Assessing the impact of infertility on patient quality of life: a study based on social media in france

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Abstract

Background: Infertility is defined as the inability to achieve a live birth after one year of regular sexual intercourse, affecting 1 in 6 couples in France. The use of ART for infertility issues has been steadily increasing in recent years, with in vitro fertilization being the most common type of ART. Infertility is frequently regarded as a significant life crisis for many individuals, potentially leading to depression, anxiety, social isolation, and sexual dysfunction. Couples experiencing infertility demonstrate a high prevalence of negative emotional responses and decreased life satisfaction as a result of infertility and its treatments. Social media have become key tools for finding and disseminating medical information.

Objective: This study aims to explore the most discussed topics among patients with infertility and to characterize the impact of infertility and ART on their quality of life by analyzing social media data.

Methods: This retrospective observational study includes French messages from patients in France discussing their infertility between 2019 and 2022. A Biterm Topic Model (BTM) algorithm capable of automatically identifying the different topics discussed was applied. A quality of life (QoL) algorithm classified the messages according to 5 dimensions: physical, psychological, activity-related, social and financial.

Results: An analysis was carried out on a corpus of 26,919 messages written by 9,807 patients. The subjects most frequently discussed were the ART procedures, marked by miscarriages (21%), ovulation cycle monitoring (19%), and baby trials in relation to professional life (13%). Concerning the impact on quality of life, patients mainly expressed a physical impact (62%), particularly linked to miscarriages (59%). Psychological impact (52%), including fear and anxiety (61%), was also mentioned. The social dimension of infertility (11%) - notably its effects on married life (67%) - the financial burden of infertility treatments (9%), and the impact on activities (9%) were also addressed.

Conclusions: Patients facing infertility share their experiences on social media. We observed a strong impact on their quality of life, affecting their physical and psychological health, as well as their social, financial and professional lives. These results underline the importance of taking into account the multiple dimensions of infertility when caring for patients, and highlight the crucial role of social media in supporting and understanding this reality. Clinical Trial: Not applicable

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ASSESSING THE IMPACT OF INFERTILITY ON PATIENT QUALITY OF LIFE: A STUDY BASED ON SOCIAL MEDIA IN FRANCE.

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Abstract

Background: Infertility is defined as the inability to achieve a live birth after one year of regular sexual intercourse, affecting 1 in 6 couples in France. The use of ART for infertility issues has been steadily increasing in recent years, with in vitro fertilization being the most common type of ART. Infertility is frequently regarded as a significant life crisis for many individuals, potentially leading to depression, anxiety, social isolation, and sexual dysfunction. Couples experiencing infertility demonstrate a high prevalence of negative emotional responses and decreased life satisfaction as a result of infertility and its treatments. Social media have become key tools for finding and disseminating medical information.

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Conclusion: Patients facing infertility share their experiences on social media. We observed a strong impact on their quality of life, affecting their physical and psychological health, as well as their social, financial and professional lives. These results underline the importance of taking into account the multiple dimensions of infertility when caring for patients, and highlight the crucial role of social media in supporting and understanding this reality.

Trial Registration: Not applicable (not a trial).

Keywords: Infertility, ART procedures, quality of life, social media.

Introduction

Infertility is defined as the inability to achieve a live birth after one year of regular sexual intercourse, affecting 1 in 6 couples[1]. The major causes of infertility are ovulatory dysfunction, tubal infertility, endometriosis,, uterine and cervical factors, and male factor infertility[2]. According to the Report on the Causes of Infertility submitted to the French Ministry of Health, nearly 3.5 million people in France are impacted by infertility. One in every four couples of childbearing age are unable to achieve pregnancy after one year of unprotected intercourse[3]. The proposed treatments for infertility include lifestyle changes, medication, surgery, and Assisted Reproductive Technology (ART)[4,5]. The use of ART for infertility issues has been steadily increasing in recent years[6], with in vitro fertilization (IVF) being the most common type of ART[7]. According to the French Biomedicine Agency, the use of ART has been on the rise with 3.6% of children, or roughly one in every 28 births, born through ART[8]. Despite ongoing research efforts, up to 25% of infertility cases remain unexplained[9].

Infertility is frequently regarded as a significant life crisis for many individuals, potentially leading to depression, anxiety, social isolation, and sexual dysfunction[10]. Couples experiencing

infertility demonstrate a high prevalence of negative emotional responses and decreased life satisfaction as a result of infertility and its treatments[11].

The psychological burden on couples substantially affects their overall well-being, willingness to continue treatment, and satisfaction with treatment outcomes[12,13]. Drop out from treatment is a major cause of not fulfilling the child desire, therefore, it is essential to assess and consider quality of life (QoL) in the context of infertility.

In recent years, the rise of digital platforms and social media has provided a unique window into the experiences of patients. Online communities and forums offer spaces for individuals to share their stories, seek advice, and find support from others facing similar challenges[14,15]. These platforms also serve as valuable repositories of patient-generated data, offering insights into the nuanced ways infertility affects individuals' lives. By analyzing the discussions and themes prevalent in these online spaces, researchers can gain a deeper understanding of the multifaceted impact of infertility, especially with the lack of social media listening studies on this matter.

This study aims to explore, for the first time, the most discussed topics among patients with infertility and to characterize the impact of infertility and ART on their quality of life by analyzing social media data. By examining a substantial dataset of messages from various online platforms, this research seeks to highlight the key concerns, emotional and physical challenges, and the overall experiences of individuals navigating infertility.

Methods

Study Design and Population

This is an observational, retrospective, real-world study encompassing data extracted from social media posts of patients with infertility. The duration of the study spanned from 2019 to 2022.

Data Extraction

Messages written in French, geolocated in France and posted between 2019 and 2022, were included. The data ultimately retrieved is composed of messages from public sites (e.g., X , formerly Twitter) and health-related forums (e.g., Doctissimo). Due to restricted data access, only public Facebook pages and open groups were analyzed (i.e., Fiv.fr, PMA, Asso BAMP, Notre bataille contre l'infertilité, Avoir un enfant à 40 ans, Fertilog), while Instagram and WhatsApp were excluded from this study due to the complexity of their extraction (Application Programming Interface).

To gather relevant data, a list of keywords associated with infertility (e.g., "infertilité" (French translation for infertility), "fiv" (French translation for ivf-in vitro fertilization), "fausse couche" (French translation for misscarriage), was meticulously compiled and subsequently inserted in the extraction query. The complete list of these carefully selected keywords was subsequently used in the extraction query (**Appendix 1**).

Data extraction was performed by the Brandwatch® extractor (Cision Ltd.)[16]. First, we collected publicly available posts found on X and forums featuring one of the relevant keywords. In parallel, we performed Web crawling -or data collection- on the previously selected, publicly accessed Facebook pages. Posts were retrieved along with their associated metadata (e.g., author, or publication date). As a result, the dataset was created in Microsoft Excel.

No distinction was made in the treatment of posts obtained from different platforms, ensuring equal consideration and analysis across all sources. During the pre-processing phase, pertinent messages were selected based on the following exclusion criteria: posts consisting of five words or less, as well as those exceeding 10,000 characters, were disregarded due to their lack of relevance and to optimize text processing. Additionally, duplicates were removed as well as

sources deemed unreliable or irrelevant to our study (e.g., advertising websites, forums about cars, pets, or animals). Lastly, posts not written in French, were excluded.

To further advance the filtering process, a supervised machine learning algorithm was applied to identify posts associated with patients' or caregivers' experiences. This algorithm was previously developed using a training set of 12,330 messages related to different health domains (dermatology, tobacco use, oncology, among others). The method consists of a pipeline featuring two XGBoost [17] classifiers (one for caregivers' experiences, one for patients'), applied successively. This method allowed us to identify if a post belonged to a patient, a caregiver, or neither. Evaluation of performances yielded F1 scores (a measure of accuracy combining precision and recall) of 88% and 87% for the caregiver and patient classifier, respectively.

In the present study, only posts from patients and caregivers were considered for analysis. In the remainder of this article, we will refer to all users who are patients or caregivers as "patients".

Ethical consideration

This study included data from publicly available sources; private groups/web pages were thus excluded from our data extraction process. We did not seek approval as users automatically grant their consent for the reuse of their data when they post on public platforms. Furthermore, the results of this study do not contain any identifiable information and are presented in aggregate. Information such as the name, username/handle, geographic locations, or any other sensitive data were not included. Furthermore, the names of the treatments were also removed and replaced with a generic [TREATMENT] placeholder in the messages.

Data Analysis

Demographics

We identified patient or caregiver age and gender through a manual examination of the text, particularly when this information was explicitly provided, as exemplified below:

"[...] i'm 34 and we've been trying to have a baby for 3 years..."

In cases where age and gender information were not explicitly mentioned, we categorized the data as "undetermined."

Topics of discussions

Main discussion themes were identified through the examination of all posts from patients regarding infertility. This was performed using Biterm Topic Modeling thanks to the BTM R package[18]. BTM is a natural language processing, text mining approach, which clusters similar texts based on common discussion topics and provides lists of words to be interpreted for cluster labelling[19]. Topic modeling considers documents (messages/posts) as a mixture of topics that are probability distribution over the words of the dataset. A post can then be associated to its most prominent topic. The Biterm Topic Modeling provides, for each topic, a list of the twenty highest probability words and all the posts associated to the topic. To ensure an unbiased analysis, we applied BTM without any presuppositions about the topics that might emerge from the data. As a result, BTM automatically organized the posts into categories, ranked by the frequency with which they appeared in the dataset. Through human interpretation, these lists of words were used to label the topics, and the associated posts were thoroughly scanned to ensure correct interpretation.

Impact on QoL

To assess the impact on the QoL, we developed a deep learning algorithm using regular expressions (Regex) to detect relevant keywords and phrases. The algorithm categorized messages into five dimensions: physical (with keywords related to physical health concerns or limitations) psychological (emotional distress or mental health challenges), social (changes in interactions or isolation), financial (financial difficulties or work limitations), and daily activities (alterations in daily routines or lifestyle).

The algorithm was refined and validated based on established QoL questionnaires, the EQ-5D [20] and SF-36 [21], to ensure accuracy and consistency in the categorization process. Subsequently, qualitative analysis was performed via annotation of messages to validate and interpret our findings.

Results

Population and Posts

Between 2019 and 2022, a total of 536,708 messages were retrieved written by 141,051 internet users discussing infertility. After data cleaning, 26,919 messages from 9,807 users were retained (Figure 1).

Figure 1. Flow chart of the data cleaning and sample selection processes

A total of 37 sources were included in this study (Appendix 2). More than 80.0% of the retrieved data was extracted from 3 main sources: Doctissimo (9,281 [34.5%]), babycenter.fr (6,949 [25.8%]) and au féminin.com (5,670 [21.1%]); Subsequent analyses were not segmented between sources.

Table 1. Top 10 data sources

Forum/Social Media	Number of posts, n (%)	Number of users, n (%)
DOCTISSIMO	9,281 (34.5)	1,716 (17.5)
BABYCENTER.FR	6,949 (25.8)	3,438 (35.1)
AU FEMININ.COM	5,670 (21.1)	1,802 (18.4)
FIV.FR	1,597 (5.9)	739 (7.5)
X	1,103 (4.1)	850 (8.7)
ENCEINTE.COM	911 (3.4)	335 (3.4)
PARENTS.FR	254 (0.9)	108 (1.1)
FACEBOOK	231 (0.9)	216 (2.2)
HARDWARE.FR	224 (0.8)	134 (1.4)
PSYCHOLOGIES	149 (0.6)	103 (1.1)
Others	550 (2.0)	366 (3.7)

Among the extracted posts where users specified their gender (8,813 [89.9%]), more posts were written by females (7,942 [81.0%]) than males (871 [8.9%]). The gender of the rest of the posts was undetermined (994 [10.1%]). The average age was 35.0 years.

Topics of discussion

Following the application of the Biterm Topic Modeling (BTM) on the dataset including all the messages retained (N=26,919), various discussion topics were identified thanks to human interpretation of each topic's most associated terms (Table 2).

Table 2. Proportions of messages by main discussion topics, including examples of messages

Topics	Proportion of messages, n (%)	Example of message
Assisted Reproductive Technology (ART) procedures, and miscarriages	5,671 (21,1%)	*"Yes, don't be too fooled by the figures: not all women produce the same amount of beta hcg. That's why the gynecologists don't dwell on it. I'm in ART..they say that it's only the ultrasound that counts. I also had a miscarriage in March and I tell myself that when it's going to work again I'm not going to be happy right away."*
Tracking ovulation cycles	5,068 (18,9%)	*"Here I am at day 37, stillno menstruation, although it's been almost2 years since my cycles last exceede3d1 days! The abortion upset me"*
Balancing attempts to conceive with work responsibilities	3,476 (12,9%)	*"Yes, girls, I'm trying not to think about it too much after two miscarriages, I'm scared. What scares me is that at work I sometimes have to carry heavy things, I'm going to be careful, I can't tell my boss, she could fire me".*
Pregnancy and ovulation testing	3,446 (12,8%)	*"Here, I did the insemination on Monday. I'm not sure when I ovulated though. I've done ovulation tests, but I'm not sure how to interpret them. Since I took [TREATMENT] last Saturday, I think that influences the result. Since Monday, my tests have been dark. What do you think?"*
Ultrasound scans	3,142 (11,7%)	*"Transfer done! Now I just have to wait... I got a picture of the embryo and another of the ultrasound "*
Waiting periods before pregnancy	2,981 (11,1%)	*"we had a baby after 20 years of infertility and 12 years with my husband ... We did the mourning of having children and bam pregnant!!!"*
Egg donation	1,525 (5,7%)	*"As someone who has had to deal with repeated failures, I try to tell myself that the most important thing is to be able to bear a child one day. there's still egg donation. I'm holding on to this idea because I know it would make me very happy."*
Pain and physical discomfort	1,286 (4,8%)	*"Girls, has [TREATMENT] DPO 10 disappeared yet? This morning when I got up I felt pain on my right ovary like a stitch on the side, weird, has it ever happened to you?"*

The discussions among patients dealing with infertility covered a range of deeply personal experiences. The most talked-about topics included users sharing their experiences with ART procedures, particularly those resulting in miscarriages (21.1; 5,671). Many users discussed their complicated journeys involving multiple miscarriages, expressing the stress and anxiety

of facing potential future losses. They also shared stories of successive failures, detailing the emotional and physical toll of repeated unsuccessful attempts. Some users shared positive messages including encouragements and sharing of experiences between women going through the same ordeal, as well as positive stories of ART journeys, despite the many obstacles along the way. Users also shared the detailed tracking of their ovulation cycles (18.9; 5,068). They discussed their ovarian stimulation: the process, their treatment and check-ups. Together, they tried to better understand their cycle and recognize its signs. Furthermore, they described their experience with balancing attempts to conceive with work responsibilities (12.9; 3,476), particularly the exhaustion they experienced during conception attempts or early stages pregnancies, whether it was a natural process or induced by various treatments. In some cases, it became impossible for them to continue working or they would have to adjust their activities to favor implantation and reduce miscarriages.

They therefore discussed the need to "slow down" or even take a break from work. Another prominent topic is the rollercoaster of pregnancy tests and ovulation tests (12.8; 3,446). Users turned to social media to find a community that helped them interpret their tests in case of ambiguity. They also shared their disappointment when the results were negative. They discussed the "right time" to take tests and which tests were reliable, and communicated their fears regarding the results. Updates from ultrasound scans (11.7; 3,142) also featured prominently, and the conversations extended to the waiting periods before achieving pregnancy (11.1; 2,981), the complexities surrounding egg donation (5.7; 1,525), and the pain and physical discomfort associated with fertility treatments and the reproductive system as a whole (4.8; 1,286).

Impact on QoL

In our study, 59.0% of users (n = 5,786) expressed at least one impact on their quality of life.

Figure 2. Proportions of users expressing an impact of infertility on QoL

Users turned to social media to describe the extent of infertility's impact on their QoL. The most frequently reported impacts were physical (62.4; 3,610), followed by the psychological (52.2; 3,015), social (11.3; 651), financial (9.0; 518), and daily activities (8.7; 503) (Figure 2).

Figure 3. Proportional breakdown of infertility's impact on Quality of Life

The physical impact (62.4; 3,610) mainly included miscarriages (59.2; 2,137), where patients may endure multiple miscarriages and ongoing repercussions. Menstruation and pregnancy symptoms (38.1; 1,375), such as pain and nausea and treatment side effect (15.3; 552) such as fatigue andweight gain, were also common (Figure 3). An example of a message shows the extent of the physical impact *“I’ve had several miscarriages and the pain never gets easier, horrible cramps and losing blood, it’s excruciating”*

The psychological impact (52.2; 3,015) included feelings of fear, anxiety and distress (60.3; 1,818), such as stress over test results and fear of miscarriage post-complication trauma (26.0; 784), and feelings of despair (8.3; 250), were also described. An example message: *“My period is here ... a 26-day cycle. I can't take it anymore, I'm fed up ... I never thought we'd have so much trouble getting pregnant. One more month and it'll be a year for us trying ... I already don't have the strength to fight any more, so how will I have the energy to go any further with the tests, to make an appointment for ART as my doctor advised?”*

The social impact (11.3; 651) affected couples' relationships (67.3; 438) and family dynamics (21.4; 139), The social impact is shown in the following example *“That's the way it was with us! Simply, I couldn't stand any more FiV, my moral state was destroying our family, so we would either accept not having children or ask for help.”*

The financial impact (9.0; 518) mainly revolved around treatment costs (57.3; 297), which were related to users’ desire to attend reputable centers in France or abroad, leading to additional expenses, or when social security reimbursement limits were reached after multiple IVF failures. Pregnancy tests (19.0; 98) were also a concern as they are non-reimbursed. The following message illustrates the financial impact “*Appointment taken at [CITY] for July 17, I had my file transferred. although I know that nothing is easy in ART but financially I’m stopping after [CITY]! Visits cost 130 euros, 50 of which I pay... 350 per hospitalization. everything is times 3! Damn, I missed a great vacation... yeah well, I'm a little angry now".*

The impact on daily activities (8.7; 503) affected professional life (46.2; 232), with many taking time off for appointments and exacerbated symptoms. Daily life disruptions (28.4; 143), impacts on sexual life (15.1; 76) were also noted. An example message *“I'm just the opposite of you, I had to go to great lengths to get off work because I didn't feel well in the evening when I got home from work. I'm also pregnant following IVF, and my gynecologist told me that if I wanted to be off work, I'd have to check with the occupational medicine department.”*

Discussion

The most discussed topics about infertility on social media included the emotional and physical challenges of ART procedures, particularly those resulting in miscarriages (21.1%), and the detailed tracking of ovulation cycles (18.9%). Balancing attempts to conceive with work responsibilities (12.9%), the rollercoaster of pregnancy and ovulation testing (12.8%), and updates from ultrasound scans (11.7%) also featured prominently. The conversations extended to the waiting periods before achieving pregnancy (11.1%), the complexities surrounding egg donation (5.7%), and the physical discomfort associated with fertility treatments (4.8%). In our study, 59.0% of users (n = 5,786) expressed at least one impact on their quality of life.

The impact of infertility is complex, affecting all aspects of a patient's life. It encompasses physical, psychological, social, financial, and daily activity domains, significantly impacting individuals with infertility. Our analysis revealed that the consequences of infertility and its treatments were important, with patients requiring a comprehensive understanding and approach. Our findings align with findings of previous research in infertility [11,22–26].

Our research revealed a dominating physical impact of infertility that is closely intertwined with psychological effects. Physically, infertility and its treatments introduce a host of challenges. Patients undergoing fertility treatments often experience side effects such as physical discomfort, poor tolerance, fatigue, dizziness, abnormal menstrual bleeding, which can lead to the discontinuation of treatments[22,27].

The stress associated with infertility and its treatments can lead to feelings of anxiety, depression, and emotional distress[27]. Patients often face cycles of hope and disappointment, particularly when waiting for test results or fearing miscarriages. Failure in conceiving can leave lasting emotional scars, sometimes resulting in post-traumatic stress symptoms, especially in the case of recurrent pregnancy loss[28]. Feelings of despair and hopelessness are common, especially after repeated treatment failures, leading some individuals to abandon their hopes of having children. This creates a vicious cycle, as infertility increases stress levels[29,30], and stress may, in turn, exacerbate infertility[11]. The emotional impact of miscarriages following ART procedures is particularly devastating. with patients experiencing profound grief, sadness, and a sense of loss. The psychological toll can be compounded by feelings of failure, guilt, and loneliness[31], as well as the fear of experiencing subsequent miscarriages[32]. These findings underscore the importance of robust psychological support systems tailored to

the needs of infertility patients.

The physical and psychological impacts often spill into all aspects of patients' lives. The time and mental energy required to manage this condition are immense. Managing treatments, coping with potential failures and losses, rigidly tracking ovulation cycles, and meticulously planning each decision consume significant portions of a patient's life, leaving little room for other interests. This overwhelming burden affects everything from work responsibilities to simple leisure activities, depriving individuals of the time and space needed for a balanced life. Women suffering from infertility often find it challenging to maintain high work productivity while coping with the side effects of treatments and the numerous medical examinations and procedures[33]. These treatments are often time-consuming and unpredictable, complicating the ability to manage daily life effectively[23]. Many women choose not to discuss their infertility treatments at work, but this can become complicated, especially when increased absenteeism due to medical appointments or managing treatment side effects becomes necessary[33]. The amount of time dedicated to the management of infertility limits patients' ability to engage in simple leisure activities, hobbies, and self-care[23,34]. This raises concerns about the potential impact on their psychological state, as the constant stress and lack of respite can be overwhelming. Furthermore, the absence of time for their usual activities and hobbies may cause their identity to become solely defined by their infertility struggles.

These significant impacts inevitably extend to affect patients' relationships. The constant stress can strain the couple's life, and their sexual relationship may also suffer as a result[25,35]. Sexual intercourse becomes unenjoyable, and only a means to conceive[23]. Some women express feelings of anger and resentment towards their partner, particularly when their partner is identified as the cause of infertility. Additionally, some women perceive their partner as being less invested and more passive in the journey to conceive, leading to further emotional distress and tension within the relationship[23]. What exacerbates the situation is the social stigmatization that couples, particularly women, might face and the pressure from their social environment. This often leads them to conceal their condition, and avoid social gatherings and events related to babies, such as baby showers and children's birthdays. Consequently, their relationships with family members may suffer, potentially leading to social isolation and feelings of shame[35–40].

On a financial level, patients reported treatment costs as significant concerns. This is

particularly the case of repeated IVF failures as IVF is only reimbursed up to 4 cycles[41]. Despite comprehensive health insurance in France, research found an increased risk of non-access among women below the poverty line and among populations living in remote areas far from fertility centers[42]. Some women, who have the financial means, opt for cross-border fertility treatments, including oocyte and sperm donation, in countries such as Spain, Belgium, and Greece[43], which may exacerbate financial costs.

Given the profound impact of infertility on patients' lives, as well the possible secrecy and stigma surrounding this situation in relation to their social environment, many patients find solace and support on online communities. Social media can offer information[44] as well as the ability for patients to connect with other people with similar experiences[14,45]. The ability to engage anonymously in online forums is highlighted as one of the most appreciated aspects[45]. Numerous women indicate a preference for this anonymity, as it enables them to express their feelings and find resources to support their psychological well-being without needing to reach out to those around them. This also allows them to maintain a sense of human connection[45,46].

In practical terms, ART services in France have started implementing several measures to help patients and professionals manage the psychological impacts associated with infertility treatments more effectively. Many clinics now integrate psychological counseling into their fertility treatment protocols. This is particularly beneficial given that French patients were more likely to have required support by a mental health professional due to fertility problemst[47]. Engaging in therapy can help couples alleviate emotional distress, gain fresh perspectives, and expand their range of actions, instead of succumbing to unrealistic expectations, blame, guilt, resignation, and hopelessness[48]. Additionally, guidelines for mental health specialists for counseling and training of medical staff are increasingly being developed to help couples navigate their infertility journeys more effectively[48,49].

Limitations

This study shares the inherent limitations of social media research, namely that patient-provided information is both authentic and voluntarily shared in the public domain. This analysis relied solely on publicly available social media posts, precluding data collection from non-public platforms like closed Facebook groups. The quality of insights derived from digital conversations relied upon the depth of information disclosed by patients, encompassing details concerning their health condition, frequently discussed topics, and overall QoL. In cases where information was lacking, context and representativeness became uncertain. Data quality also

depended on the digital literacy of users, affecting their ability to convey information accurately, including specific details about their condition and treatment. These self-reported data may be susceptible to recall bias, relying on memory and personal recollection. Individuals who contribute to social media discussions may not accurately represent the broader infertility patient population, as they may constitute a group with serious impactful condition. We are unable to verify contributor characteristics, such as demographics and clinical information, which could limit the accuracy of testimonials. Moreover, it is worth noting that relevant posts might have been mistakenly eliminated during the filtering process, and the potential for duplication exists in cases where users were engaged on multiple forums. To reduce background noise, we employed threshold values similar to our previous work [51–53] which may have constrained the natural processing analysis. Despite these limitations, this study provides valuable insights into the impact of infertility on patients' lives, derived directly from their input.

Conclusion

The findings of this study underscore the profound impact of infertility on patients' lives, touching on physical, psychological, social, financial, and daily activity domains. By analyzing the extensive discussions on social media platforms, we have gained valuable insights into the lived experiences and challenges faced by individuals struggling with infertility. Notably, miscarriages were the main reported concern of patients. These online communities provide an important space for patients to share their stories, seek support and answers, and find solace, often benefiting from the anonymity these platforms offer. These narratives reveal not only the physical and emotional toll but also the broader social and financial burdens that traditional medical settings might overlook. Healthcare professionals can leverage this understanding to develop more empathetic, personalized, and effective care strategies.

The study highlights the urgent need for holistic approaches in infertility treatment and support. Beyond the medical interventions, there is a critical requirement for robust psychological support systems tailored to the unique needs of infertility patients and for the management of the physical impact of infertility and its treatments. Addressing the emotional distress, anxiety, and depression associated with infertility is as vital as managing the physical aspects of treatment. Comprehensive care should also include strategies to help patients navigate the social challenges they face and alleviate the impact of infertility on their daily life. In conclusion, incorporating insights from social media discussions into clinical practice can enhance the quality of care provided to individuals dealing with infertility. By adopting a

holistic approach that integrates medical treatment with psychological support and social care, healthcare providers can better support patients in their journey, ultimately improving their quality of life and treatment outcomes.

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Conflicts of Interest
MMA has disclosed that he is employee of Ferring.
PV, JM, MT and SS have disclosed that they are employees of Kap Code, a CRO, with contracted with Ferring to carry out this study.
PEB and NM have nothing to declare.

Abbreviations
ART: Assisted Reproductive Technology
QoL: quality of life
BTM: biterm topic model
IVF: in vitro fertilization

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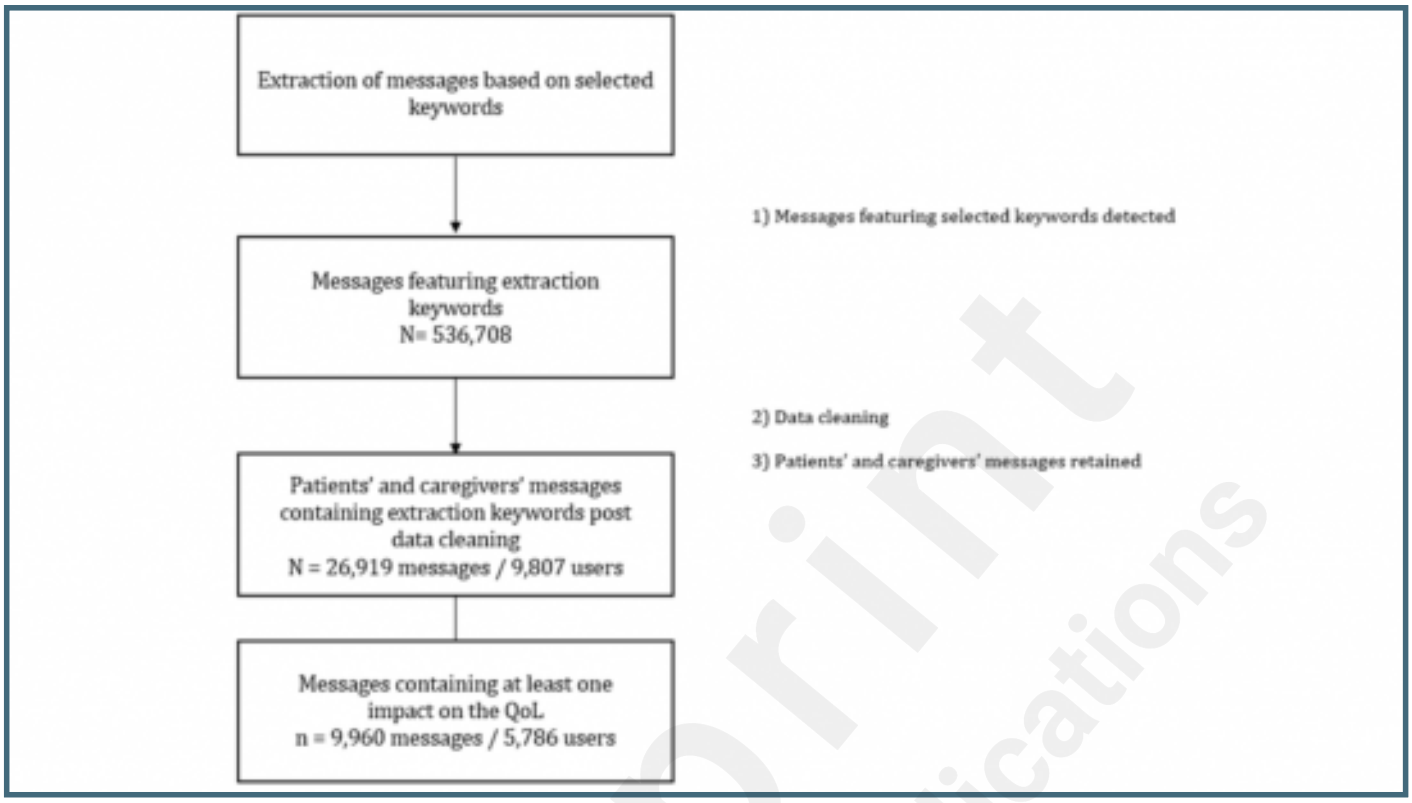
Supplementary Files

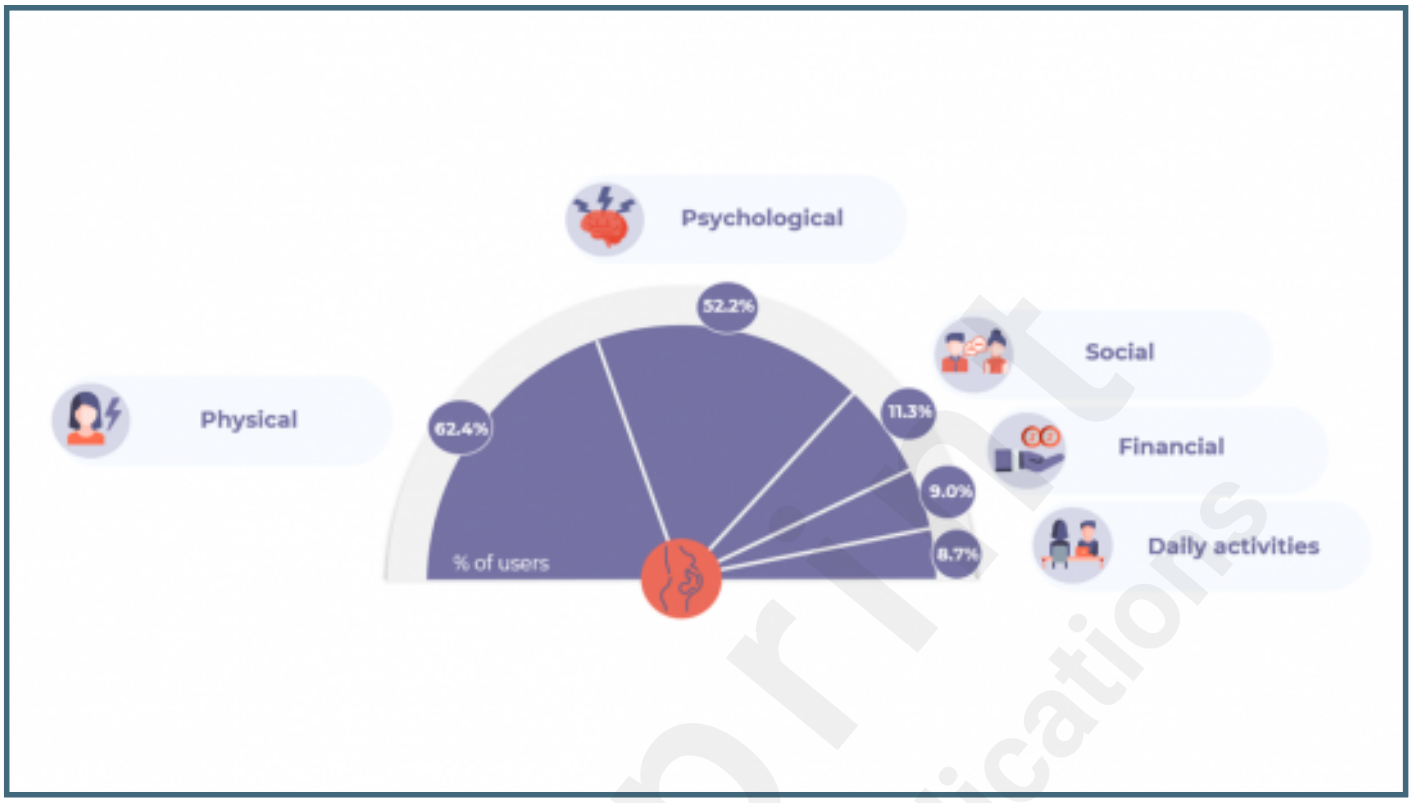
Untitled.

Figures

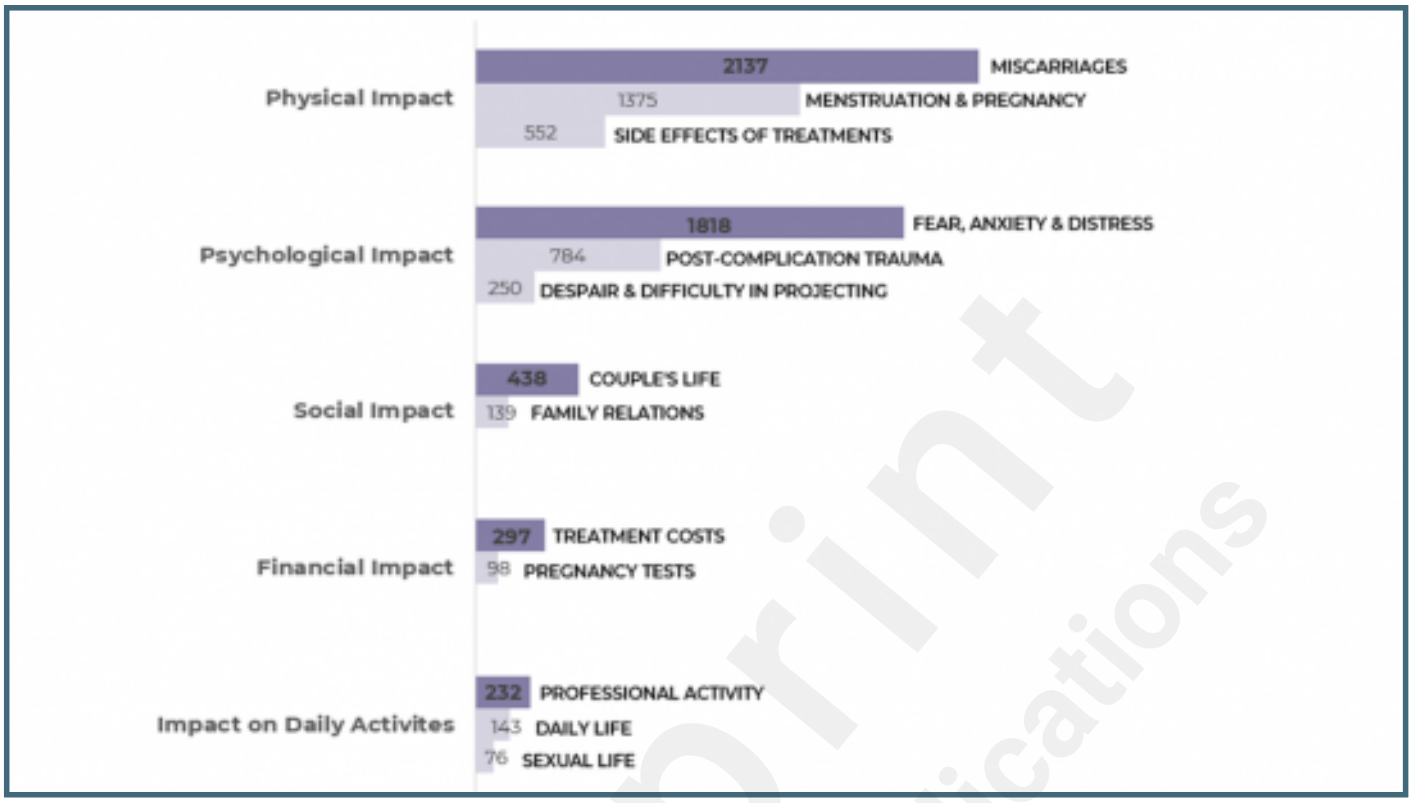
Flow chart of the data cleaning and sample selection processes.



Proportions of users expressing an impact of infertility on QoL.



Proportional breakdown of infertility's impact on Quality of Life.



Multimedia Appendixes

The extraction query.
URL: http://asset.jmir.pub/assets/8d6c2c16afdeef02ceb0e3199f99d808.docx

Sources were included in this study.
URL: http://asset.jmir.pub/assets/1e3a8e68b9a2da644df8e961a8919049.docx