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Opinion paper

Dry facts are not always inviting: a content analysis of Korean videos regarding Parkinson's disease on YouTube

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ABSTRACT

This study aimed to evaluate the accuracy of Korean videos regarding Parkinson's disease (PD) on YouTube and viewers' responses to them. YouTube search was performed using the search term "Parkinson disease" in Korean language on March 28, 2017. Two independent neurologists categorized the videos into "reliable", "misleading" or "patient experiences". The number of views, days since upload, video length, number of "likes" and "dislikes", and upload source were collected for each video. A total of 138 videos were included in this study. Of these, 91 videos (65.9%) were reliable; 31 (22.5%) were misleading, and 16 (11.6%) were of patient experiences. The videos with patient experiences had the highest number of mean views with 9710.4 ± 3686.9 , followed by misleading videos with 5075.0 ± 1198.6 , and reliable videos with 2146.8 ± 353.4 (ANOVA, $p < 0.001$). The number of mean views per day was 4.0 ± 0.6 for the reliable videos, which was significantly lower than the misleading videos (9.7 ± 3.4 , $p = 0.020$) and the videos of patient experiences (11.3 ± 4.6 , $p = 0.023$). The reliable videos were mostly uploaded by university hospitals (46.2%) and misleading videos by health-related commercial entities (74.2%). The misleading videos as well as the videos of patient experiences advocated "diet" as a treatment of PD. The current study found that only two-thirds of the Korean videos regarding PD on YouTube provide reliable information. More importantly, the videos with reliable contents were less popular than videos with misleading contents. Further efforts are warranted to effectively increase the dissemination of accurate and scientifically proven PD information to YouTube users.

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1. Introduction

Parkinson disease (PD) is the second most common neurodegenerative disorder with considerable complexity and heterogeneity in the etiology, symptoms and signs, and treatment [1]. Thus, even a medical professional can have misconceptions regarding PD, and it is no wonder that patients cannot be sophisticated about the complicated therapeutic strategies [2]. In addition, they often seek resources without scientific support or evidence for efficacy because there is no current scientifically proven and medically recommended treatment to slow the neurodegenerative process [3]. These unvalidated practices may result in serious adverse events without any benefit [4]. Accordingly, it is important to provide accurate information about PD to patients and their caregivers as well as to medical professionals.

The internet has recently become a primary source for medical information [5]. One of the most popular sources of internet-based medical information is YouTube which is a video-sharing website with the third most visited internet property globally and in Korea [6]. It provides free and easy access to hundreds of thousands of videos associated with PD. However, the accuracy of the medical content on YouTube varies widely because videos are uploaded by users with little or no curation [5,7–16]. If YouTube could provide accurate PD-related information, it could be a great option to educate patients and their caregivers about PD because a video is worth a thousand words [17]. Therefore, the aim of this study was to evaluate the accuracy of Korean videos on PD hosted on YouTube. Additionally, we assessed the responses of the viewers to the PD videos.

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2. Methods

2.1. Selection of videos

A search was performed on YouTube (<http://www.youtube.com>) using the search term “Parkinson disease” in Korean language on March 28, 2017 with the default filter by relevance. The computer history and cookies were deleted before searching because they can affect the search results. A total of 9450 videos were retrieved. Given that users seldom go beyond the first few pages of any search result [18], only 200 videos from the first 10 pages (20 videos per page) were screened. We included videos whose primary content was “Parkinson’s disease”. Videos not in Korean language or without audio were excluded. Multipart videos were counted as one and the parameters of the viewers’ responses for these videos were averaged over the number of parts. Therefore, 138 videos were analyzed in this study.

2.2. Assessment of the videos

Two independent neurologists assessed the videos for scientific accuracy (RK and HP). The videos were categorized into “reliable” (contains scientifically accurate information regarding PD), “misleading” (contains information that is incorrect or scientifically unproven), or “patient experiences” (contains patients’ personal experiences rather than medical information on PD). If a video included both reliable and misleading information, it was categorized as “misleading”. Disagreement between the raters was resolved by discussion.

The number of views, days since upload, video length, number of “likes” and “dislikes”, and upload source were collected for each video on March 28, 2017. The number of mean views per day was calculated by dividing the total number of views by the number of days since the videos was uploaded online. Upload source was classified into university hospital, medical and health-related commercial entities, news agency, or individual user. Medical and health-related commercial entities include business entities run by private medical and para-medical personnel. Each video was assessed for the presence or absence of information for four content domains: epidemiology, etiology, symptoms and signs, and treatment.

2.3. Statistical analysis

All statistical analyses were performed after evaluating the agreement between the 2 raters. The inter-rater agreement regarding the accuracy was measured using the kappa statistic. The kappa value was classified as poor agreement when <0.20 , fair when $0.21–0.40$, moderate when $0.41–0.60$, good when $0.61–0.80$, and very good when >0.81 [19]. Differences between groups were compared using one-way analysis of variance (ANOVA) followed by Fisher’s least significant difference (LSD) post hoc test. The level of statistical significance was set at $P < 0.05$. Calculations were performed using SPSS 18.0 (SPSS, Chicago, IL).

3. Results

When classifying the videos in terms of accuracy, the raters had very good inter-rater agreement ($K = 0.95$, 95% CI = $0.94–0.97$). There was a disagreement between the raters for six videos, which were resolved by discussion.

The demographics and viewers’ responses of the videos are shown in Table 1. Of the 138 videos, 91 (65.9%) were reliable; 31 (22.5%) were misleading, and 16 (11.6%) were of patient experiences. The total number of views was 195,361 for reliable videos,

157,325 for misleading videos, and 155,366 for videos of patient experiences. The videos of patient experiences had the highest number of mean views with 9710.4 ± 3686.9 followed by the misleading videos with 5075.0 ± 1198.6 , and reliable videos with 2146.8 ± 353.4 (ANOVA, $p < 0.001$). The number of mean views per day was 4.0 ± 0.6 for the reliable videos, which was significantly lower than that of the misleading videos (9.7 ± 3.4 , $p = 0.020$) or the videos of patient experiences (11.3 ± 4.6 , $p = 0.023$). Similarly, there were significant differences on mean number of “likes” (ANOVA, $p < 0.001$) and “dislikes” (ANOVA, $p < 0.001$), which were lower for the reliable videos. The mean length of the videos was significantly longer for the reliable videos (15.3 ± 1.8 min) compared with the misleading videos (6.9 ± 1.8 min, $p = 0.010$) but not with the videos of patient experiences (7.1 ± 2.8 min, $p = 0.051$).

Of the 91 reliable videos, 42 (46.2%) were uploaded by university hospitals; 34 (37.4%) were uploaded by news agencies, and 11 (12.1%) were uploaded by individual users. Misleading videos were mostly uploaded by medical and health-related commercial entities (74.2%) followed by individual users (22.6%). The videos of patient experiences were mainly uploaded by individual users (62.5%) followed by health-related commercial entities (37.5%).

Reliable and misleading videos had the highest coverage for treatment, whereas the videos of patient experiences had the highest coverage for symptoms and signs. However, there was no significant difference in the number of content domains covered among the three groups (ANOVA, $p = 0.351$). Misleading videos included incorrect or scientifically unproven information regarding the etiology and treatment of PD. As an etiology of PD, fifteen (34.0%) misleading videos advocated “poor blood circulation” and six (12.8%) advocated “constitution type”. In regards to treatment, a major portion of the misleading videos advocated “diet”. Of these, the highest number advocated “low-fat food” followed by “anti-oxidant food”. Three misleading videos advocated “oriental medicine”, two “acupuncture” and one “aroma therapy”. Similarly, the highest number of videos with patient experiences advocated “diet” as a treatment for PD. Other complementary and alternative medicines (CAMs) were also advocated in the videos of patient experiences (Table 2).

4. Discussion

We assessed whether YouTube videos regarding PD provide accurate and scientifically proven information. Although this has become an important issue with growing interest in internet-based medical information, the accuracy of PD-related information on YouTube has not been investigated. Our results show that only about two-thirds of the PD videos provided reliable information to YouTube users. Videos with misleading information and of patient experiences advocated various myths and misconceptions regarding the etiology and treatment of PD, and many of those were associated with CAMs. More importantly, YouTube users tended to view the videos with misleading information more compared to the reliable videos.

The proportion of reliable videos in the current study was 65.9%, which is roughly similar to previous studies evaluating the medical information of other fields on YouTube. They showed that the proportion of reliable videos ranged from 54.9% to 63.6% on topics including H1N1 influenza [12], Epley maneuver [14], gallstone disease [7], kidney stone disease [13], hypertension [8], dialysis [9], rheumatoid arthritis [15], and heart transplantation [16]. In the field of movement disorders, Stamelou et al. [5] evaluated the accuracy of movement disorders in YouTube videos associated with dystonia, PD, chorea, myoclonus, tics, and tremor. Interest-

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