



HHS Public Access

Author manuscript

Obstet Gynecol. Author manuscript; available in PMC 2024 January 01.

Published in final edited form as:

Obstet Gynecol. 2023 January 01; 141(1): 215–217. doi:10.1097/AOG.0000000000005027.

TikTok, #IUD, and User Experience With Intrauterine Devices Reported on Social Media

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Abstract

TikTok, a video-sharing app, offers a growing platform for contraception-related content. The top 100 videos tagged “#IUD” were compiled using a web-scraping application. User demographics and video content were analyzed by two independent reviewers with a third to arbitrate differences. More videos had a negative tone (37.8%) about the IUD than positive (19.4%), and 27.6% mentioned distrust of healthcare professionals. Of videos conveying patient experiences, all had a negative or ambiguous tone and 96.8% highlighted pain and other side effects related to IUDs. Videos scored low on information health quality (1.2 of 5 on DISCERN) and averaged 73.8% in understandability and 17.7% in actionability on PEMAT. #IUD videos on TikTok often portray negative experiences related to pain and informed consent.

Précis:

Popular videos about intrauterine devices on TikTok often portray negative experiences related to pain and informed consent.

Introduction

Approximately 50% of the U.S. digital population uses TikTok, a short-form, video-sharing app.(1) TikTok offers a unique and growing platform for contraception-related content among a predominantly reproductive-aged demographic. Recent media have highlighted the impact of TikTok trends on patient perception, use, and misuse of contraception, including viral videos of self-removal of the intrauterine device (IUD).(2, 3) We systematically analyzed TikTok content tagged #IUD.

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Financial Disclosure: Jonas Swartz receives personal fees as a contraceptive implant placement trainer for Organon. The other authors did not report any potential conflicts of interest.

Each author has confirmed compliance with the journal's requirements for authorship.

Presented at the Society of Family Planning Conference, December 3–5, 2022, Baltimore, MD.

Methods

We evaluated the top 100 videos by likes tagged #IUD. We utilized the web-scraping application, Apify, to automatically download, extract, and compile information about the top 100 videos (including number of views, comments, likes, and shares) on April 6, 2022 (Figure 1).(4, 5) Two independent reviewers (E.T. and M.H.) performed standardized video coding on all 100 videos with another reviewer (J.W.) to arbitrate differences. We used two standardized scales to assess quality: a modified 5-point DISCERN scale to evaluate information quality and the Patient Education Materials Assessment Tool (PEMAT) to evaluate understandability and actionability of each video.(6, 7) Duke University Medical Center's IRB determined this non-human subjects research exempt.

Results

Reviewed #IUD videos had a total of 471 million views, 32 million likes and 1 million shares and averaged 33 seconds in length. Two videos were non-English language and excluded. Most content creators were female-identifying (88.8%) and from the United States (89.8%), while a substantial minority were healthcare professionals (36.7%). Video types included personal patient experience with placement and removal of IUDs (31.6%), educational (29.6%), and humorous (24.5%) (Table 1).

More videos had a negative (37.8%) tone about IUDs than positive (19.4%). A substantial proportion of videos (39.8%) emphasized the negative IUD user experience. Distrust of healthcare professionals was highlighted in 27.6% of videos. Of 31 videos conveying patient experiences with placement or removal of an IUD, 25 had a negative tone (80.6%), six were ambiguous (19.4%), and almost all (96.8%) highlighted pain and IUD side effects. Approximately one-quarter of these videos emphasized desire for anesthesia during placement.

Of 53 videos that presented scientific claims, most were highly (50.9%) or moderately (18.8%) accurate, however a significant minority were moderately (18.8%) or highly (5.6%) inaccurate. Catchy music, audiovisual supplements, and persuasive stories were the most common factors that made videos compelling.

Videos scored low on DISCERN with an average score of 1.2 of 5 (median 1, SD 0.92). TikTok videos averaged 73.8% in understandability (median 73.2%, SD 23.3%) and 17.7% in actionability (median 0 of 3, SD 33.9%) on PEMAT.

Discussion

The most liked #IUD videos on TikTok portray negative experiences related to pain and informed consent. Awareness of this content can help healthcare professionals shape education given the high prevalence of TikTok use among patients.(1) Previous studies identified positive messaging about intrauterine devices on Twitter and YouTube.(8, 9) TikTok differs from other platforms because users primarily engage with an algorithmically-curated feed individualized to the user's interests and demographics.(10) Popularity of negative videos about IUDs suggests users may seek a broader array of perspectives

than traditional patient-physician interaction or what scores as high-quality on normative scales like DISCERN. Frequent discussion of pain and medical distrust highlights a communication gap, and potentially an opportunity to improve care.

Strengths of this study include a standardized procedure to capture content and inclusion of two standardized measures. Limitations include low relevance of standardized scales for short-form videos, the subjective nature of content analysis, and inability to measure viewer assessment of information quality.

TikTok is an influential information source. Healthcare professionals comprise a substantial proportion of popular creators and can be a bridge in dispelling misinformation, guiding expectations, and improving patient-centered care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Funding:

This work was conducted with the support of award K12HD103083 from the National Institute of Child Health and Human Development (NICHD) of the U.S. National Institutes of Health. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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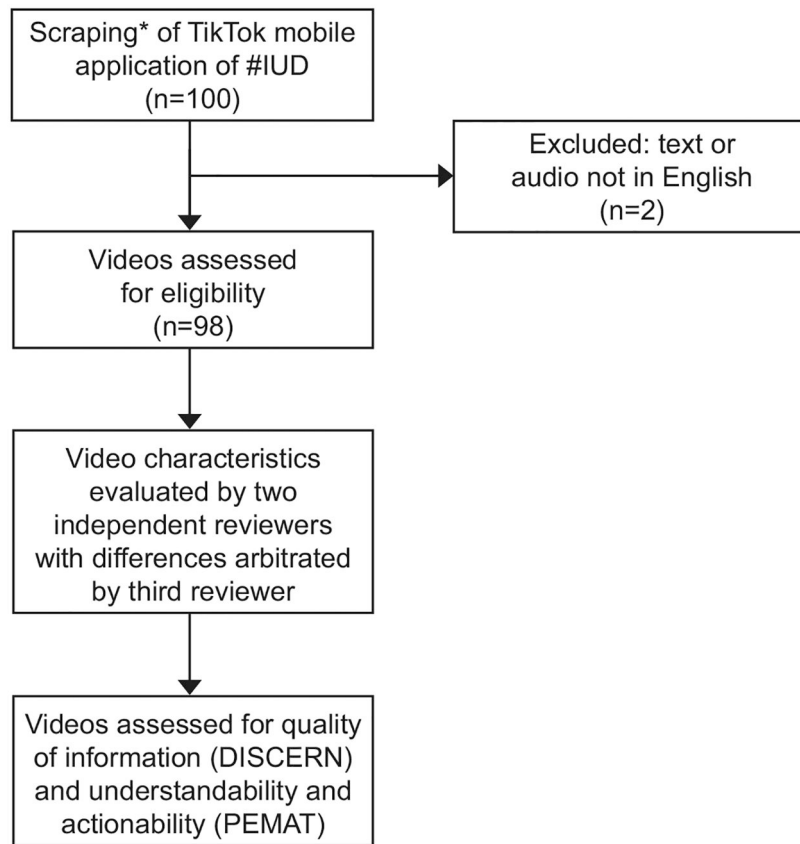


Figure 1: Flowchart of methodology and video selection. *Characteristics scraped: username, follower count, comment count, hashtags, music, shares, view count, likes, caption, video duration, URL. IUD, intrauterine device; PEMAT, Patient Education Materials Assessment Tool.

Table 1:

Video characteristics of 98 TikTok videos evaluated

Characteristic evaluated		N (%)
Creator gender	Female	87 (88.8)
	Male	5 (5.1)
	Transgender/unspecified	6 (6.1)
Healthcare professional	Yes	36 (36.7)
	No/unsure	62 (63.3)
Country of origin	United States	88 (89.8)
	Canada	5 (5.1)
	Europe	1 (1.0)
	Other	4 (4.1)
Creator age	21 years and younger	20 (20.4)
	21+ years	76 (77.6)
	Unspecified	2 (2.0)
Type of video	Educational	29 (29.6)
	Placement experience	23 (23.5)
	Removal experience	8 (8.2)
	Humorous	24 (24.5)
	Reaction video	10 (10.2)
Tone of video	Unrelated/other	4 (4.1)
	Positive	19 (19.4)
	Negative	37 (37.8)
	Neutral	22 (22.4)
Negative experience with IUD	Ambiguous	20 (20.4)
	Yes	39 (39.8)
	No	59 (60.2)
Discuss pain	Yes	34 (34.7)
	No	64 (65.3)
Discuss other side-effects	Yes	31 (31.6)
	No	67 (68.4)
Highlight distrust with health care professionals	Yes	27 (27.6)
	No	71 (72.4)
Compelling Factors	Catchy music	31
	Compelling story	26
	Audiovisual supplements	26
	Humor	23
	Trustworthy source	22