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SHORT COMMUNICATION

A content analysis of direct-to-consumer DNA testing on TikTok

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Abstract
Despite the fact that the internet is a popular source of health information, limited research has been conducted on the ways in which direct-to-consumer (DTC) DNA testing has been discussed by consumers on the internet, and on social media platforms specifically. The purpose of this study was to describe the content of 100 videos that addressed DTC DNA testing on TikTok, a video-sharing social network. The 100 videos included had a combined 77,498 comments and 9,680,309 likes.The majority (> 50%) of videos reviewed mentioned using DTC DNA testing kits to find family roots (94%), included information on commercial DNA testing kits (67%), and featured a person taking or talking about taking a DNA test (92%). These videos also received a majority of the total comments/likes. Neither the use of music ($p = .06$ and $p = .07$) nor the mention of using DNA testing to locate family ($p = .08$ and $p = .09$) had a significant effect on a video's comments or likes, respectively. Genetic counselors, health care providers, and public health professionals should be aware that there is a need to present both benefits and disadvantages of DTC DNA testing on social media platforms. A greater presence of comprehensive information on social media platforms can increase the likelihood that one makes erudite decisions.

Keywords TikTok · Direct-to-consumer genetic testing · Social media

Introduction

Direct-to-consumer (DTC) DNA test kits market is expected to exceed a market value of 2.7 billion US dollars by 2030 (Transparency Market Research n.d.). These tests allow consumers to learn more about their DNA in terms of paternity, ancestry, or indications of disease risk—all without involvement from a health care provider (Norrgard 2008). Norrgard raises an important question that should be asked when considering DTC DNA testing, and that is, "Just because testing *can* be done without the involvement of a health care provider, does that mean it *should* be done? (Norrgard 2008)."

While these factors seem empowering, participating in DTC DNA testing is accompanied by risks, which are often unforeseen by consumers (Hogarth et al. 2008). These issues include validity of testing (Tandy-Connor et al. 2018), and issues with interpretation of results in the absence of a genetic counselor or health care provider (Marietta and McGuire 2009). As Pray (2008) points out, for the vast majority of these tests, there is no way to definitively determine whether an individual will actually ever develop the disease in question. This is especially true in genome scans for disease risk, whereby lifestyle factors often are highly influential and are not taken into consideration (Horton et al. 2019). Consumers can make health decisions based on their DTC DNA results that may not be endorsed by a health care provider. These results can also cause undue anxiety about disease risk for which there is no intervention (Horton et al. 2019). In addition to health-related complications of DTC genetic testing, there can be unanticipated results which can cause upheaval in families (Crawshaw 2018; Hunt 2018; Zhang 2018) and potentially have an influence on health insurance and employment(Suter 2019). Further, DTC DNA test results can be used by law enforcement agencies, and immigration officials (Burroughs 2005; Karlsson et al. 2007; Kennett 2019). For example, while DTC DNA companies store the data they collect, they often provide disclaimers about the ways in which they will ensure that data is kept safely and privately. However, as Ram and colleagues (Ram et al. 2018) point out, "although these disclaimers are

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usually unambiguous, they are sometimes buried in terms of service or privacy policies that many individuals do not take care to read or fully understand."

Despite the fact that the internet is a popular source of health information (Fox and Duggan 2013), limited research has been conducted on the ways in which DTC DNA testing has been discussed by consumers on the internet, and on social media platforms specifically. A social media platform that is increasing in popularity is TikTok, a video-sharing social networking service. In the United States, this platform boasts more than 30 million monthly users and 37 billion video views generated monthly (Sehl 2020). On this platform, short videos are posted, which are largely entertainment based and can be identified by topics using hashtags. At the time of this study, there were no published studies describing the content of videos that addressed DTC DNA testing on TikTok, which was the purpose of this study.

Methods

The methods for this study were based on a content analysis involving TikTok on a different topic (Basch et al. 2021a, b). A total of 100 TikTok videos related to DNA testing were garnered for this study, by using the hashtag #dnatest which was chosen over other hashtags because it had the highest number of collective views at 434.5 million in February 2021, when this study occurred. This number was decided upon arbitrarily and was simply chosen as these methods were proven to garner adequate insight for prior studies (Basch et al. 2021a, b). Videos were excluded if they were not in English ($n=22$), or if they were irrelevant, such as pertaining to a popular song rather than DNA testing ($n=55$), or if the DNA testing pertained to animals rather than humans ($n=37$). The videos were viewed for certain predetermined content characteristics. Coding categories mirrored those in a prior study of DTC DNA testing content on a different social media platform (Basch et al. 2020), which were derived from fact sheets (United States National Library of Medicine 2020). These categories are noted in Table 1.

One reviewer (NQ) determined the presence of this content for all 100 videos. Another (CB) reviewed a random sample of 20 videos for the same content. The two reviewers differed in only 5 out of 611 data points resulting in a high inter-rater reliability score ($\kappa=0.97$). Descriptive statistics were performed on the collected data and independent one-tailed *t*-tests ($\alpha=0.05$) were run to determine if observations of note were statistically significant. All analysis was conducted using Microsoft Excel. The policy of the Institutional Review Board at William Paterson University indicates that non-human subjects' studies, such as this, are not reviewed.

Results

The 100 videos included had a combined 77,498 comments and 9,680,309 likes with averages (standard deviations) of 777.10 (3265.63) and 96,842.88 (459,354.91), respectively. Table 1 displays 15 different content characteristics and indicates how many of the 100 videos viewed included this content. The table also shows the number of likes/comments garnered by videos with a given content characteristic. The relative percentages of likes and of comments for videos featuring a particular content characteristic are also displayed.

The majority (> 50%) of the videos reviewed mentioned using DNA testing kits to find family roots (94%), included information on commercial DNA testing kits (such as a specific company and what data they provide to a consumer) (67%), and featured a person taking or talking about taking a DNA test (92%). In all three instances, these videos also received a majority of the total comments/likes. Interestingly, videos that used music (39%) or mentioned DNA testing to locate family (36%) made up fewer than 50% of the total collection of videos sampled but received a majority of the likes/comments. More specifically, videos that used music received around 80% of the total comments and just above 80% of the total likes. Videos that mentioned DNA testing as a way to locate family received around 75% of the total comments and just above 75% of the total likes. To determine if these observations of note were statistically significant, independent two-sample one-tailed *t*-tests ($\alpha=0.05$) were performed. In all four cases, the resulting *p*-values were above 0.05 indicating that neither the use of music ($p=0.06$ and $p=0.07$) nor the mention of using DNA testing to locate family ($p=0.08$ and $p=0.09$) had a significant effect on a video's comments or likes, respectively.

It is important to note that an additional 16 content characteristics were looked for but not found in any of the 100 videos. They were mentioning a DNA testing kit: to solve crimes, is confidential, requires no appointment, needs no approval form, with regard to genetic advice/counseling, may be more accessible through health care provider, may be less expensive if obtained through health care provider, collecting samples for future medical research, pinpointing any health conditions/traits, cannot tell definitively the probability of obtaining a specific disease, may lead to decision-making despite inaccurate information, having little oversight/regulation, may compromise genetic privacy, providing results that may impact insurance eligibility, can reveal information directly related to family members that may not want to learn this information, and that genetic databases have been used by law enforcement to track suspects.

Table 1 Observed characteristics/content and comments/likes of 100 TikTok videos related to the DNA testing kits

	N	Comments	%	Likes	%
	100	77,498	100%	9,680,309	100%
Uses dance	4	5958	7.69%	2,033,295	21.00%
Uses music	39	61,517	79.38%	7,841,689	81.01%
Uses humor	32	14,214	18.34%	1,678,664	17.34%
Finding your family roots/ancestry	94	77,200	99.62%	9,635,284	99.53%
Mentions commercial DNA test	67	39,985	51.59%	6,057,793	62.58%
Features a person taking a genetic test	92	45,379	58.56%	6,103,521	63.05%
Mentions direct consumer genetic testing, promotes awareness	2	1111	1.43%	153,100	1.58%
Mentions DNA testing to locate family/ancestors	36	58,182	75.08%	7,493,129	77.41%
Mentions DNA provides personalized health info linked to family/ancestors	7	1444	1.86%	237,364	2.45%
Mentions DNA testing can result in being more proactive about health	1	331	0.43%	43,200	0.45%
Mentions DNA sampling may provide unexpected information about health/family/ancestry	28	4028	5.20%	150,665	1.56%
Mentions DNA test results may be stressful or life changing	24	2138	2.76%	106,785	1.10%
Mentions DNA testing could be misleading or not have enough evidence to link a particular genetic disease/trait	1	37	0.05%	2031	0.02%
Mentions genetic databases can be used to track down undocumented persons	1	267	0.34%	2441	0.03%

Discussion

The findings of this study indicate that the social media platform, TikTok is being widely used to feature videos related to DTC DNA testing. The posts that are generating an abundance of comments are those which pertain to DTC DNA testing as a way to locate family. Additionally, this forum is being used to showcase the process of DNA DTC testing and has a heavy focus on finding family roots. These results are in concert with those of prior work examining content of videos on YouTube related to DTC DNA testing (Basch et al. 2020).TikTok is an increasingly relevant social media platform. The TikTok app has been downloaded over 2.6 billion times across the world, and the United States has approximately 100 million active users (Wallroo Media 2021). The age group with the largest number of users in the United States are ages 10–19 (32.5%), and those aged 20–29 years of age (29.5%) (Wallroo Media 2021). Given the fact that there is a paucity of research on DTC DNA testing in these age groups, this research could be extended to determine the extent to which younger populations understand the risks of engaging in such tests.

Similar to the aforementioned study of DTC DNA testing on YouTube (Basch et al. 2020), this study also noted little to no mention of many of the more concerning aspects of DTC DNA testing. For instance, the videos featured in this sample tended to highlight the entertaining aspects of DTC DNA testing, with few of the detrimental aspects (such as privacy or provision of unexpected health information indicated) of this process. While unexpected information about health/family/ancestry and the fact that test results may be stressful or life changing were noted in roughly one-quarter of the videos analyzed, there was no mention ofother concerning categories ranging from accuracy of testing to privacy and unauthorized use by law enforcement. While it may not necessarily be expected that videos on an entertainment-based platform such as TikTok include indicators of potential problems with DTC DNA testing, omission of this information has ramifications. For example, consumers may gather that the DTC DNA testing experience is entertaining and fun, without understanding the potential for negative consequence of the testing process or the potential issues raised by social networking about their results (Resnik 2009). Making the decision to participate in DTC DNA testing is an important one, in which results can have effects beyond the individual who took the test (Soo-Jin Lee and Borgelt 2014). Therefore, policy implications could, at minimum, include links on social media platforms to direct users to more comprehensive information from valid and reliable sources.

This study has limitations that necessitate mentioning. This was a cross-sectional study with a relatively small sample size; these factors eliminate the possibility of generalizing findings. Further, this study was restricted to English language postings. The inclusion criteria of 100 videos were arbitrary. Also, because the TikTok platform is so popular, one can assume that content will vary over time. Despite these limitations, this study fills a gap in literature as the first to examine DTC DNA testing content on TikTok.

Additional research is needed to determine the extent to which DTC DNA testing is being used to generate appealing content across social media platforms. Genetic counselors, health care providers, and public health professionals should be aware that there is a need to present both benefits and disadvantages of DTC DNA testing on social media platforms.

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Author contribution CB conceptualized the study and NQ collected the data. JF analyzed the data. All contributed to the writing and revision of the manuscript.

Data availability Not applicable.

Code availability Not applicable.

Declarations

Ethics approval As per the protocol at William Paterson University, the Institutional Review Board does not review studies that do not involve human subjects. This article does not contain any studies with human or animal subjects performed by the any of the authors.

Consent to participate Not applicable.

Consent for publication Not applicable.

Conflict of interest The authors declare no competing interests.

References

Basch CH, Hillyer GC, Wahrman MZ, Garcia P, Basch CE (2020) DNA testing information on YouTube: inadequate advice can mislead and harm the public. J Genet Couns. https://doi.org/10.1002/jgc4.1375

Basch CH, Fera J, Pierce I, Basch CE (2021a) Promoting mask use on TikTok: descriptive, cross-sectional study. JMIR Public Health Surveill 7(2):e26392. https://doi.org/10.2196/26392

Basch CH, Meleo-Erwin Z, Fera J, Jaime C, Basch CE (2021) A global pandemic in the time of viral memes: COVID-19 vaccine misinformation and disinformation on TikTok. Hum Vaccin Immunother 1-5.https://doi.org/10.1080/21645515.2021.1894896

Burroughs AM (2005) The medical examination in United States immigration applications: the potential use of genetic testing leads to heightened privacy concerns. J Biolaw Bus 8(4):22–32

Crawshaw M (2018) Direct-to-consumer DNA testing: the fallout for individuals and their families unexpectedly learning of their donor conception origins. Hum Fertil (Camb) 21(4):225–228. https://doi.org/10.1080/14647273.2017.1339127

Fox S, Duggan M (2013) Pew Research Center. Health online, http://www.pewinternet.org/2013/01/15/health-online-2013/. Accessed 31 Mar 2021

Hogarth S, Javitt G, Melzer D (2008) The current landscape for direct-to-consumer genetic testing: legal, ethical, and policy issues. Annu Rev Genomics Hum Genet 9(1):161–182

Horton R, Crawford G, Freeman L, Fenwick A, Wright CF, Lucassen A (2019) Direct-to-consumer genetic testing. BMJ 367:l5688. https://doi.org/10.1136/bmj.l5688

Hunt E (2018) Your father's not your father: when DNA tests reveal more than you bargained for**,** https://www.theguardian.com/lifeandstyle/2018/sep/18/your-fathers-not-your-father-when-dna-tests-reveal-more-than-you-bargained-for. Accessed 31 Mar 2021

Karlsson AO, Holmlund G, Egeland T, Mostad P (2007) DNA-testing for immigration cases: the risk of erroneous conclusions. Forensic Sci Int 172(2–3):144–149. https://doi.org/10.1016/j.forsciint.2006.12.015

Kennett D (2019) Using genetic genealogy databases in missing persons cases and to develop suspect leads in violent crimes. Forensic Sci Int 301:107–117. https://doi.org/10.1016/j.forsciint.2019.05.016

Marietta C, McGuire AL (2009) Currents in contemporary ethics Direct-to-consumer genetic testing: is it the practice of medicine? J Law Med Ethics 37(2):369–374. https://doi.org/10.1111/j.1748-720X.2009.00380.x

Pray L (2008) DTC genetic testing: 23 and me DNA Direct and Genelex. Nat Educ 1(1):22

Ram N, Guerrini CJ, McGuire AL (2018) Genealogy databases and the future of criminal investigation. Science 360(6393):1078–1079. https://doi.org/10.1126/science.aau1083

Resnik DB (2009) Direct-to-consumer genomics, social networking, and confidentiality. Am J Bioeth 9(6–7):45–46. https://doi.org/10.1080/15265160902893924

Sehl K (2020) Everything brands need to know about TikTok in 2020. https://blog.hootsuite.com/what-is-tiktok/

Soo-Jin Lee S, Borgelt E (2014) Protecting posted genes: social networking and the limits of GINA. Am J Bioeth 14(11):32–44. https://doi.org/10.1080/15265161.2014.957417

Suter SM (2019) GINA at 10 years: the battle over 'genetic information' continues in court. J Law Biosci 5(3):495–526. https://doi.org/10.1093/jlb/lsz002

Tandy-Connor S, Guiltinan J, Krempely K, LaDuca H, Reineke P, Gutierrez S, Gray P, Tippin, Davis B (2018) False-positive results released by direct-to-consumer genetic tests highlight the importance of clinical confirmation testing for appropriate patient care (12):1515–152. https://doi.org/10.1038/gim.2018.38

Transparency Market Research (n.d.) DNA Test Kit Market, https://www.transparencymarketresearch.com/pressrelease/dna-test-kits-market.htm#:~:text=DNA%20Test%20Kits%20Market%20to,by%202030%3A%20Transparency%20Market%20Research&text=According%20to%20the%20report%2C%20the,16%25%20from%202020%20to%202030. Accessed 31 Mar 2021

United States National Library of Medicine (2020) What are the benefits and risks of direct-to-consumer genetic testing? https://ghr.nlm.nih.gov/primer/dtcgenetictesting/dtcrisksbenefits. Accessed 31 Mar 2021

Wallroo Media. TikTok statistics (2021) https://wallaroomedia.com/blog/social-media/tiktok-statistics/#:~:text=Total%20App%20Downloads%20%E2%80%93%20The%20TikTok,quarter%20by%20any%20app%2C%20ever. Accessed 31 Mar 2021

Zhang S (2018) When a DNA test shatters your identity, https://www.theatlantic.com/science/archive/2018/07/dna-test-misattributed-paternity/562928/. Accessed 31 Mar 2021

Norrgard K (2008) DTC genetic testing for diabetes, breast cancer, heart disease and paternity. Nat Educ 1(1):86