


YouTube as a source of patient education in idiopathic pulmonary fibrosis: a media content analysis

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ABSTRACT

Purpose: Idiopathic pulmonary fibrosis (IPF) is a common cause of pulmonary fibrosis, with millions of individuals affected in the world. Patients may use multiple resources to educate themselves regarding their illness, including popular social media video hosting site YouTube. We set out to determine the quality of patient education material discussing IPF available on YouTube.

Methods: 100 consecutive videos were surveyed for review, of which 59 were included in the final analysis. Three independent blinded reviewers were assigned to score each video on a scoring system designed along patient education material available publicly at the American Thoracic Society and the American College of Chest Physicians. Scores by each reviewer were compared to others using means, standard deviation, Cohen's Kappa, and intra-class reliability.

Results: Video content had a mean score of 5.9, SD 3.96 out of a maximum of 20 points. Cohen's Kappa between the three raters was calculated to a value of 0.92 and Interclass reliability was 0.79 (0.70–0.86, 95% CI) indicating appropriateness of comparison between the three raters.

Conclusion: Patient education material regarding IPF on YouTube was found deficient in quantity and quality. Providers should be aware of the best information resources available and utilize these to educate their patients.

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KEYWORDS

Idiopathic pulmonary fibrosis; patient education; YouTube

1. Introduction



Idiopathic pulmonary fibrosis (IPF), also known as usual interstitial pneumonia is a cause of idiopathic diffuse parenchymal lung disease. Characterized by progressive fibrosis leading to restrictive lung disease, the incidence of IPF appears to be higher in North America and Europe (3 to 9 cases per 100,000 person-years) than in South America and East Asia (fewer than 4 cases per 100,000 person-years) [1]. In the USA, the prevalence of IPF has been reported to range from 10 to 60 cases per 100,000, although in one study, the prevalence was 494 cases per 100,000 in 2011 among adults over the age of 65 years, which was twice as high as the prevalence recorded ten years earlier [2]. Increasing rates of hospital admissions and deaths due to IPF also suggest an increasing burden of disease [1].

Unexplained exertional dyspnea, chronic dry cough, and Velcro crackles are the characteristic of IPF. Unfortunately, a large majority of IPF patients are first misdiagnosed as heart failure or chronic obstructive pulmonary disease and a diagnostic delay of 5 years is not uncommon [3].

Each year, approximately 10 to 20% of patients with IPF have an acute exacerbation, characterized by worsened hypoxemic respiratory failure with bilateral ground-glass opacities, consolidation, or both on high-

resolution CT imaging that are not fully explained by volume overload. Exacerbations may be triggered by a clinical event (e.g., infection, aspiration, or drug toxicity) but are frequently idiopathic [4]. These acute exacerbations carry mortality rates, ranging between 20–100% [5]. IPF, overall, carries a poor prognosis, with a median survival of 3.8 years among adults 65 years of age or older in the USA [4].

Given the natural history of the disease and the frequency of exacerbations experienced by affected individuals, it is prudent that patients be educated regarding their illness, and factors that may worsen symptoms. For a provider, effective patient education is of paramount importance. Ample literature is available in print form, mostly from professional societies, many patients may find these too time consuming, or tedious to digest. As with other disease processes, online information, which is easily accessible, can be considered a valuable resource. An informal query on the popular search engine Google, reveals that there has been a four-fold interest in IPF between 2010 and 2018 [6]. While not all these queries would be patient education related, it is safe to assume that some will be. With the evolution of media delivery and a cultural shift toward consumption of information in more palatable content in the form of videos, hosting web pages

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have enjoyed an explosion of traffic in recent years. A fore-runner is the largest video hosting platform, YouTube. With a wide array of content, a ubiquitous presence and ease of access, YouTube forms a library for many individuals regarding many topics, ranging from social to scientific.

Recent analyses have indicated that many patients use YouTube to educate themselves regarding their illness or disease [7].

We aimed to investigate the quality and quantity of content regarding IPF available to the public on YouTube, to identify whether it is a useful resource regarding the patient education.

2. Methods

100 consecutive original videos were surveyed for analysis in this study. Inclusion criteria were defined as any video which was created for transfer of knowledge. 30 (30%) were categorized as personal testimonial videos which were excluded as these videos were considered ‘experiential,’ rather than focused on being medically appropriate or educational. Of the remaining 70 videos, 11 (16%) of these videos were excluded as they had been removed by YouTube, between the time of selection and rater’s review. Removal reasons by YouTube included shutting down of the YouTube account, or marked as a ‘Digital Millennium Copyright Act (DMCA)’ violation. Of the remaining 59 videos, three independent reviewers, all internal medicine resident physicians, watched each video in its entirety. A scoring scheme was constructed, based on patient education material available from the American College of Chest Physicians and American Thoracic Society. If a video contained all information present in the standard literature items, a score of 20 points was allotted. The scoring sheet and questionnaire can be accessed at the end of this article, appendix A. The reviewers, all internal medicine resident physicians, would subsequently mark off points for each of the 59 videos based on the content that was delivered. Each reviewer was blinded to the initial selection screening of videos as well as the scoring of the other reviewers. The data analyzer was also blind to the reviewers. Data were analyzed via a combination of R2 (Vienna, Austria) SPSS (New York, USA) and Microsoft Excel (Washington, USA). Relevant analyses included mean, maximum, minimum, standard deviation, Cohen’s Kappa, intra-class reliability, ANOVA and linear regression. Graphical representations were provided by SPSS and Microsoft Excel.

3. Results

Overall, 59 videos were analyzed and had an average video length of 9.0 ± 17.5 minutes, $12601 \pm 18,101$

views, 65 ± 134 likes and 4 ± 6 dislikes. The video with the most views and likes was produced by a third-party organization (94534 views, 806 likes) with no direct medical ties. The most extended video was produced by a Medical Society (100.8 minutes) and the video with the highest average educational score was produced by a Hospital Organization (averaged 16.33 points) (Table 1). Overall the reviewers assigned a mean score of 5.9 (SD 3.6) out of a possible 20. The median score was 4.

To ensure inter-rater reliability, Cohen’s Kappa between the three raters was calculated to a value of 0.92. Interclass reliability was 0.79 (0.70–0.86, 95% CI), demonstrating appropriateness of comparison between the three raters.

The data were subsequently analyzed for linearity with a relation between view counts, video length, average video score, and likes. Poor linearity was observed between the number of views versus scores with an r^2 of 0.039. Length of the video also had a poor positive correlation with average scores, with an $r^2 = 0.34$. Number of likes also demonstrated poor correlation with $r^2 = 0.067$.

Demographically, the videos were further sorted by their origin of production, with further subgroup analysis. There was no significant difference between the average educational scores of videos, produced by the subgroups of the analyzed population ($p = 0.24$) (Table 2). While pharmaceutical company produced videos appeared to score lower, on average, the current study was likely underpowered to detect this effect. Of the content delivered by the videos, the most commonly discussed was a correct definition of IPF, mentioned on average, in 63% of the videos. The least commonly discussed topics were often related to patient education, such as yearly flu vaccination, smoking cessation and seeking medical attention in case of acute exacerbation (10–15% of videos). Other variables such as physiology of disease and symptomatology were only mentioned 51% and 53% of the time respectively (Table 3).

4. Discussion

YouTube has become a favorite educational resource for many people worldwide, since its inception over a decade ago. With models predicting viewership which reaches 15 billion visitors per month [7,8], it

Table 1. Demographics of video content.

	Minimum	Maximum	Mean	Std. Deviation
Video Length (m)	0.4	100.8	9.0	17.5
Views (#)	68	94534	12601	18101
Likes (#)	0	806	65	134
Dislikes (#)	0	36	4	6
Avg score (#)	0.0	16.3	5.9	3.9

Table 2. Video characteristics by source.

		LENGTH		Views	Likes	Dislikes	Avg
		(m)					
Hospital (n = 11)	Mean	6.1	6633	22	2	6.8	
	SD	13.0	9163	30	3	4.5	
Medical Society (n = 11)	Mean	24.7	7009	28	1	6.4	
	SD	34.5	8030	30	3	4.8	
Physician (n = 5)	Mean	6.7	11712	65	2	6.7	
	SD	6.3	9170	80	2	5.1	
University (n = 9)	Mean	4.1	7056	32	2	4.7	
	SD	1.6	8455	35	3	3.0	
Third Party (n = 17)	Mean	6.5	21130	147	6	7.0	
	SD	6.0	27282	225	7	3.2	
Pharmaceutical (n = 6)	Mean	2.6	20338	37	11	2.3	
	SD	2.1	23159	40	15	2.1	
Biotech (n = 1)	Mean	2.0	10430	0.00	0.00	3.0	
	SD	

would be reasonable to assume that many patients use it as a source of medical education. Studies to date have pointed towards YouTube videos being a poor source of patient information [9,10]. Our study adds to previous studies, demonstrating that most videos produced do not meet the specific goals of relaying the appropriate amount of information to the patients.

Consequently, patients obtain inaccurate and misleading information that does not adequately explain their disease, diagnostic workup, and treatment. This may add stress and unnecessary burden to the patient and their family. However, there is room for improvement on this platform. YouTube can be a source to reach patients with the accurate and right amount of information. With its vast viewership, it contains video content created by a variety of producers. As noted in our study, the video with the highest average educational score was produced by a hospital, therefore, medical societies and hospitals have an opportunity to reach patients on this platform. This illustrated that YouTube is an underutilized platform by hospitals and medical societies.

Currently, many medical society organizations and medical information websites publish information brochures to provide education to patients regarding

their disease. These downloadable education brochures are free, but often difficult for the average patient to fully understand and difficult to localize, as patients are not aware of these medical societies. Furthermore, the average patient may not be aware of the medical terminology which physicians and medical professional use.

This study demonstrated that regardless of the origin of the video, be it hospital mediated or third-party mediated, information conveyed continues to be poor. We hypothesize that this is due to the financial implications of publishing content on YouTube. YouTube employs specific algorithms to aid viewers in choosing the correct video. It is theorized that videos of a specific length appear more frequently, which subsequently attracts more views, and therefore, continues to appear more frequently when specific terms are searched. This drives the producers of videos to employ strategies to increase their viewership by creating content that is focused on satisfying the viewer experience, instead of focusing on the appropriateness of content. The viewers subsequently suffer, as videos which obtain an increased number of views begin to appear more frequently in search algorithms, without regard for their content. This becomes a perpetuating cycle which may drown out the few videos which do produce significantly higher educationally appropriate content.

The American Society of Chest Physicians, American Thoracic Society, and the Pulmonary Fibrosis foundation have made high-quality patient education material available to the public free of cost. This literature forms the basis of standardized patient education, which consists of a few key areas. Care has been taken to define the disease process in a manner palatable for the lay reader. IPF has been distinguished from other lung diseases, especially other interstitial lung diseases. Epidemiologic data, including prevalence estimate and incidence rates, are cited, as well as mortality rates. Diagnostic information, in the form of elements of the clinical history, physical

Table 3. Frequency of content containing specific educational elements within videos categorized by reviewer.

Educational Element	% of Videos that contained the element in the review by				
	Reviewer 1	Reviewer 2	Reviewer 3	Average	
Definition of IPF	69.4	64.4	55.9	63.2	
Symptoms of IPF	57.6	54.2	45.7	52.5	
Long Term Effects	11.8	11.8	13.5	12.4	
Identification of High risk population	20.3	22.0	15.2	19.2	
Physiologic Background	64.4	54.2	35.5	51.4	
Disease Presentation	32.2	52.5	25.4	36.7	
Information on Imaging/Testing	54.2	45.7	44.0	48.0	
Treatment Options	Immunosuppressive therapy	33.8	44.0	33.8	37.2
	Targeted therapy	15.2	16.9	13.5	15.2
	Pulmonary Rehab	20.3	28.8	10.1	19.7
	Transplantation	37.2	42.3	27.1	35.5
Education	Patient support groups	18.6	25.4	8.4	17.5
	Evaluation for Home Oxygen	23.7	18.6	15.2	19.2
	Smoking Cessation	11.8	20.3	13.5	15.2
	Yearly Flu vaccination	8.4	16.9	5.08	10.1
	Exacerbations	13.5	16.9	10.1	13.5
	Information on Experimental studies	30.5	33.8	27.1	30.5

examination, radiographic findings and pathologic appearance on biopsy are dealt with in some detail. Therapeutic options, including pharmacotherapy and pulmonary rehabilitation, are also explored with considerable effort. Finally, long-term management, including routine healthcare monitoring, spirometry, symptom management, exacerbation prevention and lung transplantation or palliative care options are also discussed [11,12]. Much of what a patient needs to know about the disease is carefully curated to make it a comprehensive educational document for patients and providers alike.

Our study highlights that not only is educational content regarding IPF scant on YouTube, but a clear majority of easily accessible videos are also severely deficient in providing patients and providers with the information required to make them clinically useful. While many videos defined the disease entity with varying clarity, most videos lacked essential information. 80% of videos, for example, were devoid of risk data and failed to mention that the disease rarely affects individuals less than 50 years of age and is more common in men. Less than 50% made a note of clinical and radiographic features respectively, and only about 20% discussed the importance of smoking cessation, yearly vaccination and prompt contact with a medical provider in case of worsening symptoms. Overall, the videos fared poorly against the standard set by professional educational literature. It is also important to note that many videos failed to highlight the importance of critical preventative measures, particularly smoking cessation. This intervention is stressed in all professional literature, and content intended to guide patients on IPF would be well advised to contain some information regarding this important preventative measure.

The lack of standardized information regarding a severe disease process at a widely accessible forum may lead to misconceptions about the illness, and foster uncertainty when conflicting opinions are received from healthcare providers. It may cause premature anxiety or unreal expectations on a case-to-case basis and would require more effort on the part of providers to sway opinion. Not to mention, the confusion one may experience. Echoing the findings of prior studies [9], it appears that inconsistent quality in patient education material for other disease processes is like that of our sample.

Interestingly, content quality is not directly correlated with popularity. This is important, as machine-driven algorithms will frequently promote popular contents when queried. Numerous factors come into play regarding video popularity, and are, as such beyond the scope of this discussion, suffice to say, technical understanding and practical viability of the material are not among those factors. This could lead to a low scoring video being the first available for viewing, making for

misleading information more readily available than quality content which is ‘unpopular.’

This cross-sectional survey of available content on YouTube is limited by the nature of the platform itself. Changes in available content are rapid and constant, and as such new content may be available each day, as well as existing content may be removed. The use of different query terms, filters, and locations will yield differing results. The popularity data will not encompass the demographics of users, and as such cannot predict what videos are watched by whom. Sampled videos reflect the most available videos. Moreover, finally, since IPF is uncommon, there is a paucity of material on YouTube.

Future inquiries into patient education literature regarding this debilitating illness would need to consider other venues of social media.

5. Conclusion

Patient education material regarding IPF on YouTube is deficient in quantity and quality. In a world where printed literature is rapidly being replaced by electronic media, providers need to be cognizant of the sources of information available to their patients. Recommendations need to consider the variety of content available, and adjustments need to be made. Providers should be aware of the best information resources and prescribe these just as they would, pharmacotherapy.

Disclosure statement

No potential conflict of interest was reported by the authors.

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