is still framed as a female problem as cis women are assumed to be *natural* mothers.^{7,11} Further, the technical definitions presented by many organizations maintain a heteronormative, cis-gender focus that does not address possible infertility experiences of LGBTQIA+ couples and/or individuals.^{12,18} Given the difficulties in describing and defining infertility and the experience of fertility treatment(s), individuals who are already using social media are turning to applications (apps) like IG and Facebook to discuss treatments, ask questions about doctors and supportive therapies and offer and receive emotional support.¹²

In our book, *You're Doing it Wrong! Mothering, Media, and Medical Expertise*,¹² we examined the impact of social media platforms on the conversation around infertility diagnosis and treatment; specifically, the long history of the phrase *just relax*, including how medical language shifted throughout the last century to maintain the notion that female patients could mentally control their fertility. We traced this pattern into the present, where we found it populating the methods of alternative practitioners, social media influencers and even traditional doctors on blogs, YouTube, social media platforms and products like eCourses for fertility. Responding to our own call for future research, we investigated communication around infertility treatment on social media. In this study, we observed the unique ways medical expertise was exchanged on IG before, during and/or after IVF treatments. The multimodal capacity of social media platforms like IG allows users to index multiple layers of information and experience by way of a single post, availing themselves of multiple discursive resources at once. In turn, these semiotic practices are recontextualized as the spoken discourse dynamics of healthcare, providing patients new strategies and vocabularies to introduce into their practitioner-patient relationships.

Social media use for health information

While the earliest conceptualizations, frameworks, and algorithms for what became today's social media landscape were well underway by 1965, the coding for the World Wide Web was not available until 1991. Between 1991 and today, the majority of individuals in America gained access to the Internet, web search engines and social media platforms, mainly through hand-held devices known as smartphones.¹³⁻²¹ After the advent of the Internet and before the popularity of social media, scholars began investigating movements of individual users navigating health information collected by search engines as they sought advice and expertise online.²²⁻²⁴ Initially, Internet use focused on desktop computers, and then more portable laptops.¹⁹ Today, individuals favor smartphones; as of January 2014, 56% of American adults own a smartphone.²⁵ The prevalence of smartphone use drastically increased mobile, instant, interactive communication through social networking. Today, smartphones redirect health information gathering to smartphone apps and social media platforms.^{13,26,27}

Instagram

IG, one of many available social media content-sharing platforms, is now the second most used, with over 700 million active users.²⁵ Instagram launched a mere six years ago and quickly became popular because of its photo-forward character and easy editing features.²⁸ In its first three years, IG amassed more than 150 million followers and was purchased for more than \$1 billion by Facebook.²⁸ Users post more than 95 million photographs per day and "like" 4.2 billion times each day.²⁵ To use IG, individuals or groups represented by an account (i.e., *Users*) can upload (i.e., *post*) photographs, videos, comments, hashtags, links, and other materials (i.e., *User content*). Instagram is designed for smartphone use, since photographs, videos, text and hashtags can only be posted and hyperlinked via the mobile application.

While early Internet adopters preferred search engines and WebMD,^{29,30} *millennial parents* (and those seeking to be parents), "spent their formative years steeped in personal technology," according to Bruce Feiler of the *New York Times*.³¹ As adults, this demographic favors smartphones and other portable devices (Apple watch, etc.) to access social media platforms and a range of smartphone apps.^{26,31,32} Recent research supports the idea that parents today seek information specific to parenting, including medical expertise for their babies and young children.^{26,27,32} Deborah Lupton² addressed smartphone apps used specifically by mothers to monitor their pregnancies and the behavioral patterns and health data of their young infants (e.g., eating and sleeping times, weight). Gender scholar Sophia Johnson²⁶ referred to the *device-ification of motherhood*, an intrusion by and integration of social media platforms in the everyday lives of mother and child

through smartphone apps, tablets and mobile devices.²⁶ In agreement with Lupton,² we also observed the increasing dataveillance integral to mothering with young children and the shift from *Dr. Google* and WebMD and toward social media and interactive apps. In our book, we investigated the ways motherhood and mothering begin earlier and earlier, now including pre-conception. With that, expectations for behavior and approaches to conception require engagement in cultural scripts surrounding mothering.¹²

Not surprisingly, the research underscores the pervasive influence of social media platforms such as Facebook, IG, Twitter and others on day-to-day interactions, including seeking medical expertise.^{26,27,33-35} Surprisingly, IG also provides a space for sharing or resisting medical expertise. During infertility treatments, individuals hoping to conceive or partner with a surrogate engage IG as a space to interrogate medical protocols, seek lay expertise on medical decisions, exchange medicines and engage in a semiotic community, bounded by unique acronyms, language constructions and hashtagging patterns. The interactions popular on IG (e.g., hashtagging, tagging accounts, etc.) are *affordances* or aspects of usage and design that assist users in finding popular posts and content with which to engage.

Experts and those who seek medical expertise and health information continue to assess the utility of hashtags, a word or short phrase (without spaces) beginning with a #, which creates a digital *tag* associated with a user's post; this is a type of affordance. Hashtags can be used across social media platforms, including Facebook and Twitter. On IG, servers use hashtag metadata to group similar posts, make posts searchable, and track popular themes. For users, hashtags encourage the creation of niche groups within IG, referred to as a hashtag public.^{36,37} For example, in this study, hashtag use on IG guided members of the #ttc (*trying to conceive*) community to medical expertise on IVF. Hashtag publics assign a connotative, relational context to certain words, phrases or acronyms that represent meanings shared among members, which are then signified by the hashtag.^{37,38} Hashtag publics may also use hashtags in a way that differs from the denotative meaning of the term or phrase such as #fail representing a social mishap or embarrassing moment rather than unsatisfactory performance.^{39,40} The social impact of hashtags is significant, as they now appear in everyday language, when a person might say aloud, "hashtag *tired!*" Hashtag publics can also act as counterpublics for users who resist normative ideologies and narratives (e.g., trans individuals using hashtags such as #trans and #transgender with uses in the millions).^{30,37,38} Irrespective of the narrative, hashtags are integrated within the text posted with images, so through these embedded hashtags, members are connected to the information they are seeking. Currently, scholars are studying the use of hashtags to understand better how hashtag users find or distribute health information and medical expertise.⁴¹⁻⁴⁴

Originally purposed as topical markers, the first hashtag appeared in an August 2007 tweet by Twitter co-founder Chris Messina.⁴⁵ Hashtags are now used to represent a range of meanings in various social media messages, those these meanings vary and remain contested. Scholars analyzing semiotics on social media platforms refer to hashtagged text as *hypertextual* and view affordances either as intertextual elements emergent from or built within platform designs. In online domains, intertextuality could be seen as the connection between texts and other pages of the same website through hypertextuality (e.g., hyperlinks, icons, or buttons), where this hypertextuality is *site-internal*.³⁸⁻⁴⁰ *Hashtag publics* coalesce around the use of these hypertextual tags, which further bound, define and redefine these groups as they create meaning together.^{33,35-37}

With consideration to Barthes' traditional explanation of semiotics – where the signified and signifier develop signs – hashtags act as a signifier where the signified is the underlying meaning of the word or phrase.⁴⁶ A hashtag is a semiotic act, and as such, illustrates that hashtags hold socially constructed meanings.^{38,47,48} A hashtag acts as a marker, guide and record on social media platforms, signifying a distinct, constructed meaning that is understood and used by a hashtag public, bounding that public and signaling community and social similarity to potential members.^{42-44,47} For example, the hashtag #ttc could represent several different acronyms. However, when it is paired with #infertility, it is understood to mean *trying to conceive*; in that usage, those trying to conceive through infertility treatments will find accounts to follow by searching or engaging with the hypertext of that usage.

To guide our study, we explored how medical expertise was communicated, negotiated and exchanged within the infertility/#ttc community. We considered the importance and increasing use of social media platforms to seek medical expertise and how these exchanges (both intertextual and hypertextual) function within the particular hashtag public of the infertility/#ttc community.

Materials and Methods

In our study of Instagram, we utilized Kress and van Leeuwen's⁴⁹ multimodal discourse analysis framework⁵⁰ because it allowed us to explore the complex interrelations of social media discourse. With the rise of social media platforms as sources of news and information, including health and medical information, a multimodal discourse analysis allowed the authors to examine the text, image as intertext, and hypertext (e.g., hashtags), both separately and together.^{37,47} As Berger⁵¹ discussed well before the advent of the Internet, images are as important as texts since they also contain multiple meanings, communicate with and impact the viewer in varying ways.

Mitchell⁵² urged scholars to recognize the ways im-

ages can be understood as a kind of language. Later, he referred to *imagetexts*;⁵³ Jensen⁵⁴ explained imagetexts in her work on blogs, noting that “visual images are often read using text, associative images are generally accompanied by text, and more often than not, text and images are presented together (p. 4). As Jensen⁵⁴ argued, websites provide the rich material with which to examine *hypertextual arguments* (p. 4) given that images and text appear together in new and revolutionary ways. When performing a multimodal discourse analysis on an image-forward social media platform like IG, the notion of *imagetexts* is useful. And while imagetext allows for the investigation of both text and image, multimodal discourse analysis goes further, by engaging intertextual and hypertextual relationships as well, including text that is *live* or linked to other locations or accounts on social media platforms. As Miller⁴⁷ argued, multimodality closely parallels hypertextuality and intertextuality which were both integral to our analysis. We were interested in how texts develop throughout the analysis period (e.g., two weeks) and, as comments collect under images, references to other texts and digital hyperlinks emerged. As such, we monitored IG’s affordances in the design and performance functions (e.g., hashtags, comments, images, links in bio, formatting of text, and filters).⁵⁵

Data collection

After Institutional Review Board approval, the authors and another research assistant, Rachel Ayers, collected 199 IG posts between October 10th and 24th of 2016. The study’s sample consisted of IG *users* and *followers* who posted comments/info and visual media content on their own or others’ IG feeds related to a diagnosis of infertility and/or fertility treatment (Johnson received numerous infertility treatments over a period of four years; however, she did not utilize IG during this period).

The search term *infertility* was entered into IG’s hashtag search engine to identify posts related to infertility, which revealed the most popular infertility-related hashtags and formed our sample of public posts to be analyzed. We gathered individual posts through hashtag use. The research team selected hashtags with the largest number of uses that referenced REI treatment. In our first exploratory views, it became evident that a majority of the posts focused on IVF treatment cycles. As such, we narrowed the treatment focus to IVF given that it requires a serious commitment of time and monetary resources – the procedure happens throughout several months and even if there is insurance coverage, costs many thousands of dollars.^{8,15} Furthermore, patients perform much of the treatment on their own, out of the office (e.g., injections).^{8,15} The first two hashtags we chose to appear as a *set* because they are often paired in posts. We selected: i) *#ivfsisters/ #ivfcommunity*; ii) *#IVFfail/#infertilitysucks*; ii) *#ivfjourney*.

The research team also selected what we termed *outlier hashtags*, meaning hashtags that frequently accompa-

nied IVF posts, but do not always address the IVF cycle (e.g., shots of a patient on vacation). These were: i) *#ttc*; ii) *#ttcsisters*; iii) *#infertility*.

Selected posts used at least 1 of the total 7 hashtags, and a majority used 2 or more. We collected 199 images and analyzed the first 25 comments (or all if there were fewer) for types of discourse (e.g., discourse around medical expertise) and themes emerging from that overarching discourse.

Any IG user who used our searched hashtags may have appeared in this study’s sample. The specific demographics of these individuals remains unknown, given that users can reveal as little or much about themselves as they choose (e.g., age, real name, geographic location). However, individuals sometimes included specific personal information in their feeds, such as demographic location, medical status, insurance information, and doctors’ names, REI practice names, and their bioinformatics.⁵⁶ We were vigilant about privacy concerns, and thus this sampling procedure allowed us to collect the most popular public posts.^{47,57-61} We did not interact directly with participants; to further protect our participants, identifying information was blurred within images.

Once the team collected images, screenshots were taken with a smartphone and then uploaded to a secure site. Once uploaded, those images were arranged in linear rows, with the singular image and caption, then the first 25 comments (not all posts had 25 comments). Depending on the number of comments, some rows included seven images and others had as few as three. To label the images, we called each spreadsheet INSTA with a letter for each sheet, which resulted in INSTA A through INSTA J, with each row numbered and images were identified by sheet and row. For example, B-7. Our files were stored on Johnson and Quinlan’s password protected computers. Due to the high quality of the images and the number of images (posts and comments) the files were too large to email and had to be stored in a locked folder on our secure Dropbox. Once we collected enough images to populate ten spreadsheets, with comments for each image, we reached saturation. For instance, comments and posts began to repeat and no new information was gathered.

Throughout, we reviewed the data collection process to ensure we could approximate the IG experience of *scrolling* within a spreadsheet. As with other social media platforms, IG images and resulting discourse are best viewed *in situ*.⁴⁷ However, images and accounts can be deleted at any time, and the hypertextual hashtag feed changes every few seconds; to get a *snapshot* of the discourse during the two weeks of our study, we captured the images and place them in a more permanent location (e.g., a spreadsheet) for analysis.

Data analysis

As qualitative researchers, we proceeded both induc-

tively and deductively. We immersed ourselves in the data and analyzed and re-analyzed our dataset inductively, searching for commonalities and repetitions in the language, images, and intertextual and hypertextual discourse.⁴⁷ The team met on three occasions to create a system for notes and observations, to discuss themes emerging from the images, text and hypertext and to compare personal research notes and observations for reliability regarding emerging themes. The team used a series of spreadsheets from which to make notes on observations. To the far left of each spreadsheet, we used a column which listed the main and outlier hashtags for each post, as well as the number of user followers and notes. These notations and observations assisted us in distilling our themes and providing examples for each. After the team agreed on initial themes we selected representative images and blurred them to obscure personal information and potential identifiers.

We also proceeded deductively, by recording frequencies by which patterns occurred, and situating those patterns within an interpretive context for discussing our overarching themes. The major themes were classified through prioritizing, synthesizing, and abstracting.⁶² In the last reading, the researchers analyzed the intersemiotic relationships conveyed by hashtag publics such as the interaction of visual, textual and hypertextual elements, including both explicit content and implicit connotations.⁶³ To explore intertextuality and hypertextuality in our data set, we made notes on the affordances we observed (e.g., intertextual elements such as likes and emoji in response to images and/or comments) and hypertextual elements such as hashtags and tagging practices and how these elements impacted discourse around medical expertise.⁴⁷

After analyzing images, hashtags and other hypertext through up to 25 comments, the research team coded the discourse for medical expertise such as *information on reactions to (in)fertility treatment* and *evidence of pregnancy/pregnancy symptoms*. We found that the overarching discourse centered around patient perceptions of (and most often resistance to) medical expertise. Our final three themes included: treatment protocol choices, treatment side effects, and pregnancy diagnosis/confirmation. In the findings, intertextual and hypertextual data were included to provide evidence for the researchers' interpretations of semiotic signaling.^{47,64}

Results and Discussion

As a result of the availability of social media, many IG users ask for and provide medical expertise before, during and after IVF treatment and in response to posted images and accompanying text. At times, we perceived the personal struggle of individuals seeking medical expertise, projected into the public space of the social media world, and these posts were far more evocative, even discomforting. For example, the image an account holder

posted of her cervical mucus, wondering if its viscosity hinted at pregnancy. Users offered followers hypertext with hashtags, #ivfsuccess, #ivfmeds, #ivfsucks while also tagging other account holders to come back to the discourse for further engagement, or as a marker of information they may need later (e.g., after the tagged account holder started her own IVF cycle). Importantly, each of these inclusions represents particular choices of self-disclosure, and engagement with the discourse around the power of medical expertise during the IVF process. These divulgences and the paring of intertextual and hypertextual affordances (e.g., hashtags, tagging, acronym use) comprise a multimodal form of communication, which can deepen bonds between users and obscure information for outsiders not practiced in the language of IVF treatments in the #ttc community.

Treatment protocol choices

During infertility treatment, particularly IVF, different practices create and rely on particular treatment protocols, including pre-treatment tests.⁶⁵ For example, some protocols privilege certain drugs (e.g., Gonal-F®, Menopur®), some prefer freezing embryos prior to transfer, though age limits vary (e.g., some require an egg donor for cis female patients over 40), some practices prefer progesterone injections (via an injection) to creams or suppositories. Practices rely on their protocols to produce superior results (i.e., confirmed pregnancies), which they can advertise publicly to attract clientele and as a result, can be resistant to patient requests to adjust or alter the preferred protocol.^{11,65}

Against this backdrop, #ttc and IVF patients use social media platforms to ask about the protocols of others in their hashtag public, and what to discuss with their doctors, "Any suggestions for questions to ask or tests to try?" And below a post about a failed cycle a commenter offered, "...Maybe you could also do a repeat pregnancy loss panel?" Another commenter disclosed a miscarriage they experienced and the poster provided medical expertise in response, including urging specific testing and asking about hormone levels: "I am sorry to hear about your miscarriage [broken heart] did you PGS test your embryos... Don't go into your 3rd cycle without knowing of you have endometriosis...have you been tested for NK cells? APA panel? Immune issues in general? What is your TSH now?" These types of comments suggested medical expertise but also bound the community through language, acronyms and procedural references that would be confusing or opaque to outsiders, even medical practitioners outside the field of reproductive endocrinology. The implicit message is *if you know, you know*.

But posts also addressed when and how to resist doctor-mandated treatment choices. For example, one account seeks to answer protocol-based and other medical questions and in one post, focused on an *endometrial receptivity array test* or ERA. Commenters questioned whether they

would be *good* candidates for the test. However, other commenters entered the discourse to remind IG users what this test was *really* about: “Don’t forget to add that it’s basically a mock cycle so you are pumping your body with all the synthetic hormones you are just not getting the benefit of retrieving your eggs.” In these instances, individuals with unknown training and expertise sought to draw the conversation back to what could be a hurdle for many women undergoing the test: all the treatment, and no egg retrieval. The implicit connotation is if you are going through a cycle you’ll want something to show for it.

Items in images included medical instruments, medicines, supplies, and even bruised and swollen abdomens and marked injection points. Multiple images were paired with extensive commentary using the terminology of technical, medical expertise. One post included a woman pictured in her kitchen, hand on hip, head angled up at the camera with a slight smile – here, the user signaled to the viewer that she is competent, ready to perform her injection at home and armed, literally and figuratively, with the capacity and information to complete this treatment. She also complicated stereotypical ideations around infertile bodies; the user appears to be white and cis female, but she also young (early 20s?), with a full arm of tattoos and a lip ring, she signals to the viewer that she understands this tension with the hashtag #thisiswhatinfertilitylookslike. While the image might inspire confidence and is suggestive of self-sufficiency, the text confirmed this inference, while utilizing the language of medical expertise:

A lot of people have asked me what that nasal spray is for and I’m not sure my explanation was very clear. Here’s a better one: Nafarelin is a gonadotropin-releasing hormone agonist (GnRH agonist). Its proposed mechanism of action is the desensitization of pituitary GnRH receptors leading to a decrease in gonadotropin release...

Instagrammers may encounter this image, the accompanying text, and the hypertext hashtagged beneath the picture (e.g., #infertilitysucks, #ttcjourney) by searching any of these hashtags and/or through other accounts following this user. While informative, the image was also empowering, illustrating the courage and confidence one can achieve in an otherwise isolating and difficult process.

Some of the posts operated similarly to a Yelp review for fertility practices. One image has a purple background with a text bubble: “Has anyone been to Seattle IVF?” The text underneath the image read: “...I would love to hear your experiences if you’ve been there!” One commenter offered, “My cousin did and had a great experience.” A former employee from a local, competing REI practice discussed their former employer and then stated, “I hope it works out with Seattle IVF! They seem like a great company who cares about the patients more than just the \$\$\$ [heart emoji]!” Alongside this recommendation to visit Seattle IVF the poster attempted to soften the comment with symbolism – the commenter never *said* money, but the dollar sign had explicit connotations. The

heart emoji seems to offer good luck and well wishes, but it is paired with a direct critique of the way some REI employees saw their practices and their bosses. The commentary was a warning to newcomers too; at some practices, it was not altruism, it was business.

Also connected to protocols was the practice of posting pictures of medication that the IG user intends to gift, or has received from another member in the community; these posts are also hypertextual (e.g., #ivfmeds, #menopur). Regarding the use of these medications, practitioner opinions vary: some refused to participate in the practice, others understand the difficulties in paying for medicine, particularly without insurance and allow their patients leeway; others take unused medication from their patients and keep it for other patients. As User 2 reported: “I am so happy I had a doctor who bucked the rules and took all my unused meds for patients without IVF coverage” (Figure 2).

Some posters offered to ship medicine: “[lists medicines] these need to be used in the next three weeks – so if you need them, I’d love to help you out & donate them to you!! DM me so we can figure out shipment!” In the comments, some wondered about the legality of shipping medications through the mail: “Question is it legal to ship medication...I think the post office throws them out if it isn’t from a pharmacy.” The sale of medication between individuals through the mail is illegal. The sale and exchange of medications is also risky – drugs can be tampered with and sent or stored in improper temperatures. However, that is not what is happening here. Individuals are donating medications to one another, which is an important distinction. Still, shipping medications through the mail can lead to a charge of mail fraud.^{66,67} Despite the risks, the most common response to these posts are others providing offers of left-over drugs or further requests for medication: “I have some that expire next month, interested?” “I have so many left over!! Not sure what to do with them.” There was an even a partner advocating for medications: “Hi, my wife and I are starting our IVF journey and none of our meds are covered. Does anyone have any they are willing to donate?” We cannot ascertain the actual incidence of medicine exchange, but the number of posts showing gifted drugs suggested that IG posts can facilitate the practice. Regarding sharing/shipping medicines, many posters showed what they received, discussed the market value of fertility drugs, and celebrated their ability to return to treatment. The economic pressure of *Fertility, Inc.*, the biomedical system driving reproductive endocrinology today is well studied; what we discovered is that social media presents a place to explicitly and implicitly work around some of these economic constraints to maintain REI protocols, regardless of cost.^{16,68}

While the text focused on gratefulness for the medications or desires to share it with someone else, the images and hashtags do specific work here. Using hashtags such as #ivfmeds, #menopur could potentially help users track

medication donors through IG’s search engine. The images are intertextual too – they illustrated medications with valid names and packaging and are shown in decent lighting and offer users close-ups to prove they are intact, unadulterated and safe, whether or not they are. But when medicine is proffered, it is always pictured. Another reason for including a picture is that the same drug can be packaged in pens or vials and with varying doses, so a patient has to see the particular doses offered again to understand if or how it overlaps is there parallel with a patient particular protocol.

Treatment side effects

Infertility drugs can cause many side effects including weight gain and hot flashes, bloating and achiness. During IVF treatment patients take a host of these drugs simultaneously to facilitate ova growth and prepare for egg retrieval. Patients often turned to their hashtag public for expertise on side effects related to the medicine specifically (e.g., how to prepare and draw up meds for injection) and then to discuss their reactions to these drugs. Throughout this theme, the research team noted that within the comments section, users relied on symbolic imagetext like

emoji and hypertext like hashtags and account tagging, helping other users come back to the post and add to the discourse or use the information during their own treatment cycles. Altogether, these elements create an imagetext tapestry, which included numerous perspectives, sources of information and forms of knowledge, within and because of intertextual and hypertextual discourse.

One user posted a picture of their medicine in the background with a sizable needle in the foreground and asked, “anybody else had blood SPRAY out after this injection?” While the poster did not provide context, the treatment issue was implicit and commenters responded without requests for further clarification: “I hope the next one is easy peasy!” Others added their own experience and suggested varying angles or positions to lower the chance of drawing blood. There is explicit solidarity here through the expertise proposed, but also emotional support through encouragement and understanding from others that used the drug, knew what it was for and already used it safely.

Another user posted a picture of the drug [Merional®] ampoule: “so...any tips on snapping the glass so it doesn’t go everywhere?” Commenters recommended a range of

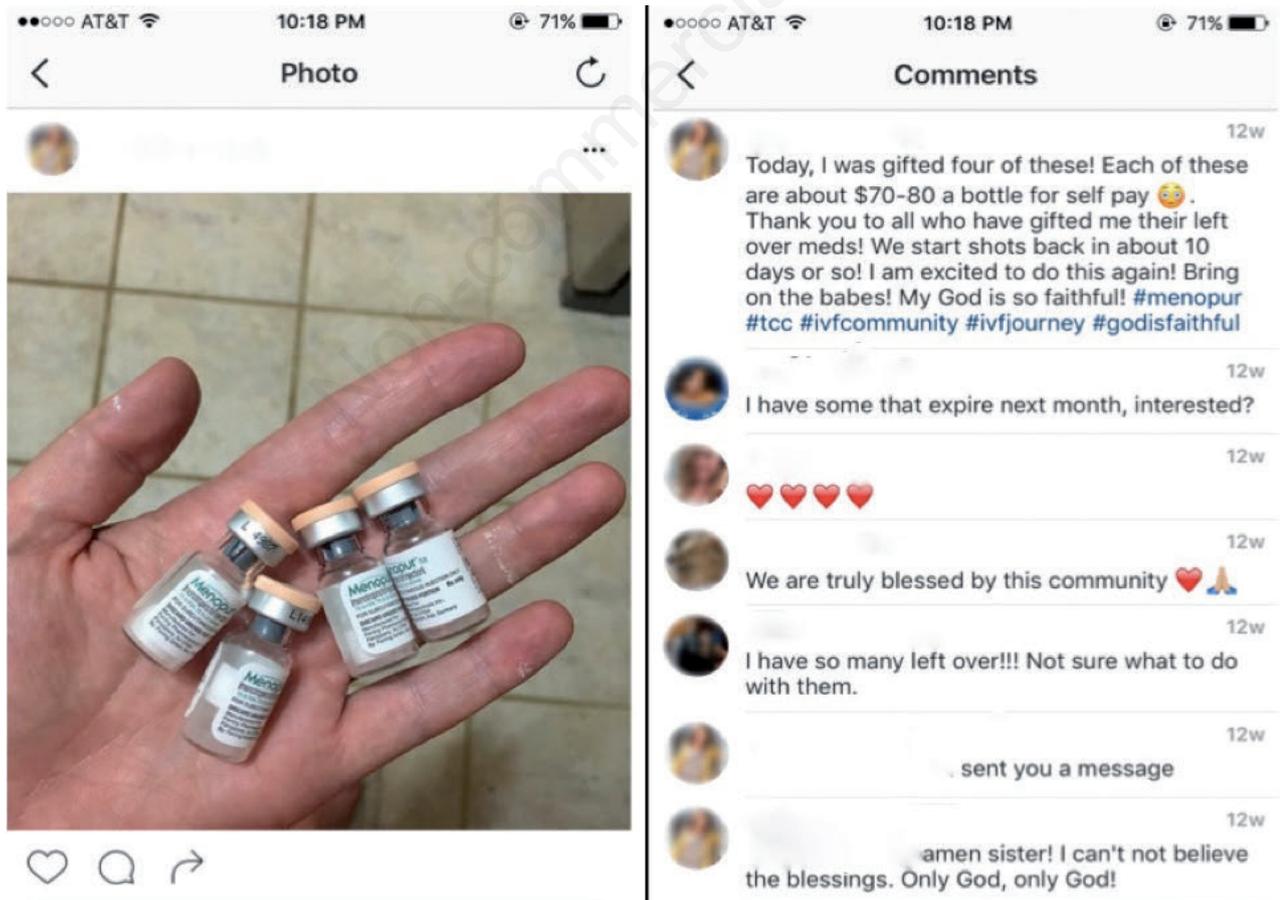


Figure 2. Medicine distribution, Menopur®.

methods and identified themselves as both patients and technical experts. One directed: “as a nurse we fold gauze (or a napkin if you don’t have gauze) and pinch the glass with the gauze over it and snap it at the line. This allowed any broken pieces to end up in the gauze and not everywhere else. Hope that made sense (blushing smiley face emoji).” The nurse cancellare gave detailed expertise but then ends with an emotive tone, symbolizing friendliness and perhaps even humility – almost an apology for her expertise – with the emoji.

One IG poster bemoaned the “revenge of teenage acne/IVF problem spots” and shared her journey from great skin to acne as a result of IVF treatment. In the image, she displayed *before* and *after* pictures, but showing regression, with what appeared to be flawless skin to skin with obvious blemishes. The user linked 20 hashtags in her post, among them: *ivfsupport*, *ivfmeds*, *etc.*, *ivfwith-icsi* and *shareyourstory*. The poster uses the term IVF SKIN in all capital letters twice in the caption, suggesting that this may be a common experience with others who have received treatment. The number of hashtags used at the bottom also implies the user is trying to draw people to her post, potentially to engage in dialogue, invite the stories of others, commiserate or find expertise on battling hormonal acne. The other hypertext in this is the user’s location, which is marked as her REI practice, so it is also possible *IVF skin* is a term she discussed with her medical team, though she does not intimate there is a cure. There are four follower comments, but all remarked on the strength of IVF patients. While the poster did not explicitly ask for support, the use of a series of selfies illustrating a treatment side effect such as acne, which can foster pubescent angst, embarrassment, anxiety and shame, represented an intertextual attempt to situate personal experience and boost confidence while seeking affirmation.

Pregnant diagnosis/confirmation

In our previous qualitative research on infertility treatment support participants disclosed practices REI practitioners advised them on what to avoid.^{15,16} These include but are not limited to: sharing medications and taking pregnancy tests before the beta test (*e.g.*, a blood test at an office). REI practitioners we interviewed realize patients often take pregnancy tests anyway, but they continue to discourage the practice, which can cause anxiety and emotional upset from false negatives or excitement and then devastation from false positives. There are posts discussing when to start home pregnancy tests after embryo implantation, all communicating that patients *know better* but then providing detailed images of test results, asking for feedback on symptoms, and querying other IG users for positive stories and experiences. All of the discourse around pregnancy testing reflects resistance to medical expertise on testing early. While testing is emotionally wrought, it reflects the individual desire to reinstate some control over the process, to *know* what is

happening in the body after treatment and before the beta.

Some pregnancy-related posts showed pictures of pregnancy tests with results or discussed if positive lines were growing darker and more apparent, while others discussed *testing out* or monitoring the drop of synthetic HCG from the *trigger shot* (*e.g.*, Ovidrel®), which prompts ovulation before egg retrieval. Once that level disappears, some continue testing to see if their body produces its own HCG and thus a positive pregnancy test, indicating the IVF cycle was successful. However, using pregnancy tests from the drugstore, with dye-based lines instead of digital readings can produce confusing results, so some turn to IG for feedback. There is also an economic constraint here – low-cost pregnancy tests are accessible (*e.g.*, at the Dollar Tree, where tests are \$1 if you buy 4 or more) and attractive for patients struggling to cover treatment costs, but these tests are notoriously unreliable. This tension is well understood in the #ttc community, especially among those on self-pay for meds and treatment, so, IG users present visual and textual supports when posts seek clarification on test results.

User 3 posted an image of three pregnancy tests, each from successive days with a positive line becoming slightly more noticeable across the three days. In the picture the tests are labeled as 5DP5DT, 6DP6DT, 7DP7DT, meaning 5, 6, or 7 days post-five-day transfer, *etc.* The text says, “Last Ivf cycle, I didn’t get a line UNTIL day 7 (and it was a squinter to say the least)...However, each day the line continues to get darker and my confidence grows...[little plant emoji; #ivfsuccess].” Commenters were encouraging: “Looking good!!” and “You’ve got a sticky one in there! Keep testing for as long as it makes you feel good” Post viewers understood both the explicit and implicit question the image posed, and responded by confirming the tests became *more* positive over time. There is no contextual information about the picture, including the lighting for the image, the filter used or other information addressing the impact of setting on the appearance of the result lines. Some users asked the question directly through their posts: “I KNOW everyone is different...I just wanted to hear from you guys when your trigger was gone if you tested it out? How many days after the shot were your tests negative?” The user goes on to discuss the progression in the comments and is second-guessing her results. User 3 concluded: “If it’s still there I’ll ask when we have our WTF appointment next Friday” (Figure 3).

Perhaps the most visually provocative image we encountered showed the user’s cervical mucus. The poster realized their post was unusual, though the hashtagging within the post made the image discoverable to hundreds of thousands of IG users. The caption read: “This is very TMI, ladies!!! Can you tell me what kind of cm [cervical mucus] this is? I’m having a hard time understanding this cm. [Anxious face with sweat]...Sticky? School glue? Btw, my breasts are still sore. [Face with medical mask emoji] P.S. I’m so sorry if this picture is disturbing you. I

might be deleting this pic after I know the answer.” The commenters did not seem deterred by this and instead responded very positively: “I’d call it somewhere between sticky and creamy” and “Not to get your hopes up or anything but my body produced stuff like that when I was pregnant,” or “Creamy/school glue I think!” This image is certainly explicit in its signaling – this is clearly a body fluid. Yet the apologetic tone and use of TMI (which means *too much information* and flags information some users might find too personal) with the image are intertextual, asking for forgiveness with a parallel demand for confirmation. The responses were effusive and mimic the intimacy of the image by pairing adjectives common in pregnancy manuals and doctor’s pamphlets with encouraging words, positive emoji and assurances based on an image in an unknown setting. Again affordances matter here – we wondered where the picture was taken (context), in what lighting, at what time of day, and posted with what IG filter? All of these contextual elements could change the appearance of the opacity and viscosity of the material on the poster’s fingers and as a result, the actual answer to her question.

Research implications

Based on our findings, patients before, during and after IVF treatments are using IG to give and exchange medical expertise, but also to build community and support one another (*e.g.*, sharing words of encouragement, donating surplus drugs to each other). The intertextual and hypertextual nature of these posts (*i.e.*, the use of image-text to communicate) makes them accessible to potentially

millions of IG users and creates a time-specific record of a dialogue between members of this hashtag public. Given the public nature of this discourse and the personal information and data that is often shared, there are legal issues to consider. Legally, problems may arise from medicine exchanges, particularly if sending donated drugs is considered mail fraud. Is there liability in situations where IG users make personal health decisions based on IG discourse, and if so, who would be responsible? Ethical guidelines and legal frameworks are far behind the potentialities of social media interactions, and so much of what we observed reflects this gap. On the other hand, the lack of oversight and regulation create meaningful spaces where individuals can build community and impact each other in tangible ways, which is vital given the isolation commonly experienced by fertility patients.^{11,13,14,17}

Considerations of legality also intersect with privacy issues. In our data set, posters included images that revealed their full names, birthdates and social security numbers, as well as screenshots of private emails received from their REI practices, with the first and last names of their practitioners publicized. Interestingly, many of these were posted through accounts in which the individual’s IVF-specific account is obscured or hidden so strangers were potentially more likely to view this information than close friends or family. In the email instance, the nurse in question was clarifying a treatment error and commenters revealed the particular medical system and location of the practice. We are unaware if anyone from the practice was aware of this post, and the nurse may or may not have had anything to do with the clinical error in the message.

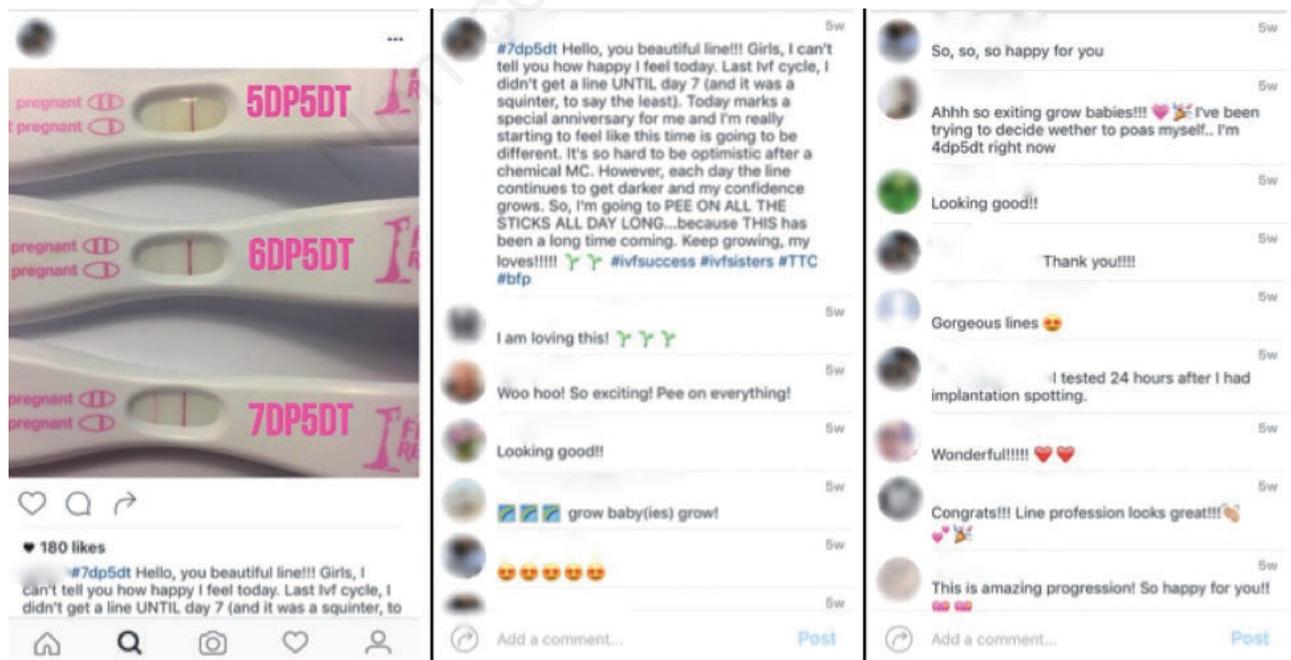


Figure 3. Blur of pregnancy tests, 5DP5DT.

Furthermore, it is unclear if IG users understand the searchability of their images based on their use of hash-tags; do users realize that anyone that uses the same hash-tag or searches that hashtag can view their information and potentially use it in ways the poster did not envision or would not approve (e.g., identity theft)? One protection available to users is to set their account to *private* but in the #ttc community, accounts are often public so users can follow the hypertextual trail to find and support each other.⁶⁹ And if you have a private profile but leave a comment on a public account, your profile is visible and other users can click on your username.⁶⁹ Because IG delineates the privacy policy in their user agreement,⁶⁹ it is unclear whether or how Instagram supports users who claim invasion of privacy or identity theft; hypertext is an affordance, so it leaves a trail by design. Lastly, for some IG users, IG represents a safe space to share their fertility journey *because* they are not discussing it openly with friends and family. The popularity of hypertext in these posts complicates the idea that simply obscuring one's identity with a username provides the sort of anonymity expected or desired.

For REI practices, it may be valuable for doctors and nurses to understand where patients are seeking and receiving information to better prepare patients to ascertain what is accurate advice. As we have seen from our previous research, telling patients *don't Google* is not effective,¹⁵ and during IVF cycles, treatments (such as injections) happen in the home and generally not during business hours. Patients understandably have questions or concerns but due to long wait times and/or lack of availability, talking to a practitioner immediately might not be possible. Given how quickly some posters turned to IG to gather information or share their frustration with medical experts (4 minutes in the case discussed), it is likely some users will find expertise and support on IG prior to making contact with a practitioner. On social media platforms, the contingent nature of information is visible – the way expertise is framed, consumed, and resemiotized through inter- and hypertextual discourse continues to confound the expertise binary of *lay* or *technical*.¹² In this setting, users validate expertise through the nature of the discourse, by what is posted and what is *liked* rather than by clear standards and structures external to this discourse. For example, when patients receive support for activities against the recommendation of medical personnel (e.g., pregnancy testing during the *two-week wait*, or the time between embryo implantation and the beta test).

Regarding medicine exchanges, is it possible that medicine received from another IG user is no longer viable, was accidentally contaminated or damaged during shipping? As these medicines are posted, they become parts of hypertextual discourse, but they also lead to offline communication and interaction, including mailing packages and thank you notes. Furthermore, these posts can be removed at any time, making the success of medicine exchanges challenging to

gauge and track. Practitioners might consider that patients' resistance to or questions about protocols can result from expertise gleaned on IG (e.g., information on multiple embryo transfers). All of these practicalities highlight the power and complexity of imagetext on social media platforms, showing the richness of these spaces for semiotic discourse, as well as the complications introduced by hypertextuality.

Conclusions

Given the availability of social media-based data, there are countless entry points for other scholars to analyze multidimensional discourse on social media platforms. In terms of health issues, other studies could examine hormonal therapy, surgery, intrauterine insemination and other procedures or treatments distinct from the conversations we studied. Future research could query the impact of alternative REI treatments (e.g., meditation, yoga, dietary changes). A multimodal analysis that seeks out the perspectives of women of color, queer women, trans women, women with lower socioeconomic status and other individuals in treatment would provide more information about the impact of IG's affordances such as hashtag use, tagging, emoticon/emoji use and help interrogate the analytics of silencing alternative voices and perspectives. This silencing is a practice Rachel Cargyle (@rachel.cargyle) and others refer to as being *shadow banned*, wherein IG blocks an individual's hashtag from appearing in searches without their knowledge (most users find out from their followers). Reviewing a range of these discourses can also provide information on the varying experiences of communities at potential crisis points in the life-cycle of early motherhood.¹²

Another call for future research is to broaden the system of data collection. There is no efficient tool to perform textual and visual analysis of IG imagetext, unless posts are individually collected, compiled and coded. Netlytics and other programs focus on likes and other metrics, but do not have tools available for rhetorical analysis. Radian6, which collects social media data, gathers text from IG, Twitter, blogs and Facebook but does not collect images. To analyze the imagetext in context we had to pair screenshots with comments in a linear progression, a tedious effort that worked but could be cumbersome to analyze. Despite the challenges of data collection, IG is a social media platform with rich and wide-ranging research opportunities. Future scholars might also conduct multi-discourse analysis on other stigmatized diseases (e.g., STIs, diabetes). What types of health information and medical expertise are sought and exchanged in these communities on IG? Future studies could analyze discourses available through Facebook or IG live or stories functions and analyze users' direct messaging to poster content. Finally, researchers could closely examine emoji use within the #ttc community,

and in other hashtag publics. Emoji are a semiotic, inter-textual form unique to the social media age, and their role offers complex, fascinating material for study.

Today, we engage in a mediated world, where most discourses allow for multifaceted analysis (e.g. of inter-text, hypertext, etc.). Social media is just one level of our mediated realities. On Instagram, users in the #ttc community act as informal patient advocates for themselves and others experiencing IVF treatments, while creating a multimodal, digital extension of the formal, textual medical record. For users, the unique nature of the IG platform, the power of hypertext and the utility of images, offers a unique refuge from the biomedical gaze. As one user commented: “I’ve learned one thing, gotta advocate for yourself and pay attention to every detail.”

The lack of acknowledgment by individual health practitioners, practices or systems regarding the impact of multimodal discourses on social media platforms actively denies the lived reality of many patients. This denial refuses to grasp the dynamic nature of multimodal communication in which expertise is negotiated, recontextualized, and even disseminated in new forms (e.g., through hypertext such as #ivfmeds).^{12,70} With cautious optimism we urge healthcare practitioners and administrators to consider these dynamic, intertextual and interconnected discourses to keep practitioner-patient dialogue open and evolving in tandem with social media platforms available today and in the future.

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