

NARRATIVES OF A STRUGGLE: THE EXPERIENCE OF ASSISTED REPRODUCTIVE MEDICINE IN ONLINE INFERTILITY COMMUNITIES

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ABSTRACT. *Narratives of a Struggle: The Experience of Assisted Reproductive Medicine in Online Infertility Communities.* Although ART (assisted reproductive technology) has become a well-established field in modern medicine, the subject is still taboo in many modern societies. This prompted infertility patients (roughly 15-20% of the general adult population) to find online platforms to discuss options, treatments, experiences and create virtual communities – mainly forums and Facebook groups. I shall focus on aspects concerning the narratives of trauma, loss and empowerment in two online communities - *Infertilitate. Fertilizare in vitro. Sustinem Asociatia SOS Infertilitatea (Infertility. In vitro fertilization. We support the SOS Infertility Association)* and *Fertility Friends*, from two different geographical areas – the UK and Romania, in order to reveal the dynamics of advice giving, information sharing, experience narratives and patient support. Communication is paramount to infertility treatment, yet specialized clinics often underestimate the importance of this aspect. Online forums and social media have provided patients with opportunities to connect, shaping particular jargons and textual strategies with regard to the medical journey of ART. I intend to outline the structure and relevance of these verbal constructs, in order to explore the specific manner in which online platforms offer a valid environment for a positive exchange of information among ART patients while also creating a medium of emotional support. My interdisciplinary focus will involve methods specific to medical humanities, text and discourse analysis and linguistic commentary.

Keywords: *assisted reproduction, infertility, loss, online communities, support groups, trauma*

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REZUMAT. *Narațiunile unei lupte: experiența reproducerii asistate medical în comunitățile online despre infertilitate.* Cu toate că tehnicile RUAM (reproducere umană asistată medical) au evoluat spre coagularea unui domeniu bine stabilit în medicina modernă, subiectul este încă tabu în multe societăți contemporane. Acest fapt determină pacienții infertili (aproximativ 15-20% din populația generală adultă) să caute platforme online unde să își discute opțiunile, tratamentele, experiențele și să creeze comunități virtuale – în principal forumuri și grupuri Facebook. În studiul de față mă voi concentra asupra unor aspecte ce vizează narațiunile traumei, pierderii și ale susținerii, în două comunități online - *Infertilitate. Fertilizare in vitro. Sustinem Asociația SOS Infertilitatea și Fertility Friends*, din două spații geografice diferite - Marea Britanie și România, pentru a revela dinamica schimbului de sfaturi și informații, a narațiunilor despre experiențe și a susținerii între pacienți. Comunicarea e esențială în tratamentul infertilității, deși clinicile de specialitate adesea subestimează acest aspect. Forumurile online și rețelele sociale le-au oferit pacienților oportunități de a se conecta, generând o serie de jargoane și strategii textuale legate de experiența medicală a RUAM. Intenția mea, în acest studiu, este de a delimita structura și relevanța acestor constructe verbale, pentru a putea explora maniera specifică în care platformele online oferă un mediu viabil pentru un schimb pozitiv de informații între pacienții RUAM, creând în același timp un mediu de susținere emoțională. Interesul meu interdisciplinar va viza metode specifice științelor umaniste medicale, a analizei de text și discurs, precum și comentariului lingvistic.

Cuvinte-cheie: *comunități online, grupuri de suport, infertilitate, reproducere asistată, pierdere, traumă*

Introduction

Since 1978, when Louise Brown, the first baby conceived through in vitro fertilization was born due to the efforts of British medical pioneers Robert Edwards and Patrick Steptoe, almost ten million children were conceived through the same method (ESHRE 2022). With fertility rates decreasing across all EU countries, the number of patients seeking fertility treatment increased, and, implicitly, the need for complex psychological care and support, too. Infertility is a multi-faceted condition that has significant social, cultural and geographical roots. Despite its numerous variations in meaning, it is primarily a medical condition defined by a couple's inability to conceive after a year of unprotected sexual relations. The World Health Organization recently estimated that there is a large number of people suffering from this condition worldwide – between 48 and 148 million people (ESHRE 2022). Its etiology is particularly complicated, since the male and female factors involve aspects that can only be

diagnosed and treated in a multi-disciplinary manner. Fertility care is expensive, few countries prioritize the domain among other public health services and the great financial and emotional cost of assisted reproductive medicine deeply affects couples, leading to tensions and even the dissolution of marriage or partnership. Despite the attested shared involvement of the male and female factors in infertility, it is not uncommon that many societies tend to see the woman as more responsible for the reproductive challenges of the couple, and implicitly, it is expected that women are more active in the seeking of treatment for the couple and bear the medical and psychological burden of treatment (Aiyenigba, Weeks, and Rahman 2019, 77). Online instruments of support, such as forums and Facebook groups have been designed to help individuals cope with the challenges of infertility. However, despite their predominantly positive impact, such instruments may present important drawbacks – an informational overload that patients cannot process properly due to a lack of medical training, a potential state of addiction to the empathetic virtual bubble of the forum/group and a misplaced trust in medical opinions coming from other patients rather than doctors. Despite their apparently positive intentions, these virtual communities reunite vulnerable patients who need specialized advice. However well-intended it may be, exchange of experiences, illness stories or adverse outcomes - such as missed miscarriages, pregnancy termination due to severe prognoses, fetal intrauterine death or stillbirth require professional intervention. Unauthorized advice and negative information may have a harmful impact on the emotional wellbeing of the user and on the outcome of the fertility treatment. Since the condition is difficult to treat, given its many possible etiologies (physiological, morphological, endocrine, immunological, genetic, environmental, to name just a few), empirical treatment is often proposed to patients, and, in their turn, some patients often offer advice to other patients, based on their own experience. Since anecdotal success of such treatment – the so-called “add-ons” - has little or no scientific basis, the side effects may interfere with medication, leading to unpredictable treatment outcomes. Moreover, the diversity of serious (if rare) situations concerning pregnancy, birth and maternity may prove triggering for some patients, thus increasing the emotional burden they must carry throughout their treatment.

It is important to note that, despite the dominant perception that infertility is a women’s issue, the male factor contributes to half of the cases (Vander Borgh and Wyns 2018, 2). This aspect is culturally determined, as fertility often appears indistinguishable from motherhood in many culturally-driven contexts; however, it is remarkable that the social platforms investigated here had very few (if any) male members, with female partners inquiring about male pathologies such as low sperm count, azoospermia or urological disorders. Poorly researched, the emotional dimension of male infertility fuels the cliché

that men repress their emotions and resort to different coping mechanisms than women. Recent studies revealed the common-sense reality that men perceive infertility as a difficult diagnosis in each of the three circumstances they could find themselves in: infertile patient, the healthy partner of a subfertile spouse, or part of a couple with unexplained infertility (Joja, Dinu and Păun 2015, 360; Hanna and Gough 2016).

Ann V. Bell noted, in a comprehensive study regarding marginalization in infertility that the process is highly feminized and it involves various degrees of hardship and exclusion in the case of specific categories, based on race, gender, socio-economic status and sexual orientation (Bell 2016, 39). Moreover, it is relevant to note that, compared to the *Fertility Friends* UK forum, Romanian social platforms have remained opaque and silent in what concerns same-sex couples' struggle to conceive. A stringent contemporary issue, marginalization has gained increasing scientific attention especially in women's studies (Richburg, Jackson and Moravek 2022, 44).

My investigation of online infertility communities shall focus on two examples from two different geographical areas - *Infertilitate. Fertilizare in vitro. Sustinem Asociatia SOS Infertilitatea (Infertility. In vitro fertilization. We support the SOS Infertility Association)*, a Facebook support group from Romania and *Fertility Friends*, an infertility forum from the United Kingdom. My aim is to reveal significant cultural, linguistic and discursive aspects emerging from the diverse ways in which patients narrate their experience of illness and trauma stemming from infertility in these two online communities. The obvious drawback of such an initiative is the virtually impossible task to read tens of thousands of Facebook and forum posts in order to draw scientifically valid quantitative results. However, humanities researchers can bypass the rule of exhaustivity in favor of analytical depth, despite the potential reproach that such an endeavor may draw conclusions based on a limited number of examples. Moreover, there is a certain fluidity pertaining to online narratives and interventions such as the ones on Facebook infertility groups and online forums. Users can edit their texts or delete them, administrators can ask for revisions or elimination of certain expressions or arguments that others may find offensive or triggering. An overview of these online ecosystems can, therefore, be based on a reasonable number of relevant examples without prejudicing the scientific quality of the entire project. The fundamental condition, which I intend to firmly adhere to in the present study, is that of using clear methodological instruments that help articulate a consistent set of arguments leading to valid, significant conclusions. Medical humanities is a research area that fills the major gap between medical sciences and the humanities, therefore my investigation is an effort to analyze representative examples of discourse in online infertility communities with the

instruments and concepts of this interdisciplinary field - text and discourse analysis, observations concerning cultural differences, linguistic commentary, narrative structures and strategies.

The online underground of infertility patients

Fertility forums and Facebook groups are currently the main stage reuniting infertility and assisted reproduction patients who navigate the complex process of receiving treatment for an equally complex pathology. Although numerous and well organized, assisted reproduction clinics rarely have enough employees (nurses, coordinators, assistants) to cater to the vastly diverse needs of their patients. Online support groups are a recent social media phenomenon, although real life infertility support groups had existed long before the advent of the internet. The experience of infertility generates specific traumatic responses. Given the highly individualized perception of this medical condition, infertility is rarely made visible and discussed openly on a wider scale. Compared to the trauma caused by a historical period or event, infertility trauma is less socially acknowledged. The experience of patients seeking online support has been the object of study in a variety of domains, from clinical psychology to medical sciences, and, given the growing relevance and popularity of social media and online communication tools, it should be analyzed from a thematic, narrative and linguistic perspective as well. Fulfilling the fundamental emotional need of confession and storytelling based on one's singular experience of a dramatic event, online narratives and interventions concerning infertility can be explored as subjective accounts of a transformative event.

Vulnerability is the fundamental notion that may be used to define the position of infertility patients in relation to social norms, health systems and the normal fertile population. Treatment is, in most European states, highly regulated and restrictive, even in generous states, such as France, where a couple can benefit from six attempts at artificial insemination and four courses of IVF treatment paid by the health insurance system before the age of 43 in women (Gomez and De la Rochebrochard 2013, 3103). Moreover, since 2021, an important landmark has been established in the process of making fertility treatment available to all women – single women and women in same-sex relationships gained the right to benefit from state-funded fertility treatment in France. EU countries such as Belgium, Spain, Denmark, Finland, Ireland, Luxembourg, Malta, the Netherlands, Portugal and Sweden have already activated similar legal provisions in recent years. Outside the EU, Iceland and Norway offer identical rights to this category of patients. One of the important challenges infertile patients face in a social context is the painful yet inevitable confrontation with the situation in which people in their social circles, with

unimpaired fertility, manage to obtain pregnancies and live births. Users on infertility boards and Facebook groups face a complicated variant of this situation inside the apparently protective universe of the group, as they empathize, offer (and receive) support for a while, then they are faced with the inevitable - other members become pregnant, have the children they desired and, at one point or another, they “graduate from the group” (Chocano 2020). There are numerous such situations in online fertility groups and, despite it being a joyous moment and the ultimate proof that infertility can be overcome, it can also be a challenging moment for some users. In a nuanced, yet targeted intervention in *The New York Times*, Carina Chocano outlined the uncomfortable position of all parties involved in this type of unusual graduation. She spoke with infertility patients who ran blogs on trying to conceive and gathered information about the group dynamic at significant moments, such as those when members announce they managed to get pregnant. In the pragmatic dimension of group dialogue and information exchange, it is important to maintain an emotionally balanced environment, therefore pregnancy announcements are considered sensitive content, with great potential to trigger a negative response. The administrators of the *Pregnantish* blog, for example, decided to apply a particular tag to all posts containing pregnancy announcements so that users can choose to avoid the sensitive content - “Good ‘Ments” (that is “good announcements”) (Chocano 2020). Andrea Syrtash, a writer specialized in dating and relationships, learned that she might have fertility issues at a young age, when she was diagnosed with endometriosis. Years later, after many failed attempts to get pregnant, she started *Pregnantish*, a blog focused on fertility-connected issues. Her story reached a sensitive point when she announced she was expecting, with contradictory feelings of guilt, joy and compassion for those still struggling. Commiseration, a certain type of group solidarity and a generally empathetic mode of relation to the challenges other members face are characteristics of online communities observed by numerous studies (Malik and Coulson, 2008; Dănilă and Băban 2018; Zappavigna 2012). Less frequently, but medically more consistent, online expert forums provide patients with similar support although patients tended to give more informational than emotional cues (Aarts et al. 2015).

Social support and a sense of belonging to a community have been revealed as paramount in the process of managing an infertility diagnosis, even before the internet era (Jirka, Schuett and Foxhall 1996, 55). Hirsch and Hirsch concluded that social support played a significant role in improving marital relations, the couple’s sex life, their identity perception and self-esteem. It directly influenced what the authors called “the measures of contentment” (Hirsch and Hirsch 1995, 517) in the lives of those affected by difficulties to conceive. Moreover, J. Boivin’s 2003 review of psychosocial interventions in infertility revealed that group interventions were more effective (and generally perceived

as more useful) than counselling interventions. In the author's opinion, a group format is more effective in facilitating the exchange of opinions and experiences than individual communication. As many users confirmed, asynchronous communication and permanent availability, regardless of the time of day, play an important role in making online group support a consistent psychological tool that many infertility patients embrace (Malik and Coulson 2008, 106). The survey conducted by Malik and Coulson in 2008 gathered participants by posting invitations on websites such as www.fertilityfriends.co.uk, www.infertilitynetworkuk.com, www.fertilityzone.co.uk, www.acebabes.co.uk, www.repromed.co.uk and www.fertilethoughts.com. 95 participants (93.7% women) completed the online questionnaire and the results unequivocally revealed that users found mainly positive aspects in joining online infertility groups (Malik and Coulson 2008, 112). The authors propose an "essentialist/realist framework, which aims to report on the experience, meanings and reality of participants" (ibid, 108) which is, I believe, an efficient approach that can be replicated in any other exploration of the communication dynamics in online infertility communities. However, I consider linguistic observation and discourse analysis equally relevant, as they offer a comprehensive framework of the multi-level exchange of support, ideas, suggestions, and emotion that occurs between users. The exploration of "digital practices underlying peer-to-peer interactions about stigmatized conditions" (Jaworska 2018, 25) is an occasion to discover an entire ecosystem, usually reflecting a particular effort to raise awareness about a certain condition, illness or trauma.

Infertility narratives – an overview and analysis

The most important features of online interaction among the participants in infertility groups, as outlined by the participants in Malik and Coulson's investigation were convenience, uninterrupted availability, emotional support, the asynchronous and anonymous nature of online communication, encouragement of honesty to discuss sensitive issues, individual control over participation and involvement, positive impact on partner relationship. Chief among the drawbacks mentioned are a form of addiction to the group, a stringent need to be permanently connected to group activity; and, what I consider most significant among the negative aspects mentioned, a raised awareness of what might go wrong during treatment and pregnancy, given that users often post dramatic stories of loss, stillbirth, postnatal depression or partner and family conflicts over parenting styles and child-rearing philosophies.

Infertility is often an isolating experience, a traumatizing diagnosis that comes unexpectedly. On the contrary, the illusion of ever-lasting fertility is frequently entertained by today's culture of endless youth, donor conception boards being eloquent proof of this trend. It is a common occurrence to find

press articles about famous women in the entertainment industry who become mothers well beyond the reasonable age limit of natural fertility. Their public flaunting of such unusual fertility makes this private aspect part of their extraordinary personality and enviable success, any mention of the concrete means that led to their becoming mothers remaining shrouded in mystery. It has been scientifically proven that assisted reproduction has a very poor prognosis past the age of 45. However unethical it may be to sensationalize one's fertility, given the already minimal background of fertility education in both Western and more traditional societies, such misleading voices should also be a cause of concern for the medical community, as they create false hope for the women who postpone motherhood. For example, in the *Infertilitatea...* Facebook group many posts are written by patients aged 42 and above who lament their doctor's recommendation to follow egg or embryo donation treatment instead of classical IVF with their own genetic material. Such posts are usually triggers of heated disputes, as many fellow members of the group recommend persistence and patience, as they know a friend, relative, TV personality who succeeded even at older ages. Other members, some having had their own experience with adverse IVF outcomes due to advanced age, strongly advise against "wasting money", "believing charlatan doctors" or feeding an illusion, since the IVF success rate above the maternal age of 43 is more or less theoretical. Of special relevance are donor conception posts, especially those focusing on egg donation, as this constantly proves the conservative attitude towards the issue in Eastern Europe (Todorova et al. 2017).

The *Infertilitate. Fertilizare in vitro. Sustinem Asociatia SOS Infertilitatea* support group had 31200 members, as of August 7, 2022. Numerous IVF clinics have opened in Romania in the past decade, offering specialized services of various medical quality, and the number of patients is constantly growing (Nahman 2016). Founded in 2009, as a Facebook extension of the *SOS Infertilitatea* forum, the group gained visibility and traction as more users preferred the Facebook platform over the now obsolete forum format. Although many users connect with their "official" Facebook account, choosing to reveal their identity while posting, many others either opt for a clone account, posting under pseudonym, or for a newer tool, allowing them to post anonymously as a "group member", with no name displayed. As Nancy Baym noted, "on a societal level, anonymity opens the possibility of liberation from the divisions that come about from seeing one another's race, age, gender, disabilities, and so on" (Baym 2015, 34). The orderly fashion in which topics were arranged in the forum frame is no longer in place on Facebook, despite constant efforts made by administrators and moderators to create hashtags and topics. The group works on the principle of a permanent influx of questions, stories and answers, and few users actually rely on the "search" function of the page in order to get answers to already answered questions. However, a few elements have been banned from the

group – the “Is it positive?” question followed by pictures of ovulation or pregnancy tests, or the use of colored backgrounds for posts in order to make them more visible and potentially attract more comments. Ultrasound confirmation of ovulation, b-hCG blood tests and visits to the hospital emergency room are firmly encouraged by moderators and posters when patients need medical advice or intervention.

The group offers excellent opportunities of linguistic, anthropological, social and cultural analysis and observation. As Dănilă and Băban (2018) pointed out in their study of infertility representations in Romanian discussion forums, there is a set of universal themes recurring in this particular online environment: “Infertility as a personal battle; infertility as an unfair destiny; infertility as a threat to the feminine identity; divinity as a last resort to infertility” (Dănilă and Băban 2018, 25). Although my observations do not contradict these conceptual parameters, I shall try to refine them further.

Thematically, the interventions of users on the *Infertilitate...* Facebook group fall into some major categories, such as: medical narratives aiming to elicit narratives of similar experiences from other patients (short pathographies, heavily focused on the emotional dimension); brief, punctual interventions seeking concrete answers preceding doctor’s answers (laboratory results, beta-hCG levels, drug dosage, etc.); crisis interventions (depression, anxiety, inability to cope with an infertility-related diagnosis, couple and family crises, financial difficulties, work problems, etc.); encouragement posts meant to give hope to patients still undergoing treatment (from patients who had recently become parents, either biologically or through adoption). It is noteworthy that, until 2020, when the group was reported to Facebook for infringement of community standards, it was not unusual for patients to try to sell or donate leftover drugs, as fertility drugs are known to be expensive and sometimes difficult to find. Infertility is mostly viewed as an often religiously charged challenge, a trying period that can be overcome, a test of personal resilience and couple strength.

The *Infertilitate...* Facebook group is interesting to investigate from another perspective, that of the online phenomenon of trolling². I shall exemplify with the case of a group user who unusually chose to post under her real name, despite her illicit intentions. The case of M.B., which unfolded over a period of three months on the group is a relevant example illustrating the pitfalls of online patient support. Although rare, cases such as this prove that anonymity may encourage readers to create false narratives, assume fake identities beyond the scope of privacy and ultimately betray the trust of other members who shared sensitive personal details. Interestingly enough, M.B. used her real

² “troll - someone who leaves an intentionally annoying or offensive message on the internet, in order to upset someone or to get attention or cause trouble”; Cambridge Dictionary, <https://dictionary.cambridge.org/dictionary/english/troll>.

name, joining the group under the pretense that she was pregnant with twin girls in her second trimester. She even met other members in real life, participating in some events organized by the SOS Infertility NGO, displaying a small but obvious pregnant abdomen. As it was later revealed by angry users, she contacted members privately, engaged them in conversation about their infertility issues, asking them to send her laboratory test results and other medical documents. Her incessant online activity in the group quickly earned her the sympathy of the founding members of the association, who gave her moderator rights. M.B. detailed her far-fetched life story in long, sophisticated and often delirious posts, resulting in a divided attitude of the audience: many members were captivated by her phantasmagoric narrative, while others ignored her and a few monitored the situation with a skeptic eye. M.B.'s dramatic tale took a turn for the worst when she announced that her pregnancy was in danger and her 22-week-old twin girls were about to be born prematurely without a real chance for survival. Although she didn't ask for money (even bluntly refusing the financial help she was offered), M.B. copy/pasted enough details from the narratives she gathered from other members to raise suspicion that she was creating a tall tale that uncannily resembled the tragic story of the founding administrator of the organization, who lost her 25-week-old prematurely born daughters in 2008. However, despite her good knowledge of high-risk pregnancy and prematurity, N.C.B., the founder of the association and the group, was a staunch supporter of M.B., even believing the absurd story that M.B. was in labor and, in order to save her and the twins, her family rented a private American medical airplane to transport her to the United States via Paris, that M.B. had given birth to one twin and had undergone dialysis with the other one still in the womb, that she had suffered an episode of cardiac arrest yet was perfectly able to chat privately with other members while intubated, etc. When she realized the scam and the emotional farce she had been made part of, N.C.B. wrote a few posts expressing her bewildered disappointment that a group member would resort to such ruthless strategies for no apparent gain, other than an obviously pathological narcissistic fixation. A group member, who is a licensed psychiatrist writing under her real name warned the community about the dangers of providing strangers with medical personal data and of confessing delicate aspects of treatment and pregnancy in private online conversations. Such information could be appropriated by mentally ill fellow members suffering from infertility-related delusions (it remained unclear if M.B. had ever been pregnant and whether the bulging abdomen she had been displaying was real or a prop). Across seven posts dedicated to the subject, all placed under the "dezaxata" (i.e. "unhinged") hashtag, the story generated unprecedented interest in a member's story – over 3500 replies were written between April 11-14, 2017, mainly to express shock, disapproval, disgust and blame, as M.B. was finally exposed as a fraud and excluded from the group. It is noteworthy that, after she

had been banned, all her posts and comments were deleted, therefore the narrative she had created is no longer accessible for analysis. However, for the purposes of this investigation (among others, a focus on the creation of online stories and narratives about infertility and the readers' response to such stories), there is still plenty of material available. N.C.B. decided to keep all her posts and comments and not delete those favorable to M.B., although the narrative was exposed as sheer fabrication.

Facebook replies are structured as cascading messages, not necessarily deriving one from the other. Users may write short replies or even strictly resort to emoticons in order to convey their opinion or feelings. The M.B. story elicited a massive response from users because it violated an essential community value – a sense of trust and solidarity. The mounting evidence that M.B. faked her pregnancy undermined any possible excuse (other than mental illness) that she might have had in order to proceed as she had. One user wrote:

I'm reading in sheer amazement...I cannot believe my eyes...I too believed this story and was profoundly impressed because at the time I was pregnant, too, there were a few women that had ruptured membranes, for various reasons, and I was terribly impressed...I couldn't stop thinking of them and was hoping they could manage to save them. Thank God [...] I haven't slipped down such a slippery slope after the loss of my 4th pregnancy. I hope she seeks appropriate treatment, because this story is shocking³ (Facebook user, Wednesday, April 12, 2017).

A few hours later, one of the users who closely followed the story concluded:

There is nothing to be done, one of M.'s teachers commented at one of the posts, M. is real and she is a medical student. At least that is true. The rest was probably an experiment of hers/an invention and we were the victims. My brain still cannot process what happened. It refuses to believe that there are such people [...] I would have never thought that there are people who do what she had just done. No, there is nothing to be done, we are victims, we feel betrayed, but there is nothing to be done. What do you want to do? A police complaint? Go ahead :))) they will laugh in your face⁴ (Facebook user, Wednesday, April 12, 2017).

³ "Citesc și mă minunez... nu-mi vine să cred ochilor... și eu am crezut povestea asta și m-a impresionat profund pt că în perioada în care eu am fost însărcinată, au fost câteva femei însărcinate care ajunseseră cu membranele fisurate, din diverse cauze, și m-au impresionat cumplit... mă tot gândeam și speram să reușească să le salveze... Îi multumesc lui Dumnezeu că în momentul acesta îmi țin copilul sănătos în brate și nu am alunecat pe o pantă atât de periculoasă, după pierderea celei de-a 4-a sarcini. Sper să caute tratament adecvat, pentru că e șocantă toată povestea." (Facebook user, Wednesday, April 12, 2017; my translation)

⁴ "Nu e nimic de făcut, una dintre profesoarele lui M. a comentat la una dintre postări, M. există și e studentă la medicină. Cel puțin asta e adevărat. Restul a fost probabil un experiment de-al

M.B. confessed her fraudulent behavior a few hours after she was exposed. Her confession was rather short, compared to her other rich, more elaborated posts:

I know that this post should have been written earlier, but I was incapable, I didn't feel up to it. I could only invoke the pain I feel inside, which for the last week paralyzed me completely. [...] I had 2 children. They were gone much sooner than I told you. Yes, the pain paralyzes me, and somehow it was easier to tell myself, too, that they were still there. That way, there was still a chance. [...] I'm sorry I didn't know how to share this information that brings me down every single time. I'm only asking this: whoever can forgive, fine, whoever doesn't I'm sorry I wasn't worthy of the trust I was given.⁵ (M.B., Facebook group user, April 12, 2017).

M.B.'s strategy that captivated a significant number of users, reunites a few characteristics of online patient support, providing a virtual answer to the emotional needs of participants. The narrative aspect appears paramount, as most users need to tell their story and elicit sympathetic reactions from other users in similar situations. It is noteworthy that longer posts are, paradoxically, neither encouraged nor read from beginning to end by group members – an interesting ending formulation being – “please, excuse me for the novel”. It is an expression that most often accompanied longer posts, fueling the impression that shorter and denser posts were better received. This is a feature specific to Romanian-language infertility/parenting groups, *Fertility Friends* having a rather different forum structure that involves other communication strategies.

One of the major drawbacks of online community support is the double-edged aspect of anonymity. With users often protecting their identity and not using their real-name Facebook account for privacy reasons, fake accounts could compromise the trust factor and increase susceptibility that delicate issues are shared with strangers who may take advantage of others' vulnerabilities.

ei/o invenție iar noi am fost victimele. Creierul meu încă nu poate să proceseze ce s-a întâmplat. Refuză să creadă că există astfel de oameni. Nu aș fi crezut niciodată că există oameni care să facă ceea ce ea tocmai a făcut. Nu, nu e nimic de făcut, suntem niște victime, ne simțim trădate, dar nu e nimic de făcut. Ce vreți să faceți? Reclamație la poliție? Mult succes! :))) vă vor râde în față” (Facebook user, Wednesday, April 12, 2017; my translation).

⁵ “Știu că postarea asta trebuia făcută mai demult, dar nu m-am simțit în stare. Nu aș putea să invoc decât durerea ce există în mine și care în ultima săptămână m-a paralizat complet. [...] Am avut doi copii. Ce s-au dus mai devreme decât v-am spus. Da, durerea paralizează și cumva a fost mai simplu să îmi spun inclusiv mie că încă mai sunt acolo. Așa mai exista o șansă. [...] Îmi pare rău că nu am știut cum să împart informația asta ce mă pune la pământ de fiecare dată. Nu cer decât atât: cine poate să ierte, bine, cine nu, îmi pare rău pentru că nu am fost demnă de încrederea ce mi-a fost oferită.” (M.B., Facebook group user, April 12, 2017; my translation).

Despite such rare occurrences (besides minor conflicts, this case remains unique in the history of the group) the advantages of such online support groups, outlined in other studies, remain valid and important. As Malik and Coulson concluded in 2008 (and further research confirmed, see Billett and Sawyer 2019), there are significant advantages to participating in online communities and receiving support there while battling infertility.

The great majority of posts on the *Infertilitate...* Facebook group is of medical nature and answers from fellow members are meant to share similar experiences. For example, on August 2, 2022, one user posted anonymously, under the “Group member” generic pseudonym a question regarding the possible fertilization limitation of the number of oocytes retrieved during an IVF cycle:

Hi! I'd like to know if, for various reasons, anyone requested that less eggs are fertilized in order to obtain a limited number of embryos? If the situation allowed for it, of course. If yes, who is the doctor/clinic that was open in this direction? I do not want to generate controversies, I know that such a request significantly reduces the chances of success and I apologize if my question hurts anyone, but I consider it an aspect that is part of one's personal choices⁶ (Facebook user, August 2, 2022).

The user's concerns have been thoroughly documented in IVF literature (Laruelle and Englert 1995; Provoost et al. 2010), although it is well established in current practice that high quality supernumerary embryos give patients a better chance at a successful treatment (Salha et al. 2000; Romanski et al. 2018). Firstly, we could only assume that, since the conversation concerns oocytes, the user is female and her question regards her own yield of gametes. However, she does not motivate her concerns, deciding not to disclose if her reasons were ethical, religious or otherwise. She seems aware that such a choice could be discussed “if the situation allowed for it”, again failing to mention what she meant by “the situation”. One could only speculate if she was referring to a successful egg retrieval procedure (as, rarely, patients ovulate before retrieval and oocytes are lost, or, in other cases, gametes are not fully developed - in metaphase II - and remain attached to the follicular wall) or a situation in which enough oocytes are retrieved so that a discussion about fertilizing a smaller batch becomes relevant. However, the user doesn't seem fully aware that there is no direct correlation between the number of oocytes retrieved and the number of high-

⁶ “Bună! Aș vrea să știu dacă, din diverse motive, a cerut cineva să fie fertilizate mai puțin ovocite pentru a obține un număr limitat de embrioni? Dacă situația permite, desigur. Dacă da, ce doctor / clinică a fost deschisă în această direcție? Nu vreau să creez controverse, știu că o astfel de cerere reduce semnificativ șansele de succes și îmi cer scuze dacă întrebarea mea rănește pe cineva, dar cred că este un aspect ce ține de alegerea fiecăruia” (Facebook user, August 2, 2022, my translation).

quality embryos resulted. It is not uncommon, in IVF practice, to have a zero rate of successful fertilization (2 pronuclei after 24 hours), although an adequate number of oocytes are fertilized. It is also important to note that the medical education of patients is, more often than not, understandably limited, therefore it is difficult to estimate if the patient has all the necessary information before making a radical decision or needs to be further informed by the medical professional guiding the treatment.

The user's warning that she does not want to cause controversies signals not only the sensitive nature of the issue, but also the fact that it may challenge or offend others. It also implies that her motivation could be religious and, in the history of the group, religious arguments sparked intense debate and controversies. A simple search for the word "God" returns an endless list of results, the majority of which are pregnancy/birth announcements. "When you place your faith in God and firstly in yourself and you don't give up, miracles happen!"⁷ (Facebook group user, July 18, 2022); "Only after 4 months I'm starting to believe that it is true and she is mine. All the while I dreamt that someone tried to take her away from me, I couldn't believe that God made a miracle for me, too"⁸ (Facebook group user, August 1, 2022). On September 24, 2020, less than two weeks after the death of her 3-month son, a 27-year-old user (who had conceived naturally and had a loss at 12 weeks of gestation in her medical history) announced that she had tested her ovarian reserve and the result showed she was pre-menopausal: "I hope that 2021 will be a productive year for everyone [...] be it as God wishes"⁹ (Facebook user, September 24, 2020). Memorial posts or perinatal death posts also carry a religious meaning: "May God give you strength to overcome this difficult moment"¹⁰ (Facebook user, June 19, 2019) a female user wrote as a reply (out of 784 replies) to a post announcing the loss of a 22-week twin pregnancy.

A significant element that strikes Romanian-language readers is the abundance of spelling and syntax errors present in the posts of numerous users. Not only medical terms (a "blastocyst" has been named a "balocist", a "balocid", etc. – the correct Romanian form is 'blastocist'), but everyday language has been used incorrectly "oki" for "ochi" ("eye"), "am loat" instead of "am luat" ("I took"), "umpic" instead of "un pic" ("a little"), etc. Indeed, Facebook language is

⁷ "Când îți pui credința în Dumnezeu și în primul rând în tine și nu renunți, se întâmplă minuni" (Facebook user, July 18, 2022; my translation).

⁸ "Doar după 4 luni încep să cred că e adevărat și că e a mea. Tot timpul visam că cineva încearcă să mi-o ia, nu-mi venea să cred că Dumnezeu a făcut o minune și pentru mine" (Facebook user, August 1, 2022; my translation).

⁹ "Sper că anul 2021 va fi un an productiv pentru toată lumea [...] facă-se voia Domnului" (Facebook user, September 24, 2020; my translation).

¹⁰ "Să-ți dea Dumnezeu putere să treci peste acest moment dificil" (Facebook user, June 19, 2019; my translation).

far from following literary norms, but such formulations are often sanctioned by other users or moderators. Moreover, as Naomi S. Baron argued, the sheer amount of text that literate Americans [or, more generally, online users, we may add] produce is diminishing our sense of written craftsmanship” (Baron 2008, 7). My argument is that users have a different sense of language in a Facebook group environment – a more “utilitarian”, relaxed, approach that assumes users understand the meaning of words even if misspelled, abbreviated, or anglicized.

Another significant aspect that I intend to address is the diversity and contradictory nature of interventions: users seeking empiric advice from experience, others asking about the availability of certain fertility drugs, birth announcements and posts detailing depressive episodes are all part of the same flowing discourse, with no warning for users who may find them triggering or disturbing. The *Infertilitate...* group continuously creates a massive discourse that rarely separates categories and issues, resulting in a continuous influx of information that gravitates around the many faces and consequences of infertility.

The forum format of *Fertility Friends* and its far greater outreach, doubled by its 20-year longevity online (it was founded in 2002) offers significant opportunities for comparison with smaller-scale, differently structured platforms such as the *Infertilitate...* Romanian group. It is also important to note that the number of members (104.300) and the number of posts (6.2 million) makes the forum an environment that can be explored in samples, rather than mapped exhaustively. Indeed, *Fertility Friends* is not only vast in structure, it is also very complex thematically. Each division (ovulation, fertility lifestyle, IVF, donor conception, surrogacy, etc.) has many sub-divisions, as members are allowed to start new threads with themes and issues they consider relevant. The IVF section is structured geographically, as fertility tourism is a phenomenon on the rise. Since the present investigation cannot cover even a fraction of the impressive virtual territory of the forum, I shall focus on a thread that bears some characteristics that makes it comparable to the *Infertilitate...* Romanian forum. The “Poor Response/Treatment With Low AMH/High FSH” (referring to a difficult to treat category of patients who present with low ovarian reserve – hence “Low AMH¹¹” and a significant hormonal imbalance – hence the “high FSH”¹²) is a thread reuniting patients with a poor prospect of fertility treatment success. In this section, patients created a smaller chat group, the “Low AMH/High FSH Cycle Buddies”, where 30 participants gave 366 replies in the last active part of the thread (the last post was on January 24, 2022).

¹¹ AMH is the Anti-Müllerian Hormone; According to the National Library of Medicine, “an AMH test is often used to check a woman's ability to produce eggs that can be fertilized for pregnancy” – for further reading <https://medlineplus.gov/lab-tests/anti-mullerian-hormone-test>.

¹² The FSH is the follicle stimulating hormone, a hormone produced by the pituitary gland, that plays a key role in fertility.

Each user can insert a small medical history in their signature, so that readers and fellow forum members can instantly place their messages into a comprehensive context. Some choose shorter descriptions, consisting of age, ovarian status and number of IVF treatments, while other opt for longer ones. This section offers users an excellent opportunity to familiarize with the specific jargon of infertility treatment, but also to find encouragement and consolation that others have gone or are going through similar experiences. For example, one user gave a long and detailed account of her fertility treatment status in her signature:

“Me 46 Endo, DH 38. Nov15 Lap 1 cystectomy ablation. Dec15 Natural BFP MMC 10wks. Requested Karyotype testing but hospital stored incorrectly ❤️. Apr17 Gennet PICSI. 2 eggs 2 blasts. 1trf 1 Frosties. Bleeding 7dp5dt Oct17 ARGC - ICSI. 8 eggs 7 fertilised, 3 blasts ET, 2 d6 frostie, Immune support IVIG. BFN. 2018 Dr G immune testing. 2018 - 2019 Create 3 cyc natural modified. 1 frostie d3 8 cell grade1,1 no fert, 1 d3 grade ET BFN; Apr19 Lap 2 excision, natural BFP, MC 6.5wks. Nov 21 Lap 3. Jan/Feb 22 FET BFN”¹³ (forum user, January 18, 2020).

This concise and abbreviated medical history is an eloquent example of the alternative ways in which a patient can narrate the experience of their illness. In this case, the apparently abstract discourse, lacking the usual personal and emotional markers of proper pathography offers a “map” of the patient’s journey written in the specific jargon of online patient forums. The user ‘speaks’ to a specific audience, one that is familiar with the acronyms and the forum jargon, therefore they establish a symbolic connection that is at the same time abstract, textual and visual. Telling one’s story in an abbreviated manner saves time, it is essentially informative, and it may fulfill the need of other users to find similar stories that offer hope, consolation, and information about treatment outcomes, etc.

¹³ Endo – endometriosis; DH- dear husband; lap- laparoscopic surgery; BFP- Big Fat Positive (positive pregnancy test); MMC- missed miscarriage; PICSI - Physiological intracytoplasmic sperm injection (a specific technique of in vitro fertilization in which a single spermatozoon is injected into a single oocyte for the purpose of fertilization); blast – blastocyst (5-day old human embryo); trf - transferred (referring to embryotransfer – transferring an embryo into the woman’s uterus); frostie – frozen embryo; 7dp5dt – 7 days post 5 day (embryo) transfer; ARGC – British clinic in London; ICSI (intracytoplasmic sperm injection); ET – embryotransfer; d6 frostie – 6 days old frozen embryo; BFN (Big Fat Negative) – negative pregnancy test; Create (Clinic in London) 3 cyc natural modified – 3 cycles of natural modified treatment; d3 8 cell – day 3 embryo of 8 cells; grade 1 – grade 1 embryo with little or no fragmentation; no fert - no fertilization; MC – miscarriage; FET - frozen embryotransfer.

Interestingly, users tend to structure their posts as a collage of separate answers to all the other users they interacted with, thus replicating the manner in which Facebook comments are fashioned. The fragmentary nature of each answer gives the impression of a personal narrative adapted to a specific conversation with a particular user – for example, the same user whose signature was discussed above gave medical details to a user she was sharing treatment protocols with, and just below that conversation, as if an invisible line divided the two separate worlds, she wrote to another user that she was going to Nepal on vacation with her family. Similar to the Romanian Facebook group *Infertilitate...*, this thread is emotionally charged. Users give details about their IVF protocols, sharing patient opinions on treatment, but they also discuss manners of coping with loss, depression, jealousy, and a pervasive sense of meaninglessness. One user who had been active for 8 years on this board shared the fact that, after succeeding to have a child via IVF in 2015 (despite a firm diagnosis of ovarian failure), her subsequent rounds of treatment proved increasingly discouraging. In 2021, a medical professional advised her to seek psychiatric treatment, as she had attempted IVF more than 15 times in the past 7 years. Her thoughts about her loss of fertility echo the imaginary awareness women should have about the decline of their fertility with age:

The kind of grief you get with loss of fertility is just impossible to ignore or easily get over and no time or distance seems to help. I buried myself with work but the deep sadness is still there. I also feel so angry at the whole covid situation that effectively robbed me of my last months/years of fertility as we were unable to travel. I am only 45 but it looks like I am out of the game. [...] I remember thinking that I'd draw the line at 45 but now when I am actually here I feel like I have it in me to fight if only I had any eggs left (Facebook user, August 23, 2021).

This user inserted a link in her signature to the story of her only IVF success in 2015, proving her predisposition to complex narratives disclosing a rich personal philosophy regarding fertility. A professional woman (she often mentioned her highly qualified, well-paid job), this user had a firm representation of familial harmony that she was unwilling to renounce. Despite her very low chances to get pregnant, she persevered and learned, in minute detail, the complicated physiology of human reproduction, taking charge of her treatments and negotiating with medical professionals what she felt was the best course of treatment. However, a visible and consistent sense of loss, a sadness taking the shape of mourning, a grief permeated the massive discourse she created as a user on these forum boards. “I buried myself with work but the deep sadness is still there”, with its poetic (yet plain) undertones could be read as a contemporary elegy of female agency.

A brief comparison between the two media (The *Fertility Friends* forum and the *Infertilitate...* Facebook group) highlights significant cultural differences regarding the perception of infertility by users. Linguistically, it is striking to acknowledge the divergent attitude towards acronyms and infertility treatment jargon. Romanian users are almost frugal in their use of this vocabulary, resorting to few such terms – “blasto”, FET (frozen embryotransfer), ET (embryotransfer), BFP/BFN, FIV (“fertilizare in vitro”/in vitro fertilization). English and international users use a vast idiom that works like a closeted language of a particular group, a microcosmos with its own laws and rules: terms such as PUPO (pregnant until proven otherwise), BD (babydance, meaning sexual relations), AF (Aunt Flo, that is menstruation), swimmers (spermatozoa) are as frequently used on forum threads as any other word from the vocabulary of infertility. Another distinctive trait is the separation between personal religious faith and public discourse. *Fertility Friends* has a special sub-forum dedicated to spirituality and few users invoke their religious views in current conversations with other users of the forum. Romanian users, as discussed above, tend to frequently include a religious dimension in their interactions. Sometimes users become verbally aggressive, without resorting to insults or inappropriate language. A certain discursive boldness often surfaces as a potential cultural trait, although the fundamental intentions of the users are polite and positive. Politeness (direct or negative) is fundamental on *Fertility Friends*, users intervening with great consideration to others’ feelings, given the extreme stress they undergo. Certain trigger warnings are not uncommon, as users are highly aware of the importance of emotional management during fertility treatment. No less significant is the trend on *Fertility Friends* to give more complex, nuanced and personal advice, creating small narratives that function both as therapeutic tools and information vectors. Yet probably the most significant difference is that, although it has an impressive number of users, the forum is on its way to becoming obsolete, as patients prefer social media platforms such as Facebook.

Conclusions

The public conversation about infertility is still far from having the desired form and outreach, given the growing number of young individuals and couples affected. The subculture of forums and Facebook groups, imperfect as it is, allowed for the creation of an environment where patients could find sympathy, comfort and advice from others experiencing the same challenges. The two online communities investigated display generic similarities – they are both founded on the generous intention to offer emotional support to infertility patients, filling an important gap neglected by medical institutions; users tend

to be mindful of other users' feelings and emotional needs, and thankful when they receive useful information and encouragement. In many cases, Romanian users tend to invoke religious elements, while forum posters from the UK tend to offer generic yet targeted advice, omitting culturally sensitive elements. The presence of online trolls is a relevant example of the reasons users should use online resources with a grain of skepticism and attention to warning signs when other users may try to mislead or deceive their readers. Medical advice is universally considered the primary source of healthcare, as administrators and "older" users tend to reinforce posting rules and advice sharing strategies that cannot replace medical opinion. On a strategic level, Facebook groups encourage more users to join the conversation around infertility, while forums tend to have a less flexible dynamic, giving the impression of a closed community that requires specific steps to join. However, the *Fertility Friends* forum is better organized thematically, while the *Infertilitatea...* Romanian group is more open and accessible. The information flow is inevitably more rapid on Facebook groups, while on forums it is more consistently verbalized, with useful details articulated in ampler narratives.

A closer examination of these media may prove revelatory for today's culture of eternal youth – biologically limited and highly vulnerable to genetic and environmental factors, fertility offers a lucid measure of our current illusion of control.

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