

Social media and the intrauterine device: a YouTube content analysis

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ABSTRACT

Background YouTube's online archive of video testimonials related to health information are more commonly viewed than those developed by clinicians and professional groups, suggesting the importance of the patient experience to viewers. We specifically sought to examine the accuracy of information on, and projected acceptability of, the intrauterine device (IUD) from these YouTube testimonials.

Methods We searched YouTube for videos about individual uploaders' IUD experiences, using the search terms 'intrauterine device', 'IUD', 'Mirena' and 'Paragard'. Given interest in user testimonials, we excluded professional and instructional videos belonging to commercial or non-profit entities. Two reviewers independently analysed the videos using a structured guide, with attention to inaccurate information.

Results Of 86 identified videos, four videos featured clinicians and were excluded; 62 met inclusion criteria. Interrater agreement on IUD portrayal was good ($K=0.73$). Young (mean age 25, range 19–38, years), white (75%), nulliparous (61%) women primarily uploaded content. Most described placement of the LNG-IUS (65%), were posted within 1 month of insertion (45%), and mentioned side effects (66%) – bleeding, pain, and partner sensation of the strings. About one-third of videos contained inaccurate information (34%) and were thought to project an overall negative experience (30%). Videos portraying IUDs negatively were associated with inaccurate information and/or mention of side effects.

Conclusion While one-third of IUD user testimonials on YouTube contained inaccurate information, the majority of IUD experiences were perceived by our study viewers to be positive.

INTRODUCTION

Intrauterine devices (IUDs) offer safe, effective, long-term contraception and should be considered for all women who seek reliable, reversible contraception,¹ including adolescent women.² However, IUDs are relatively

Key messages

- ▶ YouTube testimonials provide a readily accessible source of information and vicarious experience to women who may be considering an IUD for contraception.
- ▶ In this analysis, one-third of IUD user testimonials contained inaccurate information and two-thirds mentioned side effects.
- ▶ Nevertheless, the majority of IUD experiences uploaded to YouTube were perceived by our study viewers to be positive.

underutilised, representing only 5.5% of contraceptive women in the USA³ and 1.0% of contraceptive adolescents⁴ from 2006 to 2008. Lack of awareness or knowledge of the IUD and high upfront costs have been cited as barriers to IUD uptake.⁵ However, even after removing all barriers, as in the Contraceptive CHOICE project, where women seeking year-long contraception were provided with comprehensive information and individual counselling on IUDs, as well as cost-free contraception, 55% of participants still declined placement.⁶ This finding may be related to sociocultural biases underlying the IUD's acceptability; biases may be perpetuated by anecdotal experiences or misleading testimonials from young women's social networks, which can be powerfully influential.⁷ Testimonials may be perceived as more relevant than the impartial recommendations of healthcare providers, who patients may perceive as lacking the same perspective and degree of personal investment.^{8,9}

IUD experiences among one's social network, however, may be a limited resource that is not always available to women of reproductive age. The internet remains one of the most accessible and affordable sources of information for women. The Pew Internet Project revealed that nearly three-quarters of



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Americans search the internet for health information, including contraceptive information, with more than half reporting a positive impact of the internet on their healthcare decisions.¹⁰ The internet is the primary source of contraceptive information among more than 50% of young adults.¹⁰ YouTube (<https://www.YouTube.com>), an online platform for sharing videos, is one of the internet's most frequently visited websites. YouTube's diverse content includes women's IUD experiences. Of note, the majority of YouTube's videos are uploaded by individuals, and previous examinations of health-related topics on YouTube note that they generally receive more views than those uploaded by professional societies.¹¹ Consequently, the opinions and user experiences of video uploaders may be more valuable than verified content, and play a role in contraceptive decision-making. While YouTube is not the only freely accessible social media outlet (others include Instagram, Snapchat, Twitter and Facebook), YouTube is unique among these outlets given that all videos are public and searchable both on YouTube and via the Google search engine. Instagram, Snapchat and Facebook require varying degrees of uploader permissions before videos can be viewed; furthermore, videos on Snapchat are deleted on viewing by the intended recipient. No studies have specifically described independent, IUD-related content on YouTube or determined the extent to which they perpetuate inaccurate information. We performed a content analysis of online testimonials specific to the IUD.

METHODS

We conducted a search for IUD testimonials on YouTube during the first week of January 2012, using the search terms: 'intrauterine device' and 'IUD'. We included the terms 'Mirena' and 'Paragard' given anecdotal experience of patients being unfamiliar with the term 'IUD' and their preference to use brand names for contraceptive methods. We excluded videos if they were: (1) not in English; (2) duplicate entries; (3) uploaded by a business or group; (4) produced by professional production companies for educational/promotional use; (5) did not relate to the actual experience of having an IUD in place, (eg, requests for information, pre-insertion contemplation); or (6) of audio/video quality that did not allow our reviewers to understand and analyse their content. We limited our search results to the first 60 videos (three pages), as 90% of internet users reportedly rely on results from the first three pages of a web search.¹² Given concern that videos might be taken down during the time in which we were performing this research, all videos were downloaded during the week of our search. As YouTube search results do not group videos by uploader, we independently evaluated videos that depicted IUD experiences from the same uploader at different time points. Oregon Health & Science

University's Institutional Review Board declared this study design as non-human subjects research.

The research staff developed and used a standard instrument to record information about each YouTube video. The staff examined each video for uploader demographics provided on the uploader's public profile page, number of video views, IUD type, subjective insertion experience, mention of pain/side effects, and presence/absence of inaccurate information about the IUD. The staff also examined each video's potential influence or reach, which was defined as lower or higher than the median number of view counts over length of time online (days). The primary clinician (BN) subsequently checked uploader claims about the IUD, using the WHO's *Selected Practice Recommendations for Contraceptive Use* (2005)¹³ and Committee opinions from the American College of Obstetricians and Gynecologists¹⁴ as references.

Given the subjectivity entailed in the assessment of each video testimonial's portrayal of the IUD, two independent viewers from both clinical (AA) and non-clinical (RN) backgrounds analysed the videos. A third viewer (BN) arbitrated any differences. The staff categorised videos as negative if the perceived central message suggested that IUD use was not satisfactory or acceptable (eg, emphasis on severe pain, cramping, loss/expulsion, migration, heavy bleeding, etc.). They categorised videos as positive if the central message supported IUD use (eg, less bleeding, long-acting, reversibility, discretion, etc). Videos discussing negative experiences or side effects that ultimately recommended the IUD's use were categorised as positive.

We calculated descriptive statistics and performed bivariate analyses. We determined interrater agreement on IUD portrayal using Kappa coefficients. We subsequently compared uploader demographics and video characteristics against overall IUD portrayal and view counts/day online, using Chi-square tests with significance at the $P < 0.05$ level. We recorded and analysed all data using SPSS (SPSS Statistics for Windows, Version 21.0, NY).

RESULTS

Of 86 identified videos, four videos featured clinicians and were excluded; 62 (72%) met inclusion criteria (table 1). The earliest video of a user's experience with the IUD was uploaded in April of 2008. Mean video length was 6 min; median time online was 525 days; median view count was five times/day. The content was primarily uploaded by young (mean age 25, range 19–38, years), white (74%) women. Among videos mentioning when the uploader had her IUD inserted, nearly half (45%, 23/51) of women posted their video within 1 month of insertion. Approximately one-third of videos contained inaccurate information. Examples of these claims included that the IUD could not be used by adolescents and nulliparous women, that IUD users experienced delayed return to fertility

Table 1 Associations of YouTube video impact and intrauterine device (IUD) portrayal with uploader and video characteristics

Uploader and video characteristics	Total (n (%))	Video influence (view counts/day) (n (%))		P	Perceived IUD portrayal (n (%))		P
		≤5	>5		Positive	Negative	
Time online (days)							
>365	48 (77.4)	20 (41.7)	28 (58.3)	0.07	35 (72.9)	13 (27.1)	0.91
≤365	14 (22.6)	10 (71.4)	4 (28.6)		10 (71.4)	4 (28.6)	
Video length (min)							
>5	33 (53.2)	17 (51.5)	16 (48.5)	0.60	22 (66.7)	11 (33.3)	0.27
≤5	29 (46.8)	13 (44.8)	16 (55.2)		23 (79.3)	6 (20.7)	
Uploader age (years)							
≥25	27 (50.9)	11 (42.3)	15 (57.7)	0.88	15 (57.7)	11 (42.3)	0.03
<25	26 (49.1)	12 (44.4)	15 (55.6)		23 (85.2)	4 (14.8)	
Uploader race/ethnicity							
White	46 (74.2)	21 (45.7)	25 (54.3)	0.47	35 (76.1)	11 (23.9)	0.29
Other	16 (25.8)	9 (56.3)	7 (43.8)		10 (62.5)	6 (37.5)	
IUD type							
Mirena	39 (65.0)	14 (35.9)	25 (64.1)	0.38	26 (66.7)	13 (33.3)	0.71
Paragard	21 (35.0)	10 (47.6)	11 (52.4)		15 (71.4)	6 (28.6)	
Interval between IUD insertion and video upload (days)							
<1 month	23 (45.1)	14 (60.9)	9 (39.1)	0.20	19 (82.6)	4 (17.4)	0.03
1 month–1 year	19 (37.3)	13 (68.4)	6 (31.6)		12 (63.2)	7 (36.8)	
≥1 year	9 (17.6)	3 (33.3)	6 (66.7)		3 (33.3)	6 (66.7)	
False claims							
Yes	21 (33.9)	10 (47.6)	11 (52.4)	0.93	11 (52.4)	10 (47.6)	0.01
No	41 (66.1)	20 (48.8)	21 (51.2)		34 (82.9)	7 (17.1)	
Side effects mentioned							
Yes	41 (66.1)	21 (51.2)	20 (48.8)	0.53	24 (58.5)	17 (41.5)	0.00
No	21 (33.9)	9 (42.9)	12 (57.1)		21 (100.0)	0 (0.0)	
IUD portrayal							
Positive	45 (72.6)	20 (51.3)	19 (48.7)	0.28	–	–	–
Negative	17 (27.4)	7 (35.0)	13 (65.0)		–	–	

following removal, and could have severe systemic side effects from exposure to copper or progestogens. Side effects were described in two-thirds of videos; the most frequently mentioned included post-insertion pain (24%, 15/62), irregular bleeding (24%, 15/62), and partner sensation of the strings (8%, 5/62). Removal was mentioned in five videos (8%). Portrayals of the IUD were rated as generally positive (68–73%) by our raters. Interrater agreement on the negative/positive portrayal of the IUD for each video was good ($K=0.73$, $P<0.001$, 95% CI 0.54 to 0.92).

Table 1 provides bivariate associations of video characteristics with perceived IUD portrayal and potential viewer influence. Video and uploader characteristics were not associated with view count, except for receipt of a copper IUD, which was associated with more views overall. Negative portrayals of the IUD were associated with uploaders older than age 25 years, inaccurate

claims, and mention of side effects. IUD portrayals were not associated with potential viewer influence.

DISCUSSION

Given the same information on safety and efficacy of the IUD, reproductive-age women are still less likely than their gynaecologist counterparts to use an IUD for contraception;¹⁵ this disparity may be related to the vicarious experience that women's healthcare providers acquire during their clinical encounters. To better reassure themselves or validate their concerns about the IUD, women who are less familiar with the IUD may rely on video testimonials that are readily available on YouTube and accessible via the Google search engine. These women represent a population at risk of using less effective contraceptive methods or discontinuation if not met by personal, reassuring and medically accurate video testimonials.

In our study we found a substantial number of regularly viewed IUD testimonials on YouTube, the majority of which contained accurate information. About one-third of the videos made inaccurate claims, a finding not unlike other reviews of webpage-based medical information on the internet,¹⁶ even specific to the IUD.¹⁷ Specific side effects (bleeding, pain, partner sensation of strings) were also commonly mentioned and at similar proportions to those reported in actual clinical encounters.¹⁸ Yet while the inclusion of inaccurate claims and side effects was associated with the IUD's overall portrayal, the majority of IUD testimonials were still perceived as positive by our raters and neither characteristic was significantly linked to video view counts and potential influence. These findings are consistent with those of another study examining the content of YouTube videos on the single-rod contraceptive implant, which rated 61% of testimonials as positive and noted that only the minority contained misinformation.¹⁹ With respect to negative portrayals of the IUD, we noted that they were more commonly identified among videos created more than a year after a user had her IUD inserted. This finding suggests an uploader bias where users were only prompted to create a video so remote from their IUD insertion if they had recently experienced and identified a problem.

While professional videos were excluded from our analysis, we noted disproportionately fewer videos from clinicians and their professional societies. Encouraging healthcare providers to create videos that address erroneous claims, advocate for more effective contraceptive methods, and alleviate patient anxieties may be helpful in increasing uptake.²⁰ However, the impact of clinician videos may be limited, as previous studies of healthcare information on YouTube noted that testimonials were more frequently viewed over lectures or public service announcements from professional societies, irrespective of credibility.¹¹ Nevertheless, view counts may not accurately reflect a video's potential influence, as they do not account for incomplete views where the viewer may neither watch the entire video nor incorporate the information or perspective into healthcare decision-making. Additionally, positive perceptions of the IUD as rated by our reviewers may not mirror the actual perceptions of YouTube viewers. While we used predetermined evaluation criteria, obtained good interrater agreement, and employed student reviewers whose ages were expected to closely match the demographic of YouTube users, we could not guarantee that they both were unbiased about the IUD. These findings highlight both a limitation of our study and an opportunity — without collecting data from viewers, we are unable to discuss the impact of misinformation or the IUD's portrayal on viewer knowledge, interest and uptake of the IUD. Consequently, recommendations for the use of social media as a tool to promote contraception may thus benefit from directly asking women seeking

contraception about which social media outlets they used when looking for information, and the characteristics of those media that were helpful for decision-making purposes.

We acknowledge the limits of attempting to provide a complete examination of IUD testimonials on YouTube. Limitations of the YouTube search engine at the time of data collection prevented the inclusion of relevant videos with misspelled titles. Additionally, given that online content expands by the minute, the findings discussed are unlikely to be generalisable to content found online in the future. In fact, by the time we collected and analysed the IUD testimonials that were discussed, three levonorgestrel IUDs entered the market — Skyla, Kyleena and Liletta — such that the environment of IUD testimonials is likely to be different from that which was found during our original search. Nevertheless, the insights presented provide a baseline understanding and may inform future interventions or research that utilise this medium of information dissemination.

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Data sharing statement All the videos examined in this study are available publicly on YouTube.com.

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