

The portrayal of organ donation on TikTok: A content analysis of popular English-language TikTok videos

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Abstract

Objective: TikTok is one of the most popular social media platforms and plays a role in shaping public perceptions. This research examined how organ donation was portrayed on the platform.

Methods: We built a dataset of the most popular English-language TikTok videos that used the hashtags #organdonor or #organdonation. We then performed content analysis on the 400 most viewed videos after limiting data set inclusion to one video per user account.

Results: The finalized videos ($N=313$) had generated nearly 80 million views and 10 million likes. Featuring both donors (56.2%) and recipients (44.1%), videos shared experiences that celebrated and lamented lost donor lives (41.8%) while also celebrating transplantation successes (31.3%). Very few videos included public solicitation (2.9%). Common video traits included detailing medical procedures (45.4%), presenting honor walks (10.9%), and displaying donors and recipients connecting or wanting to connect (16.9%). Videos mostly had a positive (74.1%) versus negative (10.2%) leaning tone.

Conclusion: Far from superficially glamorizing organ donation/transplantation processes and procedures, popular English-language TikTok videos depicted what we perceived as highly emotional and expository experiences. While the videos likely offered learning and cathartic opportunities for individuals and communities, they also highlight some tensions between personal anecdotes and data/research. Findings from this research can inform public outreach efforts as well as policies related to protecting anonymity and celebrating donors with honor walks. Indeed, given TikTok's increasing popularity and influence, it could be a valuable tool to meaningfully learn from, and engage with, patient and donor communities.

Keywords

Public health, disease, organ donation, social media, media, TikTok, organ transplantation, health communications, general, digital health, general

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Introduction

Healthcare systems are focused on increasing organ donation and transplantation success rates. Alongside legislative, technological, and administrative changes, research is focused on understanding donation culture, including public perceptions.^{1–4} Public social media use is increasing worldwide and can influence health-related public perceptions and opinions.⁵ TikTok is a popular social media platform, receiving increased attention in public health research.⁶

Commentary has reflected on the success of TikTok's algorithm to provide TikTok users with desired content and to generate popular trends.⁷ It is valuable to analyze popular

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content as it drives attention and influences content creation. This project examined how organ donation was portrayed in popular English-language TikTok videos. We sought answers to following three questions:

RQ1. Who was creating the TikTok videos, broadly (which demographics), and specifically in relation to organ donor (e.g., live donors, deceased donors, etc.)?

RQ2. Was organ donation portrayed positively (i.e., celebrated, promoted) or negatively (i.e., critiqued, problematized)?

RQ3. Which specific video characteristics were evident across the complete dataset (video trends)?

Methods

Data collection and organization

On February 19, 2022, we created a DataMiner scraper to collect video URLs and corresponding metadata from the TikTok desktop version under the #organdonor and #organ-donation hashtags ($n = 1916$ unique URLs). Research on organ donation hashtags had revealed the two selected as the most popular. We ran the video scraper during February 19–25, 2022 ($n = 1911$, 5 unavailable for metadata collection). All videos collected were from public TikTok accounts. Video views were retrieved from a website (freevideodownloader.net), dedicated to downloading TikTok videos. Videos were downloaded and assigned a unique number. Observing numerous entries from a few user accounts, we included the most viewed video from each unique creator to ensure content diversity, leaving 922 videos. We limited our coding sample to the top 400 viewed videos for in-depth coding feasibility. Ethics approval and patient consent were not required as data were publicly accessible online content. To ensure privacy protection of video creators, no creators' content, or personal information, including TikTok account names, appears in this manuscript or any other activities from this research.

Data analysis

Given limited relevant research on TikTok, our objective was to perform a detailed descriptive analysis. Conventional content analysis is an appropriate method for such an objective as it enables a quantifiable component to rich qualitative analysis.⁸ To conduct this analysis, we developed a coding frame using inductive and deductive approaches.⁹ That is, we generated non-mutually exclusive coding categories using previous knowledge of organ donation and social media, combining it with detailed observations of 20% of the videos. After solidifying a coding frame, we tested it on an additional 10% of the data and modified it in accordance with these observations. Using

TikTok data to shape the analytical framework helped avoid potential overgeneralization or interpretive bias. The finalized codebook is available in Supplementary Materials with the findings reflected in Table 1. While coding for racialized peoples is problematic, we decided after deliberation that it was valuable to not omit in the demographic analysis. During coding, which took place online (remotely) in Edmonton, AB and Vancouver, BC from March to September 2022, the two coders met routinely (over Zoom) to clarify ambiguous content, reach agreement on coding decisions, and discuss emerging data trends—core components of an iterative team-based coding approach.¹⁰ Following coding, 87 videos were deemed irrelevant for being off-topic or in a language other than English, resulting in a final dataset of ($N = 313$). Intercoder reliability was performed on the most subjective coding category, video tone, achieving a “strong” Cohen’s Kappa score of (0.82).¹¹

Findings

Video demographics

The 313 videos generated 79,862,295 views and 9,910,757 likes. Demographics showed adults featured most often videos (53.0%) along with some presence—principal focus or in background—of healthcare providers (23.4%). Only some videos specified a location (16.0%) (Table 1).

Key video characteristics

Videos featured donors (56.2%) and recipients (44.1%), focusing most often on deceased donors (41.8%) and successful transplant recipients (31.3%). Much fewer videos detailed individuals waiting for organs (6.4%) or performing organ public solicitation (2.9%). Some videos (16.9%) included donors and recipients desiring to connect with one another. Organs were specified often (53.7%), with kidneys (21.4%), hearts (18.8%), and livers (9.9%) being most common (Table 1).

Videos commonly detailed bodies in relation to medical settings and procedures (45.4%). These included bodies connected to tubes, wires, and machines (13.1%), dialysis (8.0%), honor walks (10.9%), scars (4.8%), as well as in other situations (13.7%), such as people describing pain and recoveries, collecting urine, having organs transplanted, and performing scans or tests. Honor walks (in 10.9% of videos) are when hospital staff show respect and appreciation by lining hallways which a deceased donor-to-be passes through, often with friends and family, to the operating room. Videos detailed some administrative or systemic aspects of donation and transplantation (26.2%), with the topic of deemed consent appearing most often (8.9%). Other topics (15.2%) included donation consent, insurance coverage and costs, determining death,

Table 1. Complete coding data of popular organ donation and transplantation TikTok videos (N= 313).

Characteristic	n (%)	Characteristic	n (%)
People		Organs detailed	168 (53.7%)
1 person	183 (58.5%)	Kidney	67 (21.4%)
>1 person	130 (41.5%)	Heart	59 (18.8%)
At least 1 woman	231 (73.8%)	Liver	31 (9.9%)
At least 1 man	149 (47.6%)	Lungs	16 (5.1%)
With a white person	220 (70.3%)	Eyes	16 (5.1%)
With a racialized person	90 (28.8%)	General (“all organs”, “everything”)	11 (3.5%)
Healthcare provider focus	34 (10.9%)	Skin	5 (1.6%)
H-care provider (background)	39 (12.5%)	Health ailment mentioned in video	54 (17.3%)
Age approximation		Physiological details	142 (45.4%)
Child	35 (11.2%)	Tubes/IV/Wires	41 (13.1%)
Youth	31 (9.9%)	Honor walk	34 (10.9%)
Young Adult	95 (30.4%)	Dialysis	25 (8.0%)
Adult	166 (53.0%)	Scars	15 (4.8%)
Elderly	41 (13.1%)	Symptoms	5 (1.6%)
		Drugs	1 (0.3%)
Video type		Other	43 (13.7%)
First person	157 (50.2%)		
Not first person	156 (49.8%)	Administrative processes/ topics	82 (26.2%)
Stand-alone video (not series)	290 (92.7%)	Deemed consent (Opt in vs. opt out)	28 (8.9%)
Part of a longer series	23 (7.3%)	Waitlists	8 (2.6%)
		Abortion	1 (0.3%)
Location		COVID	3 (1.0%)
Location listed	50 (16.0%)	Vaccination (COVID)	2 (1.0%)
No location listed	263 (84.0%)	Others	47 (15.2%)
Donor	176 (56.2%)	Raising awareness	
Live donor	29 (9.3%)	Promoting organ donation	147 (47.0%)

(continued)

Table 1. Continued.

Characteristic	n (%)	Characteristic	n (%)
Signing up (to donate)	16 (5.1%)	Promotional hashtag	59 (18.8%)
Recently deceased	53 (16.9%)	Compassionate	132 (42.2%)
Deceased	78 (24.9%)	Aggressive	9 (2.9%)
Public solicitation	0 (0.0%)		
Money/Finances	0 (0.0%)		
Burden	1 (0.3%)	Additional video aspects	
		Counter misinformation	14 (4.5%)
Recipient	138 (44.1%)	Asking for likes/follows	9 (2.9%)
Living success	98 (31.3%)	Use of “for you page” hashtag (#fyp)	129 (41.2%)
Living with complications	9 (2.9%)		
Waiting for organ	20 (6.4%)	Tone	
Wait has ended (organ found)	9 (2.9%)	Positive/Trending positive	232 (74.1%)
Waiting for organ again	1 (0.3%)	Neutral	49 (15.7%)
Deceased	4 (1.3%)	Negative/Trending negative	32 (10.2%)
Public solicitation	9 (2.9%)		
Public solicitation for finances	3 (1.0%)		
Donors and recipients connecting	53 (16.9%)		
Desire to connect	12 (3.8%)		
Relationship	41 (13.1%)		

donor eligibility, family veto, medical assistance in dying, malpractice, and religion.

Nearly half of all videos explicitly promoted organ donation (47.0%). Common promotional hashtags in video descriptions included, for example: #donatelive, #givelife, #organdonorsaveslives. A few videos contained debunking or countering misinformation (4.5%). Videos mostly had a positive leaning tone (74.1%) versus a negative (10.2%). Negative videos most often focused on poor treatment in hospitals, ranging from experiences with unsympathetic staff to expressed sentiments of systemic exploitation for organ procurement. Four videos explicitly detailed perceived racial exploitation from healthcare systems. Additional negativity detailed the difficulties of waiting for an organ transplant.

Discussion

Popular organ donation and transplantation videos on TikTok offered viewers an intimate and expository window into personal lived experiences of challenges and successes. Indeed, nearly half of all videos (45.4%) showed bodies involved in medial procedures, and one in ten featured an honor walk (10.9%). Far from superficially glamorizing processes and procedures, the TikTok videos depicted what we perceived as highly emotional experiences that often celebrated and lamented donor’s lost lives (41.8%) as well as celebrated and cherished transplantation successes (31.3%). For example, excluding those with personal organ donation experiences, it is unlikely that the public are intimately familiar with donation processes, including being on dialysis or

recovering post transplant. Such visible lived experiences therefore arguably provide a more realistic window into the medical realities of organ donation and transplantation. On one hand, these videos could offer valuable learning and cathartic experiences for individuals and communities. On the other hand, they could be interpreted as overly sensationalistic, using intense medical experiences to generate clicks, likes, and shares. Indeed, over 40% of the videos in this dataset used variations of the “for you page” (#fyp) hashtag, a common tool to increase video popularity using TikTok’s algorithm.⁷ While systemic issues and realities were touched on in some videos (26.2%), person anecdotes reigned, highlighting the complex and ever-present tension between personal stories and data/research.¹² This tension is arguably heightened given that youth are increasingly using TikTok as a search engine to find information.¹³

The considerable number of videos with honor walks (10.9%) could help substantiate hospitals’ use of the practice to celebrate donor lives and generate positive donation sentiments.¹⁴ Honor walks, however, offer valuable symbolic and emotional support, but do not address other donor issues, such as financial burdens.¹⁵ Popular TikTok videos showcased the value and desire around donors and recipients connecting, which touches on the potential need to revisit debates around ensuring patient anonymity.¹⁶ The topic of deemed consent legislative changes was also observed as having presence in the popular TikTok videos (8.9%), indicating some public awareness of ongoing policy changes.

The majority of TikTok videos presented organ donation and transplantation positively (74.1%) with nearly half (47.0%) promoting donation benefits. The salient trend in negativity (10% of the videos) not only focused on individual experiences but also included broader skepticism of healthcare system practices. The four videos detailing perceptions of racial abuses in organ procurement represent only a small fraction of the data but demonstrate how critical perspectives do generate attention. This research, however, examined only popular English-language TikTok videos, and more critical content could exist elsewhere. Further research on non-English videos, or comments would be valuable in understanding the organ donation and transplantation portrayal on TikTok. Assessing the scientific accuracy of popular TikTok videos exceeded this project’s scope but would be a valuable research direction, given the rise of problematic information online.¹⁷ Indeed some TikTok users were using the platform to debunk misinformation (4.5%). Public health approaches might include working with influential online figures to help ensure the dissemination of accurate information.¹⁸

Conclusion

Organ donation and transplantation on popular English-language TikTok videos exhibit a window into personal and medically expository experiences of patients and families. While some negativity around healthcare systems

was evident, the majority of TikToks promoted organ donation, raised awareness of its benefits, and shed light on donation and transplantation realities. Connectivity between donors and recipients and honor walks was highlighted as valuable, and perhaps underutilized, aspects of donation processes. It remains essential to study, assess, and leverage TikTok to meaningfully engage with patient and donor communities.

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