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Original Article

TikTok as a Resource for Fertility Information and Support: A Patient Survey

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Abstract

Objective: TikTok is a rapidly growing social media platform with over 800 million users worldwide. Many patients access fertility-related content across social media platforms, however, this has never been studied related to TikTok. This study aimed to describe patient perspectives and experiences using TikTok for fertility-related content.

Materials and methods: We conducted a cross-sectional web-based survey from April 1st 2023 to October 1st 2023 at a large fertility center in Toronto, Canada. Patients were eligible for inclusion if they self-identified that they use TikTok for fertility-related content and had pursued any form of fertility care. Results of the survey were described with descriptive statistics and thematic analysis.

Results: A total of 23 patients with a mean age of 36.74±6.67 years participated in the online survey. Fertility-related TikTok content included lived experiences of fertility journeys descriptions of fertility treatments or procedures, live-streaming of fertility treatments or procedures, interactive questions and answers, and educational videos. Creators of fertility-related TikTok content include patients undergoing fertility treatments, physicians, naturopaths, counselors, and patient advocates. The most common reasons for liking TikTok for fertility content included empathy or shared experiences, stress relief, and self-education. Reasons for disliking TikTok for fertility information included misinformation, commercialization or advertisements, and negative emotions of stress, anxiety, or emotional upset. Misconceptions seen on TikTok included misinformation about complications and success rates for assisted reproductive therapy, as well as nutritional advice.

Conclusion: Fertility providers should have a growing awareness of information available on TikTok for patients accessing fertility care and assisted reproductive technology.

Keywords: TikTok; Fertility; Social Media; In Vitro Fertilization

Introduction

TikTok is a rapidly growing social media platform with over 800 million users worldwide and an average daily use time of 52 minutes per user (1, 2). The platform features short video clips that are targeted towards users and their associated communities through a highly sensitive and fluid algorithm (3). Any user can upload video-based

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content that is then made publicly available and promoted to other users based on the personalized data that the algorithm has collected. Per the TikTok Privacy Policy, this data includes demographic data collected during account formation, data from content produced by the user, content interaction data (ie. watch time, likes, shares and comments) and more. The role of the algorithm in creating personalize content for each user can result in the creation of TikTok "content communities" in which users are repeatedly exposed to content with a common theme or viewpoint. The sensitivity of this algorithm make TikTok stand out among other social media platforms for its great ability to quickly and effectively influence large groups of people about a variety of subjects, including healthcare.

Previous studies have demonstrated the significant impacts that TikTok can have on patient perspective and experience in relation to multiple public health topics (4, 5). In 2020 and 2021 Basch et al. analyzed content under hashtags relating to the COVID-19 pandemic and vaccinations, respectively. These studies highlighted the vast amount of health information accessible to TikTok users, from both healthcare professionals serving as "influencers" to disseminate medical information, and patients describing their experiences via video messaging (4, 5).

In 2022 Sampson et al. demonstrated that reproductive endocrinology and fertility is another public health topic that is frequently the subject of TikTok posts. TikTok features a variety of fertility-related content, including the experiences of patients undergoing infertility, video blogs of fertility treatments, as well as stories from both patient advocates and providers (6). While previous studies have found that social media may be a source of support and community for people with infertility or pregnancy losses (7), there is emerging concern regarding the potential for misinformation about public health topics. While TikTok is capable of quickly and broadly sharing health information and medical advice, this information may or may not be from reputable sources (ie. physicians or peer-reviewed studies) (8). Another concern in regard to fertility specifically, is the potential for TikTok content to trigger negative emotions or anxiety in fertility patients.

As such, the objective of this study is to analyze fertility-related TikTok content in order to gain a better understanding of the content available and its potential impacts on patient perspectives and experiences.

Materials and methods

A web-based cross-sectional survey was sent to a convenience sample of patients at a large academic-affiliated fertility center in Toronto, Canada. Patients were eligible for inclusion if they self-identified that they use TikTok for fertility-related content and had pursued any form of fertility care, including but not limited to fertility-related counseling, intrauterine insemination (IUI), in vitro fertilization (IVF), cycle monitoring, third-party egg or sperm donation, or naturopathic consult for fertility or recurrent pregnancy loss. There were no exclusions based on patient sex.

The survey was developed by a multidisciplinary team, including obstetrics/gynecology (OB/GYN) staff and reproductive infertility and endocrinology (REI) specialists. The survey was designed to be completed in 10 minutes or less. The survey included a mix of multiple-choice responses, Likert (a likelihood ranking scale), and short answers. The survey was pilot-tested by two end-users without healthcare knowledge to ensure ease of use. Specifically, the survey's content, readability of language, and time required for completion was judged.

Participants that opted into receiving research surveys were contacted with a survey link via phone call or email. All responses were completely anonymous and confidential. After minor modifications based on the pilot testing, the final survey was emailed to eligible participants via a mailing list of individuals who opted into receiving research emails. The REDCAP platform was used to ensure the confidentiality of responses. To increase response rate, personalized email reminders were sent one month after the initial mailing. There were no incentives for participants to participate in the survey. Participants were enrolled in the study if they consented for participation after reading eligibility criteria regarding use of TikTok for fertility content. Survey responses were collected from April 1st 2023 to October 1st 2023.

Results of the survey were summarized via descriptive statistics and thematic analysis. We first analyzed the multiple choice and Likert data via descriptive statistics to quantify the proportions of patients who use TikTok, the reasons for use and frequencies of use, and the responses to the Likert scale questions. We then analyzed the short-answer and long-answer data via thematic analysis. We then categorized repeated patterns of responses into coded "themes", which were interpreted via a consensus

approach by the study authors. Quotes were taken verbatim from the participants in the survey responses, in order to preserve and amplify the lived experiences of participants. The thematic analysis approach was taken from Braun and Clarke's 2019 Handbook (9).

Results

A total of 23 individuals participated in the survey, all of whom were female. The mean age was 36.74±6.67 years, with a range of 22 to 46 years. Only 3 participants (13.0%) were under the age of 30. A response rate could not be calculated as the prevalence of TikTok users among the fertility center patients could not be determined, and participation was based on self-determined eligibility.

The 23 participants included underwent diverse assisted reproductive treatments, such as cycle monitoring (n=7), ovulation induction (n=4), IUI (n=4), egg retrieval (n=9), IVF (n=4), third party egg and/or sperm donation (n=1), and naturopathic fertility consultations (n=4). Four patients were undergoing their fertility-related consult during the study and had not yet determined a treatment course.

Only 4 (17.4%) users were categorized as "frequent" TikTok users for fertility-related information, with two participants accessing fertility related-information on the platform on a weekly basis, one on a daily basis and one multiple times per day. The remaining 19 participants used TikTok less frequently. In addition to TikTok, participants reported using other social media platforms for fertility content, including Instagram (n=8), Facebook (n=3), and YouTube (n=3). WeChat was reported by one participant. No participants reported the use of Reddit or Twitter. One 40 year old participant specified that *"as an elder millennial, I only use Instagram"*, acknowledging that TikTok content is also reposted on Instagram. Similarly, another 43-year-old participant stated that they preferred Instagram to TikTok, although they used both for fertility content.

Fertility-related TikTok content included lived experiences of fertility journeys (n=6), descriptions of fertility treatments or procedures (n=4), live-streaming of fertility treatments or procedures (n=1), interactive questions and answers (n=5), and educational videos (n=7). Creators of fertility-related TikTok content include patients undergoing fertility treatments (n=7), family members or support systems of people undergoing fertility care (n=1), physicians (n=5), naturopaths (n=3), counselors (n=4), other healthcare providers (n=1), institutions (n=2), and patient advocates (n=4). One participant specified that they followed a fertility coach and acupuncturist on TikTok.

***Patient perspectives of TikTok*:** The most common reasons for liking TikTok for fertility content included empathy or shared experiences (n=5), stress relief (n=2), and self-education. For example, one 32 year old patient who had undergone IUI specified that they used TikTok "*to research further other people's lived experiences".* Reasons for disliking TikTok as a resource for fertility content were more diverse, including commercialization or advertisements (n=2), and negative emotions of stress, anxiety, or emotional upset (n=3). Two participants specifically identified that fertility-content was "triggering or emotionally upsetting". The most common reason for disliking TikTok for fertility-related content was misinformation related to fertility care (n=5).

Medical Advice on TikTok: Three participants described that they "sometimes" take medical advice from TikTok related to fertility care, while 10 participants described that they "never" take medical advice from TikTok. Of the 10 patients who stated that they would never take medical advice from TikTok, one 38-year-old patient explained *"I don't think TikTok is a place to find useful medical information, as it often comes from people who are not experts and therefore is misinformation."*

Two individuals responded that they "sometimes" talk to their fertility provider regarding something they saw or read on TikTok, while one participant responded that they "frequently" inquire regarding TikTok content. One 38-year-old patient who had undergone cycle monitoring, IUI, and egg retrieval explained: *"I'll look into things or ask my doctor about things I've learned about on social media from other doctors or other infertility warriors."*

As previously described, the most common reason for disliking TikTok for fertility-related content was misinformation spread on the application (n=5). Participants were asked how they would respond to any fertility information that they believed was false or of concern on TikTok. Five participants responded that they would simply ignore the information, four responded that they would ask for clarification from a healthcare provider, three responded that they would do their own research, two responded that they would ask a friend or family member and one responded that

they would watch another TikTok.

Participants identified several misconceptions regarding fertility seen on TikTok including misinformation about lack of complications and overestimation of success rates, as well as nutritional advice that was not factual. One participant also described seeing religious content promoted as fertility content.

Discussion

Ultimately, our survey of 23 fertility patients demonstrated diverse reasons for engaging in online fertility discourse, specifically on TikTok. Reasons for accessing TikTok ranged from emotional support to medical information regarding assisted reproductive therapy. Concerns with the use of TikTok included misinformation, emotional distress related to the fertility journey, and commercialization or advertisements. Although the majority of participants expressed hesitation about medical advice obtained from TikTok, there was a portion of patients who obtained health information from TikTok regularly and clarified information with fertility providers. Participants described multiple examples of misinformation about fertility on TikTok, including inaccurate success and complication rates. As such, it is important for healthcare providers to understand that patients may obtain information from multiple online sources with varying degrees of qualification including fertility influencers, patient advocates, and physicians. Fertility providers should engage in an open dialogue with patients to better explore patient knowledge, attitudes, beliefs and expectations in order to obtain informed consent and address any misinformation or questions.

The results of this study align well with the current literature surrounding infertility and social media. Infertility and recurrent pregnancy loss is known to be incredibly isolating, resulting in physical, emotional, and financial stressors (10-11). In addition, individuals who pursue assisted reproductive therapy often face societal stigma (12). As a result of this stigma anonymous online communities with individuals in similar circumstances can be an important source of connection, providing a space to gain validation, solidarity, and comfort without judgment. There have been several studies on fertility content in other social media platforms, specifically Instagram, which have produced similar findings to this study (13-17). These studies analyzing Instagram fertility content have also identified feelings of support and solidarity among those accessing fertility care, as well as opportunities to learn more about assisted reproductive technology. Many of the participants in this study also used Instagram for fertility-related content, and two participants specifically highlighted that they preferred Instagram for their online fertility content in comparison to TikTok. This preference for Instagram may have been effected by the age of the participants, as highlighted by one of our participants who self-described as an "*elder millennial*". Research has shown that the majority of TikTok users are under the age of 24, while the mean age of the participants of this study was 36 years (1). It is possible that as the population ages, more TikTok users will access assisted reproductive technology and thereby create a greater audience for fertility-related content on TikTok in comparison to Instagram.

Other public health studies of TikTok content in areas outside of fertility medicine have also demonstrated similar findings (8, 18, 19). Patients have reported hesitation towards obtaining health information from social media due to misinformation, as well as the tendency of the platform to enforce pervasive thinking patterns and facilitate endless scrolling due to health anxiety (20, 21). Only one of our included participants used TikTok multiple times per day for fertility-related content, but several reported feelings of emotional distress associated with the use of TikTok for fertility content. There is also a risk of obtaining biased information from paid influencers and advertisements, which was another concern expressed by participants in our study. As fertility care often features privatized clinics and commercial products (such as nutritional supplements, online lifestyle coaches, and mobile applications), it is important for patients to be able to differentiate between non-profit health information and paid product placements. On social media, the lines between advertisements and educational content are often deliberately blurred, and this should be addressed with fertility patients in the future.

Strengths of this study include its contribution to bridging the current gap in knowledge regarding the experience of fertility patients that are also TikTok users. This study highlights the need for future investigation on the impact of fertility content on new social media platforms. Although there have been multiple studies of Instagram, Twitter, and Facebook related to fertility content, this study is the first survey of patient experiences using TikTok for

fertility content (13-17). Importantly, this study focuses on the user experience, rather than relying on content assessments, which allows for a more patient-centered evaluation of the impacts of TikTok fertility content. Other strengths include the user-centered survey design and strong pilot testing, as well as preservation of patient voices through verbatim quotes.

Limitations of this study are largely due to the emerging nature of TikTok and the small sample size. The limited sample size is likely due to the difference in the average age of fertility patients compared to the average age of TikTok users. As such, this study should be considered a pilot investigation with the goal of serving as a foundation for future research. Future studies should conduct analyses of TikTok fertility content, specifically addressing misinformation that is present on the platform and stratifying this data by whether the information is provided by healthcare providers, institutions, influencers, or patient advocates. Advertisements and paid product placements should also be systematically evaluated for their evidence base, as well as purported claims.

Future studies should examine the online TikTok discourse regarding subthemes within fertility care. One topic of interest is the psychological impact of the COVID-19 pandemic on patients accessing fertility care. This is of significant interest due to the many cancellations of fertility-related treatments that occurred during the early portion of the pandemic, as well as the significant increase in TikTok usage that occurred during this time period (22-24). TikTok may also provide a valuable opportunity to explore perspectives of populations who are typically underrepresented in fertility research, such as racial and ethnic minorities or LGBTQ2S+ individuals, due to its nature as a barrier-free venue for public discourse and sharing of lived experiences (25-29). Finally, our study sample only included patients who identified as female, despite the survey being open to male and intersex patients as well. There are unique needs of non-female patients accessing fertility care, such as support through different experiences of social stigma, which could be better explored through examination of social media communities (30).

Conclusion

TikTok is a growing platform for fertility-related content. Fertility providers should have a growing awareness of information available on TikTok for patients accessing fertility care and assisted reproductive technology, and the potential impact of this information on patient perspectives and experiences.

Conflict of Interests

Authors declare no conflict of interests.

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