



Palliative Care TikTok: Describing the Landscape and Explaining Social Media Engagement



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Introduction

Palliative care is on the rise in the United States; however, there are millions of Americans with serious illnesses who are not receiving palliative care but could benefit from it. Examining the dissemination of palliative care information is a necessary step toward ensuring that patients with serious illnesses receive the beneficial services.

Platforms such as Facebook, Twitter, and YouTube have been used globally by palliative care health care professionals, researchers, and advocacy organizations to educate the public. To date, there have not been any studies investigating palliative care videos on TikTok. Given TikTok's growing popularity, widespread reach, and easily accessible videos, it is essential to explore its potential as a novel platform for the dissemination and consumption of palliative care education and support resources among its users.

Objective

The present study aimed to characterize palliative care TikTok videos. The secondary aim was to determine whether certain video characteristics were associated with higher levels of user engagement.

Methods

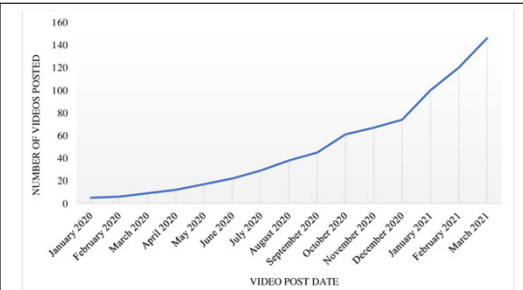
From January 1, 2021 to January 4, 2021, the investigators screened TikTok videos that used the term "palliative." Videos that did not refer to "palliative care" in the caption or verbally by the video author were determined to be unrelated to palliative care and were subsequently excluded. Videos were additionally excluded if they (1) solely focused on hospice care, end-of-life care, or palliative care for non-human animals; (2) were not in English; or (3) were deleted by the author before they could be coded.

Data collected for each video included social media engagement statistics such as the number of likes, comments, shares, and views, in addition to general video information such as the author's name, the date the video was posted, hashtags listed by the author, and the type of video. Other characteristics noted and recorded for each video included music, presentation of statistics, and number of individuals appearing on screen. Data were then collected on author characteristics, including gender, author type (health care professional, patient, caregiver, or other), type of health care professional (if applicable), and the actions performed by the author. Themes were identified before coding and each video was subsequently classified under one or more of those themes.

Analyses were performed in SPSS 28.0. Descriptive statistics were examined for all video features. As the variance was greater than the mean and overdispersion was present, negative binomial regression analyses were conducted to determine whether engagement metrics were predicted by (1) author type and (2) video themes. After conducting a goodness of fit test and omnibus test to confirm that the model fit the data well and was statistically significant, we examined each categorical predictor in the models simultaneously. Statistical significance was determined using an alpha level of 0.05.

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Figure 1



A total of 510 videos were screened, and 146 videos met eligibility criteria. All eligible videos were found to have been posted between January 2020 and March 2021, with 72 videos being posted in the first quarter of 2021 and 74 videos being posted in all of 2020.

Table 2

Themes Featured in Palliative Care TikTok Videos		
Theme	Criteria	Example Quotes
Describing personal experiences	The video portrays the experiences of palliative care healthcare professionals, patients, or caregivers.	<ul style="list-style-type: none"> • People ask me if it's depressing being a palliative care doctor. It can be sad, but it's also rewarding. • I began palliative a while back. We tried new things and switched up some of my prescriptions. Now my side effects are reasonably managed. It's still odd to think that I'm in my 20s and seeing palliative care. • Jim has his palliative care team, and they're great for managing nausea and discomfort. He's vigorously beating his illness.
Educating	The video seeks to inform about, provide facts about, and increase understanding of palliative care.	<ul style="list-style-type: none"> • How do we define palliative care? It's comprehensive support for all forms of suffering. It's for any individuals with any type of illness that disrupts their quality of life. Palliative care supports emotional, physical, social, and spiritual functioning. • Palliative care is life affirming. Death is normal, and it does not try to accelerate or delay it. Palliative care improves quality of life and might extend survival times.
Addressing misconceptions	The video is intended to approach and dispel inaccurate conceptions about palliative care.	<ul style="list-style-type: none"> • True or false, is palliative care only relevant to older adults? False. PC can help at all ages. I have seen many pediatric patients and middle-aged adults too. • Many people believe palliative care is just about the end of life. It can be, but palliative care can also be used at times when a patient is dealing with challenging concerns or hopes to better control pain.
Responding to questions and comments	The video is posted as a reply to another's user comment.	<ul style="list-style-type: none"> • Comment: How do you start palliative care? Response: It was a lot easier than I expected. I just mentioned it to my heart doctor because a few of my other doctors had brought it up. • Comment: Thanks Dr. Jones, I just wondered how does the emphasis of palliative care differ from end-of-life care? Response: Great question. Regrettably, many people still mix up palliative care and hospice. In actuality they are much different...."
Raising awareness	The video aims to increase knowledge of the existence of palliative care.	<ul style="list-style-type: none"> • Have you heard the WHO includes palliative care on its list of human rights to health? Nonetheless, the lack of awareness means that many eligible people will never get to use palliative care. • Why does palliative care matter? Most people with a serious cancer diagnosis overestimate their chances of survival. Many do not know the goals of their treatments. Talking to palliative care can reduce distress among patients and families. Let's start a dialogue. Remember to share, comment, and like.

The videos covered at least one of six broad themes: raising awareness, educating, addressing misconceptions, describing personal experiences, responding to questions and comments, and other. The greatest number of videos included the "describing experiences" theme and "educating" theme.

Tables 3 and 4

Negative Binomial Regression using Palliative Care Video Author Type and Video Theme to Predict TikTok Social Media Engagement Metrics											
Video Author	Number of Views			Number of Comments			Number of Shares				
	OR (95% CI)	p	OR (95% CI)	p	OR (95% CI)	p	OR (95% CI)	p			
Healthcare professional	1.03 (0.41-2.59)	0.954	1.18 (0.44-3.15)	0.746	0.53 (0.19-1.50)	0.233	0.25 (0.08-0.74)	0.013			
Patient	2.36 (0.91-6.17)	0.078	2.78 (1.01-7.66)	0.049	1.88 (0.65-5.45)	0.245	0.36 (0.12-1.07)	0.066			
Caregiver	5.91 (1.98-19.48)	0.003	8.71 (2.32-32.69)	<0.001	1.93 (0.56-6.68)	0.296	0.40 (0.10-1.46)	0.165			
Video Theme	Number of Views			Number of Comments			Number of Shares				
	OR (95% CI)	p	OR (95% CI)	p	OR (95% CI)	p	OR (95% CI)	p			
Describing personal experiences	3.30 (1.75-6.25)	<0.001	2.66 (1.44-4.93)	0.002	1.51 (0.83-2.72)	0.174	2.72 (1.39-5.32)	0.003			
Educating	2.66 (1.34-6.03)	0.005	2.61 (1.43-4.78)	0.002	1.92 (1.11-3.31)	0.019	3.12 (1.64-5.92)	<0.001			
Addressing misconceptions	2.64 (1.04-6.15)	0.035	1.64 (0.62-4.27)	0.059	1.31 (0.76-2.25)	0.331	1.90 (1.41-2.51)	0.015			
Responding to questions and comments	0.73 (0.44-1.21)	0.216	0.55 (0.33-0.92)	0.022	0.76 (0.45-1.29)	0.304	0.44 (0.26-0.76)	0.003			
Raising awareness	0.48 (0.27-0.85)	0.011	0.51 (0.29-0.89)	0.018	0.70 (0.40-1.23)	0.210	0.54 (0.29-0.99)	0.048			
Other	1.19 (0.62-2.30)	0.710	0.81 (0.31-2.06)	0.640	0.80 (0.31-1.97)	0.644	1.07 (0.39-2.94)	0.898			

Caregivers' videos were most likely to be viewed ($p = 0.003$) and liked ($p < 0.001$), whereas health care professionals' videos were most frequently shared ($p = 0.01$). Engagement was highest among videos focused on describing personal experiences (views: $p < 0.001$, likes: $p = 0.002$, shares: $p = 0.003$) and educating (views: $p = 0.005$, likes: $p = 0.002$, comments: $p = 0.02$, shares: $p < 0.001$).

Table 1

Descriptive Statistics for Palliative Care TikTok Videos	
Variable	N (%)
Video-level Characteristics	146 (100.0)
Video author	
Healthcare professional	81 (55.5)
Physician	59 (40.4)
Nurse	13 (8.9)
Unknown/other	9 (6.2)
Patient	48 (32.9)
Caregiver	11 (7.5)
Mother	10 (6.8)
Child	1 (0.7)
Other	6 (4.1)
Video author gender	
Female	104 (71.2)
Male	41 (28.1)
Organization	1 (0.7)
Video type	
Live recording	139 (95.2)
Slideshow	7 (4.8)
Screenshot	2 (1.4)
Video add-ons	
Music played in background	87 (59.5)
Captions on screen	56 (38.4)
Number of people appearing in video	
0 individuals	2 (1.4)
1 individual	128 (87.7)
≥2 individuals	8 (5.5)
Action performed by video author	
Talking	67 (45.9)
Dancing	23 (15.8)
Lip syncing	13 (8.9)
Making expressions	10 (6.8)
Showing surroundings	6 (4.1)
Hashtags Used	768 (100.0)
#palliativecare	98 (12.8)
#lysp	47 (6.2)
#hospice	29 (3.8)
#tiktokker	21 (2.7)
#chronicillness	20 (2.6)
#nurse	18 (2.3)
#doctor	16 (2.1)
#foryou	15 (2.0)
#tiktokdoctor	11 (1.4)
#tiktokdoes	11 (1.4)

Most videos were live recordings, with one individual appearing on the screen, usually talking. The most common hashtag appearing in videos was #palliativecare. Most videos were uploaded by women. Health care professionals appeared most often in videos, followed by patients, and caregivers. Among health care professionals, physicians and nurses posted most. Among caregivers, the vast majority were mothers.

Discussion/Conclusion

This investigation has implications for improving public awareness and understanding of palliative care via social media. Palliative care articles on Twitter, videos on YouTube, and activity on Facebook have had themes similar to "educating," but none similar to "describing experiences"; additionally, users on these platforms have largely been comprised of only palliative care professionals and organizations to date. These findings can assist palliative care clinicians, scientists, and patients in expanding their communication, health education, and patient advocacy to create and disseminate engaging video content using a novel, fast-growing social media platform.

Analyses also described what typical palliative care TikTok videos are like, which may help guide health care professionals, patients, and caregivers to the idea of using this platform. Importantly, the identification of video qualities associated with increased user engagement can assist health care professionals, patients, and caregivers in creating TikTok videos that will reach a larger audience of those seeking information about palliative care using this platform.

Our results indicate that video authors should consider focusing on themes of educating and describing one's personal experience to increase user engagement. Based on normative trends, (1) record a live self-style video, rather than a formal slideshow, (2) find ways to incorporate music, (3) use captioning, (4) talk without worrying much about incorporating more complex elements such as dance, (5) present alone, and (6) help users to find the videos by using the hashtag #palliativecare. These basics will allow palliative care experts to share their knowledge with the public successfully, and seasoned TikTokkers can experiment with more novel techniques.

Results of this study show an active and growing community on palliative care TikTok. Caregivers and health care professionals were able to engage users in learning about palliative care while videos that focused on describing personal experiences or educating fostered more social media engagement. TikTok is a novel and promising setting for disseminating information about palliative care to the general public.