

Social Media as a Source of Information of Lymphatic Filariasis: A Content Analysis of YouTube.

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This study aims to describe the characteristics of the most viewed YouTube video on lymphatic filariasis (LF). To achieve this, researchers searched YouTube videos with the keyword "lymphatic filariasis". The videos selected for this study had the criteria that they had been watched more than 100 times. The researcher selected 135 videos in English which were manually coded, categorised, and analysed. The video selected consisted of 39 consumer videos, 70 professional videos, 7 television-based news videos, and 19 internet-based news videos. The research results showed that the likelihood of consumer videos being viewed was 7.5 times higher than internet-based news videos when it came to uploaded videos about the etiology of LF (OR 7.5; 95% CI 1.092-51,518; P=0.040). Consumer video likelihood was 12.5 times higher than internet-based news videos when concerning videos about the treatment of LF patients (OR 12.5; 95% CI 1.338-116.7796; P=0.027). Consumer video likelihood was ten times higher than the internet-based news videos when uploading videos about fundraising variability with LF (OR 10.00; 95% CI 1.048-95.457; P=0.045). It was concluded that the most viewed YouTube videos were uploaded by professionals, with the majority discussing the technical aspects of the disease. It was also found that consumer uploaded videos tend to focus on social support efforts for people with LF.

Key words: *Lymphatic Filariasis, Elephantiasis, Medical Informatics, Social Media, Internet.*

Introduction

Lymphoedema, or lymphatic filariasis, also known as elephantiasis, is an impairment of the lymphatic system and can cause an enlargement of the organs. This causes abnormal pain, disability, increased weight, and social stigma (Schulze et al., 2018; World Health Organisation, 2018). LF is caused by infection of the filarial nematodes *Wuchereria bancrofti*, *Brugia malayi*, and *Brugia timori*. LF is endemic in 60 countries, affecting around 120 million people with 1.23 billion people at risk of getting infected (World Health Organisation, 2014). There are around 40 million people with associated disabilities and paralysis (World Health Organisation, 2018).

LF is targeted for global elimination as a public health problem in 2020. The World Health Organisation (WHO) established the Global Program to Eliminate LF (GPELF) (World Health Organisation, 2014). The needed cost is estimated to be US \$154 million (the US \$105-208 million) per year, which is for 2015 – 2020 to continue GPELF (Department of Control of Neglected Tropical Disease, 2015; Gedge et al., 2018). To support the efforts of the WHO in the global elimination of LF, there needs to be clear and trusted information. Additionally, the information also needs to be distributed more aggressively. The information must be able to be accessed by anyone easily. Media characters that match these needs include social media, one of which is YouTube.

In June 2017, YouTube was the social media platform listed as number two related to popularity after Facebook. For video-based platforms, YouTube is the number one platform concerning popularity (Hutchinson, 2018). YouTube allows uploaders to create and change their video, including the health message content (Basch et al., 2017). YouTube has over a billion users which equates to almost one-third of all people on the Internet (YouTube, 2018).

Research has shown that YouTube is a platform that can provide information about health (Ipa and Laksono, 2014; Laksono et al., 2014; Azer et al., 2018; Smeeton et al., 2018; Shen et al., 2019). Based on this, this research is intends to describe the characteristics of the information about LF on YouTube.

Methods

Data Retrieval

All of the data sources were obtained from searching YouTube.com using the keyword "lymphatic filariasis". The data were collected on 4th July 2018. All videos found in English were selected based on having a high definition video format (HD), a video duration that was a maximum of 4 minutes, and had been viewed by a minimum of 100 viewers. The data



characteristics of the selected LF videos were video title, web address, date uploaded, video duration, the number of people who had liked the video (like or thumbs-up), and the number of people who did not like a video (dislike or thumbs-down).

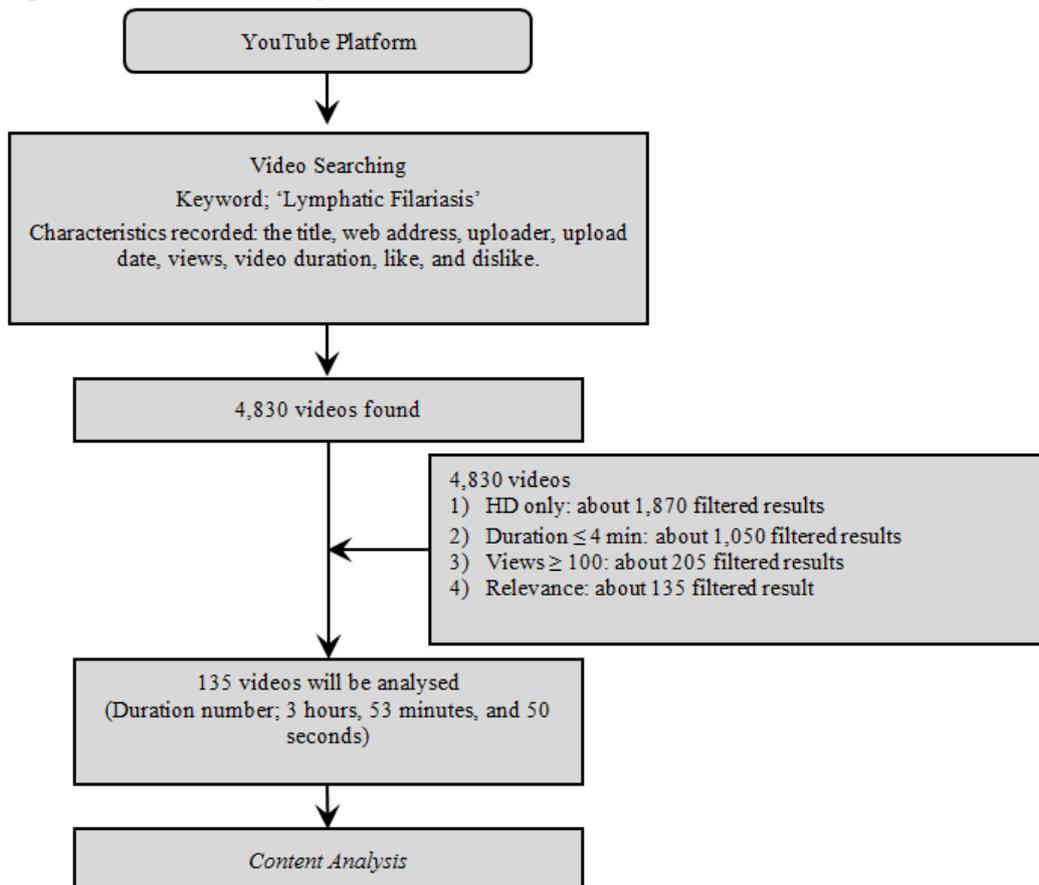
Coding of the Video Sources

Video source coding was determined manually by two independent raters. The source category of the videos uploaded was either consumer video (including testimonial), professional, television-based news, and internet-based news. Consumer videos were defined as the videos uploaded by verified YouTube accounts that include the content of their accounts, such as personal stories, product reviews, or comments. A video was classified as professional if it included an individual with a health education background. Television-based news included the videos uploaded by any verified news network. Internet-based news is a type of news that comes from an online source (Basch et al., 2017).

Coding of the Video Content

In addition to the source of the video and the characteristics of the video (views, likes/thumbs up, dislike/thumbs-down, duration), information on the content of the LF videos were also collected. Video content-coding was determined based on the following criteria: LF etiology, LF examination techniques, the prevention of LF, LF sufferer care, fundraising for LF sufferers, and LF elimination policy.

Figure 1. Research Design.



Inter-Rater Reliability

To assess the validity and reliability of the inter-rating, manual coding was conducted by another independent rater (an epidemiologist was used as the gold standard) who selected 13 random videos from the sample to recode. The results of the coding were then compared to the previous two raters, and the Cohen unweighted kappa (κ) value was calculated to get the percentage agreement.

Statistical Analysis

Because the data distribution was normal, parametric statistics were used for the analysis. The statistical analysis was started using the Chi-Square test for the dichotomous variables and a T-test for the continuous variable. This test is used to assess whether there are differences between the video sources. Because of the nature of the dependent variables, multinomial logistic regression tests were used to estimate. This study does not require ethical approval as it is not related to human or animal interventions and the direct observation of an object.

Results

One hundred percent of the variables that were manually coded reached an agreement of 100%, where $\kappa=1$. Almost all of the expert's statistics had a Kappa value (κ) of at least 0.6, and often higher than 0.7 (Landis and Koch, 1977).

The descriptive statistics of the continuous variables (views, views/day, like, dislike, and duration) have been presented in Table 1. Table 1 shows out of the 135 LF videos that were encoded manually, 39 videos were made by consumers (28.9%), 70 videos were made by professionals (51.9%), 7 videos were television-based news (5.2%), and 19 videos were internet-based news (14.1%). The overall length of the videos ranged from 0.117 to 3.95 minutes. The 135 videos had been seen by 4,495,970 viewers.

Table 1: Descriptive Statistics concerning the Video Characteristics for LF on YouTube.

Characteristic	Video Source				Total
	Consumers	Professional	Television-based news	Internet-based News	
Views (mean)	39	70	7	19	135
	(7,520.13)	(54,055.89)	(10,953.71)	(18,005.11)	(33,303.48)
Rating (mean)	39	70	7	19	135
	(38.06)	(38.24)	(7.39)	(10.98)	(32.75)
Like (mean)	39	70	7	19	135
	(44.54)	(129.19)	(10,71)	(12,89)	(82.22)
Dislike (mean)	39	70	7	19	135
	(2.82)	(14.97)	(3.29)	(2.37)	(9.08)
Duration (mean)	39	70	7	19	135
	(117.21)	(96.11)	(119.43)	(99.74)	(103.93)

The professional videos had been viewed 3,783,912 times (84.16%), followed by internet-based news videos, at 342,097 times (7.61%), consumer videos at 293,285 times (6.52%), and lastly, television-based news video were viewed 76,676 times (1.71%). The distribution of the number of people who watch the videos is statistically not different across the different source categories.

Table 2 shows that the videos made by professionals contain information about the technical matters related to LF. As much as 88.6% of the content was about LF etiology, LF technical examinations, LF prevention, and LF sufferer care. In the fundraising category for LF sufferers, there were no videos from professionals.

Table 2: Descriptive statistics for the LF Video Content Categories on YouTube.

Video Content Category	Video Source				Total
	Consumers	Professional	Television-based news	Internet-based News	
About LF etiology	15	28	2	5	50
	38.5%	40.0%	For 28.6%	26.3%	37.0%
About LF examination techniques	1	14	0	2	17
	2.6%	20.0%	0.0%	10.5%	12.6%
About LF prevention	3	8	1	3	15
	7.7%	11.4%	14.3%	15.8%	11.1%
About LF sufferer care	10	12	0	2	24
	25.6%	17.1%	0.0%	10.5%	17.8%
About LF elimination policy (ref)	2	8	2	5	17
	5.1%	11.4%	For 28.6%	26.3%	12.6%
About fundraising for LF sufferers	8	0	2	2	12
	20.5%	0.0%	For 28.6%	10.5%	8.9%

Note: P= 0.04

Table 3 displays the results of the multinomial logistic regression tests used to illustrate the differences between the video sources concerning the category of the contents of the video messages about LF. As a reference, we selected the category "about LF elimination policy". Table 3 shows there are two different video sources for the three categories of the content of the videos about the LF that are statistically significant. First, the likelihood of consumer videos being uploaded was 7.5 times than higher internet-based news videos about LF etiology (OR 7.5; 95% CI 1.092-51.518; P=0.040). Second, consumers – concerning video uploads – had a likelihood that was 12.5 times higher than internet-based news videos about the LF sufferers' care (OR 12.5; 95% CI 1.338-116.1199; P=0.027). Third, consumers had a likelihood that was 10 times more than internet-based news when it came to uploading videos about fundraising for LF sufferers (OR 10.00; 95% CI 1.048-95.457; P=0.045).

Table 3: Logistic Multinomial Regression of LF Videos on YouTube

Video Content Category	Sig.	OR	95% confidence interval	
			lower bound	upper bound
About LF etiology				
Consumers	0.040*	7,500	1,092	51,518
Professional	0.094	3,500	0,807	15,186
Television-Based News	1.000	1,000	0,098	10,166
About LF examination techniques				
Consumers	0.880	1,250	0,068	22,879
Professional	0.119	4,375	0,684	27,983
Television-Based News	-	-	-	-
About LF prevention				
Consumers	0.433	2,500	0,253	24,719
Professional	0.564	1,667	0,294	9,445
Television-Based News	0.898	0,833	0,051	13,633
About LF sufferer care				
Consumers	0.027*	12,000	1,338	116,796
Professional	0.165	3,750	0,579	24,282
Television-Based News	-	-	-	-
About fundraising for LF sufferers				
Consumers	0.045*	10,000	1,048	95,457
Professional	-	-	-	-
Television-Based News	0.482	2,500	0,194	32,194

Note: Reference category "about LF elimination policy"; *significance at a 95% level.

Discussion

The results of this research are important and interesting because of two findings. First, the source of the videos uploaded by professionals dominates all things technical that are substantive concerning LF (etiology, examination, prevention, and LF sufferer care). This can be interpreted that the internet is good enough to provide technical information about LF. Second, videos about fundraising for LF sufferers dominated the videos uploaded by consumers.

There were no videos about fundraising for LF sufferers made by LF professionals. This means that professionals care more about the substantive technical aspects of LF. Matters relating to the social aspects, stigma, and social support are not attractive to professionals, although some studies have shown that social aspects contribute to the success of eliminating LF (Alonso et al., 2017; Obindo et al., 2017). Nearly 4.5 million people watched the 135

videos on LF. This is an expression that even though LF is a neglected tropical disease, the demand for information about LF is quite large. This also shows that the internet is a popular source of health information (Machackova and Smahel, 2018; Marshall et al., 2018). Further research is needed to investigate the accuracy and validity of the health-related information found on the internet that uses a theoretical framework to see how these sources can influence behaviour (DiNardi, Guldi and Simon, 2018; Machackova and Smahel, 2018).

The professional videos that were uploaded were quite interesting for the information seekers of LF. This is possible because of the characteristics of the videos uploaded. The professional videos were short enough to catch attention, as this category was dominated by videos with a duration that was less than 2 minutes. YouTube's audience in the context of this interest can be seen from the dominance of the viewers who liked the videos with a duration of fewer than 2 minutes. This finding confirms the results of several studies on the short duration of videos that are more preferred by health information seekers on YouTube (Ipa and Laksono, 2014; Laksono, 2014; Lam, Tsiang and Woo, 2017).

There are some limitations related to the design and selection of the videos examined. The selection of videos that were only in English could remove some important information that may be available in other languages. Another important note is that the video data on YouTube is snapshot data. Videos and their characteristics continue to change, and viral effects can change over time as well (Basch et al., 2017). However, the information available on LF via the YouTube platform is very interesting because it can be used to reach out to anyone anywhere, so long as they are still connected to the internet. They have a potentially massive reach (Hutchinson, 2018; YouTube, 2018). YouTube is an important source of information that is preferred in the context of the currently available options (Gümüş, 2018). To add to the viral effect, the LF video uploader on YouTube can add video links to other social media. Uploading YouTube video links to social media such as Facebook, Twitter or Instagram will increase the reach of diffusion of information about LF to more massive targets (Laksono and Wulandari, 2011; Al Mamun, Ibrahim and Turin, 2015; Watts, Hefler and Freeman, 2019).

Conclusions

The most viewed videos about LF on YouTube were those uploaded by professionals. The videos uploaded by professionals discuss LF's technical content. The LF videos uploaded by consumers focus more on social support efforts for LF sufferers. Meanwhile, the videos from television-based news and internet-based news do not show any particular prominent characteristics. The consumer-uploaded videos were 7.5 times more likely than internet-based news videos to be about the etiology of LF. The consumer likelihood was 12.5 times more than that of internet-based news to upload videos about LF sufferer care. The video



consumers had a likelihood that was 10 times more than internet-based news when it came to uploading videos about fundraising for LF sufferers. Professionals must further expand the availability of LF information that is not only limited to the medical-technical aspects of LF. They should also touch on social aspects. This is needed to improve the success of the LF elimination campaign. YouTube was an effective medium for campaign purposes.

Ethic and Consent

This research does not require ethical clearance, because it uses secondary data collected from the YouTube platform.

REFERENCES

- Alonso, L. et al. (2017) 'Knowledge, attitudes, and practices toward onchocerciasis among local population in Bioko Island, Equatorial Guinea', *Annals of Tropical Medicine and Public Health*, 10(5), pp. 1228–1237. doi: 10.4103/ATMPH.ATMPH_726_16.
- Azer, S. A. et al. (2018) 'Experience of parents of children with autism on YouTube: are there educationally useful videos?', *Informatics for Health and Social Care*, pp. 1–15. doi: 10.1080/17538157.2018.1431238.
- Basch, C. H. et al. (2017) 'YouTube as a source of information on skin bleaching: a content analysis', *Clinical and Experimental Dermatology*, pp. 1–5. doi: 10.1111/ced.13335.
- Departement of Control of Neglected Tropical Disease (2015) Investing to overcome the global impact of neglected tropical diseases Third WHO report on neglected tropical diseases. Edited by P. Holmes. World Health Organization.
- DiNardi, M., Guldi, M. and Simon, D. (2018) 'Body weight and Internet access: evidence from the rollout of broadband providers', *Journal of Population Economics*, pp. 1–37. doi: 10.1007/s00148-018-0709-9.
- Gedge, L. M. et al. (2018) 'Economic evaluations of lymphatic filariasis interventions: A systematic review and research needs', *Parasites and Vectors*, 11(1). doi: 10.1186/s13071-018-2616-z.
- Gümüş, N. (2018) 'Consumers' Perceptions of YouTubers: The Case of Turkey', *Online Academic Journal of Information Technology*, 8(32), pp. 23–38. doi: 10.5824/1309-1581.2018.2.002.x.
- Hutchinson, A. (2018) Mind-Blowing YouTube Stats, Facts and Figures for 2017 [Infographic]. Available at: <https://www.socialmediatoday.com/social-business/mind-blowing-youtube-stats-facts-and-figures-2017-infographic> (Accessed: 4 July 2018).
- Ipa, M. and Laksono, A. D. (2014) 'Potential Analysis of Promoting the Dengue Hemorrhagic Fever Prevention Through Youtube', *Bulletin of Health System Research*, 17(1), pp. 97–106.
- Laksono, A. D. (2014) 'Cigarettes in YouTube', in Hargono, R. and Laksono, A. D. (eds) *Pros-Cons Cigarette Discourse in YouTube*. Jogjakarta: PT Kanisius, pp. 133–148.

- Laksono, A. D. et al. (2014) Pros and Cons of Cigarette Discourse in YouTube (Pro-Kontra Diskursus Rokok dalam Media Sosial YouTube). Edited by R. Hargono and A. D. Laksono. Jogjakarta: PT Kanisius. Available at: https://www.academia.edu/32356003/Pro-Kontra_Diskursus_Rokok_dalam_Media_Sosial_YouTube.
- Laksono, A. D. and Wulandari, R. D. (2011) 'Analysis of the Potential Distribution of Health Information Through Social Networks (Analisis Potensi Penyebaran Informasi Kesehatan Melalui Jejaring Sosial)', *Bulletin of Health System Research*, 14(4), pp. 358–365.
- Lam, N. H. T., Tsiang, J. T. H. and Woo, B. K. P. (2017) 'Exploring the Role of YouTube in Disseminating Psychoeducation', *Academic Psychiatry*, 41(6), pp. 819–822. doi: 10.1007/s40596-017-0835-9.
- Landis, J. R. and Koch, G. G. (1977) 'The measurement of observer agreement for categorical data', *Biometrics*, 33(1), pp. 159–174. doi: 10.2307/2529310.
- Machackova, H. and Smahel, D. (2018) 'The perceived importance of credibility cues for the assessment of the trustworthiness of online information by visitors of health-related websites: The role of individual factors', *Telematics and Informatics*, 35(5), pp. 1534–1541. doi: 10.1016/j.tele.2018.03.021.
- Al Mamun, M., Ibrahim, H. M. and Turin, T. C. (2015) 'Social media in communicating health information: an analysis of Facebook groups related to hypertension.', *Preventing chronic disease*, 12(1), p. E11. doi: 10.5888/pcd12.140265.
- Marshall, J. H. et al. (2018) 'The assessment of online health videos for surgery in Crohn's disease', *Colorectal Disease*, 20(7), pp. 606–613. doi: 10.1111/codi.14045.
- Obindo, J. et al. (2017) 'Prevalence of depression and associated clinical and socio-demographic factors in people living with lymphatic filariasis in Plateau State, Nigeria', *PLoS Neglected Tropical Diseases*, 11(6). doi: 10.1371/journal.pntd.0005567.
- Schulze, H. et al. (2018) 'Worldwide assessment of healthcare personnel dealing with lymphoedema', *Health Economics Review*, 8(10), pp. 1–11. doi: 10.1186/s13561-018-0194-6.
- Shen, C.-C. et al. (2019) 'Do YouTube Fitness Videos Help YouTube user to Learn Fitness?', *International Journal of Innovation, Creativity and Change*, 5(2), pp. 93–104.



Smeeton, B. et al. (2018) ‘A critical review of melanoma self-screening tools on YouTube – A missed opportunity?’, *Journal of Plastic, Reconstructive & Aesthetic Surgery*, 71, pp. e11–e12. doi: 10.1016/j.bjps.2018.01.037.

Watts, C., Hefler, M. and Freeman, B. (2019) ‘We have a rich heritage and, we believe, a bright future’: How transnational tobacco companies are using Twitter to oppose policy and shape their public identity’, *Tobacco Control*, 28(2), pp. 227–232. doi: 10.1136/tobaccocontrol-2017-054188.

World Health Organization (2014) *Global Programme to Eliminate Lymphatic Filariasis: Progress Report 2013*. Available at: <http://www.who.int/wer>.

World Health Organization (2018) *Lymphatic filariasis; fact-sheets*. Available at: <http://www.who.int/en/news-room/fact-sheets/detail/lymphatic-filariasis> (Accessed: 4 July 2018).

YouTube (2018) *YouTube in numbers*. Available at: <https://www.youtube.com/intl/en-GB/yt/about/press/> (Accessed: 4 July 2018).