

Evaluation and Reliability of YouTube Videos for Age-Related Macular Degeneration (AMD)-A Warning Sign!.

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Abstract

Purpose: To evaluate and investigate the reliability and comprehensiveness of YouTube Videos contents' for age-related macular degeneration (AMD).

Methods: YouTube was surveyed in November 2015 using the keywords "Age-related macular degeneration" without any filters. Videos were classified as useful, misleading or irrelevant. The contents were assessed for reliability and comprehensiveness, on a 5-point scale each based on the DISCERN criteria.

Results: 60% of videos were categorized as useful, 35% as misleading, and 5% as irrelevant. According to reliability, videos were classified as 60% partially reliable, 35% unreliable and 5% reliable. According to comprehensiveness, total videos contents' were ranked as 70% partially comprehensive, 15% comprehensive and 15% incomprehensive.

Conclusion: YouTube videos are a powerful source of information easily accessible to patients. Authoritative sources ought to use well known social media websites as learning resources to enhance patient education, raise disease awareness, and achieve better health outcomes, while avoiding misinformation, potential risks and complications.

Keywords: Age related macular degeneration; Internet; YouTube; Patient education; Quality of information

Introduction

Age-related macular degeneration (AMD) is the leading cause of irreversible visual impairment in the elderly [1]. AMD is a degenerative disease of the central part of the retina-known as the macula-that results in a loss of central vision, which is essential for most of the daily activities [2]. It is characterized by a loss of visual acuity caused by degeneration of the choriocapillaris, retinal pigment epithelium (RPE), and photoreceptors, usually beginning with drusen and pigmentary changes in Bruch's membrane [1,3].

The condition, which affects 30 million to 50 million people worldwide, is the leading cause of irreversible blindness in developed countries in people aged 50 years and older [1,2]. More than 1.75 million persons in the United States were reported to have AMD in the year 2000, and it is thought that the incidence will increase to almost 3 million by 2020 [2].

The prevalence of AMD increases exponentially every decade after the age of 50 [4]. In many Western countries, the prevalence of AMD in individuals older than 55 years is 1.6% and increases to about 13% in those older than 84 years [2].

The loss of central visual acuity leads to a reduction in the activities of daily living, mobility problems and an increased risk of falls, fractures, and depression in the elderly [5].

An estimated 52 million Americans have used the Internet to find information about diseases, medical treatments, and available clinical trials, according to a survey by the Pew Internet and American Life Project [6]. About 55% of the Internet users surveyed had accessed health information, but only 9% of those who used the Internet for health-related reasons had exchanged e-mails with their physicians. Information technology provides patients with access to health-related information, allowing them to exert much more control over their own health care than ever before [7].

With patients increasingly embracing these new technologies for

obtaining health information and not necessarily disclosing it to their physicians [8], we as physicians should be aware of the content and quality of this information, to be able to appropriately guide patients.

YouTube™ (www.youtube.com) is one of the most popular social media websites on the Internet and is often used to share patient education materials with large numbers of individuals with chronic diseases [9].

YouTube is a free online video streaming service that allows users to view, upload, and post ratings/comments on posted videos. Globally, YouTube is the third most frequently visited website on the Internet, after Google and Facebook [10].

Over 800 million users watch over 4 billion hours of YouTube videos each month, and approximately 100 million people take a social action on YouTube every week by liking, sharing or commenting on the videos that they watch [11].

Social actions are tracked using exposure and engagement metrics that are publically accessible under the "Video Statistics" function on YouTube. Health-related topics on YouTube range from general health education, to the latest medical treatments, to homemade videos produced and uploaded by individuals [12].

Any registered user may post videos to YouTube, which often leads to videos containing scientific misinformation on health-related matters [13].

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Research on YouTube and its public health implications is still in its infancy [14].

The quality of patient education videos on YouTube is unclear, calling into question how to best incorporate YouTube within health promotion interventions [12,15-20].

To the best of my knowledge, no prior studies have examined the content, quality, or viewer exposure and patient engagement of AMD educational videos on YouTube. Therefore, I conducted this research to determine the extent at which these videos were posted, viewed, rated, and commented on by YouTube users.

I conducted this descriptive study to characterize the content and quality of information on AMD on YouTube; and to analyze audience response and interaction with the videos, a unique opportunity offered by this mass media tool [21].

Materials and Methods

You tube (www.youtube.com) was searched using the keyword “Age related Macular degeneration” on November 24, 2015 for videos containing applicable information on epidemiology, pathogenesis, clinical features, diagnostic tests and treatment of AMD.

The first 20 videos (displayed on the first page), were screened for information on AMD. This was based on the results from previous studies showing that >90% of Internet users chose from the search results displayed on the first page (Table 1).

All selected videos were classified based on their content as useful, misleading or irrelevant, as follows:

1. Useful: If the video contained scientifically correct and accurate information about any aspect of the disease.
2. Misleading: If the video contained scientifically unproven or inaccurate information based on currently available scientific evidence.
3. Irrelevant: If the video contained information which is not applicable or related to AMD (Table 2).

All videos were also categorized according to source into 3 groups: university channels/professional organizations (e.g. geteyesmart , AngioOrg, Mayo Clinic, NutritionFacts.org, Distinctive Voices, National Eye Institute (NIH), Preserve Mac Forte, SENS Foundation, Penn Medicine ,Bennett & Bloom Eye Centers); health information Websites (e.g., mdconversation , MonkeySee, Insidemedicine); or medical advertisements/for-profit companies (e.g. BayerTVinternational, OptelecUS).

Other parameters including length of video and time since upload were also analyzed. Audience interaction with the videos was assessed by video popularity (defined as views per day for a particular video, calculated as total views for the specific video divided by number of days on YouTube) and video viewer “likability” (number of “likes” for a video) (Table 1).

All videos were further analyzed for reliability and completeness of information (comprehensiveness), based on a 5-point scales.

Reliability of information was scored from 1 to 5 (reliability score), based on 5 questions (adapted from the DISCERN tool for assessment of written health information), as shown in (Table 3).

Comprehensiveness of information was also scored from 1 to 5

(total content score), based on different aspects of disease information covered by the video (epidemiology, pathogenesis, clinical features, diagnostic tests and treatment; 1 point was given for each parameter covered by the video (minimum and maximum possible scores were 1 and 5, respectively) (Table 4).

The rating scale: Questions are rated on a 5-point scale ranging from No to Yes. The rating scale has been designed to help decide whether the quality criterion in questions is present or has been ‘fulfilled’. General guidelines are as follows:

5 should be given if the answer to the questions is a definite ‘yes’ - the quality criterion has been completely fulfilled.

Partially [2-4] should be given if the video being considered meets the criterion in questions to some extent.

1 should be given if the answer to the questions is a definite ‘no’ - the quality criterion has not been fulfilled at all.

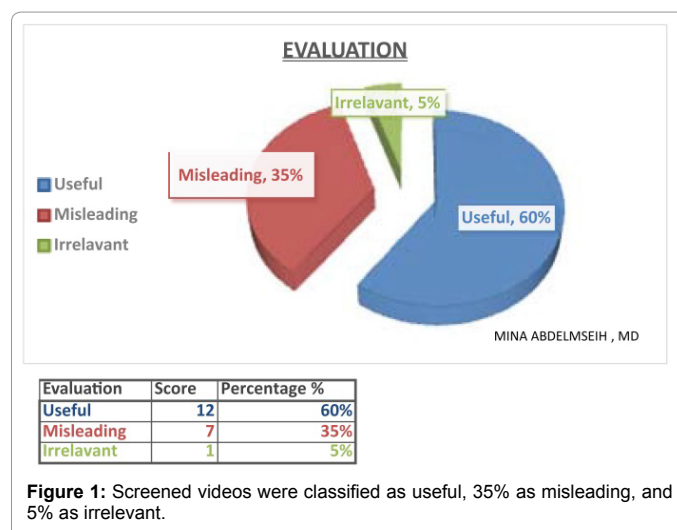
Results

Twenty videos were screened, with a total of 400,018 views. Average video duration was 5 minutes and average viewership was 20,001. The average duration since uploaded on YouTube was 1,197 days. According to their content, 60% of the screened videos were classified as useful, 35% as misleading, and 5% as irrelevant (Figure 1).

Useful videos were the most comprehensive and had the highest reliability and quality scores (Figure 2). According to reliability, 60 % of the screened videos were partially reliable, 35% were unreliable, and 5% were reliable (Figure 3) with average reliability of 2.65. According to the videos’ content, 70% of the screened videos were partially comprehensive, 15% were comprehensive, and 15% were incomprehensive (Figure 4) with average comprehensiveness of 2.80.

The most viewed video was “Video Illustration of Age-related Macular Degeneration (AMD)”. The most reliable was “Eye Disease | Age Related Macular Degeneration” (score 5). The least reliable video was “If I Had Wet Age-related Macular Degeneration (AMD)” (score 1).

The most comprehensive video was “Wake up and SEE - Age Related Macular Degeneration (AMD)” (score 5). The least comprehensive video was “Age Related Macular Degeneration Symptoms” (score 1).



Evaluation of you tube vidoes for Age-Related Macular Degeneration (AMD)-- a Warning Sign !												
SR	Name	Uploader	Number of days since upload	Duration	Views	Likes	Dislikes	Evaluation	Total reliability score	Reliability	Total content score	Total content
								Useful Misleading Irrelavant		Reliable Partially Reliable Unreliable		Comprehensive Incomprehensive Partially Comprehensive
VD 01	Understanding Age-Related Macular Degeneration (ARMD)	mdconvesation (Profit website)	1,036	12:00	8,213	35	0	Useful	4	Partially Reliable	4	Partially Comprehensive
VD 02	Age-Related Macular Degeneration (AMD)	BayerTVinternational (profit compnay)	669	02:12	9,173	16	0	Misleading	1	Unreliable	2	Partially Comprehensive
VD 03	Age-Related Macular Degeneration	eyehealthaz (independent user)	1,451	05:26	15,911	13	2	Misleading	1	Unreliable	4	Partially Comprehensive
VD 04	Age-Related Macular Degeneration (AMD)	geteyesmart (professional org)	1,814	04:28	6,857	13	1	Useful	4	Partially Reliable	4	Partially Comprehensive
VD 05	Progression of wet Age-Related Macular Degeneration	AngioOrg (nonprofit organization)	1,310	03:02	24,839	85	6	Useful	4	Partially Reliable	1	InComprehensive
VD 06	Treatments For Age-Related Macular Degeneration	MonkeySee (Non profit website)	645	03:02	4,102	16	0	Useful	3	Partially Reliable	1	InComprehensive
VD 07	Genetic Testing for Inherited Non Age-Related Macular Degeneration	Mayo Clinic (Non profit medical care)	0	08:39	21	0	0	Irrelavant	4	Partially Reliable	3	Partially Comprehensive
VD 08	Dry Age-Related Macular Degeneration (Dry AMD)	mdconvesation (Profit website)	1,036	05:09	4,098	8	0	Useful	4	Partially Reliable	4	Partially Comprehensive
VD 09	Age Related Macular Degeneration Symptoms	AMDResearcher (independent user)	2,240	01:25	21,254	13	2	Useful	3	Partially Reliable	1	InComprehensive
VD 10	Dietary Prevention of Age-Related Macular Degeneration	NutritionFacts.org (Non profit org)	139	04:22	10,760	364	3	misleading	1	Unreliable	3	Partially Comprehensive
VD 11	Age-related Macular Degeneration (A.M.D.)	Distinctive Voices (professional org)	656	52:06	1,379	5	0	Useful	3	Partially Reliable	2	Partially Comprehensive
VD 12	Wake up and SEE - Age Related Macular Degeneration (AMD)	AngioOrg (nonprofit organization)	446	02:15	75,363	53	0	Useful	4	Partially Reliable	5	Comprehensive
VD 13	Dietary Prevention of Age-Related Macular Degeneration	NutritionFacts.org (Non profit org)	694	04:51	33,996	338	3	Misleading (repeated)	1	Unreliable	5	Comprehensive
VD 14	If I Had Wet Age-related Macular Degeneration (AMD)	Insidermedicine (educational website)	2,106	02:57	20,943	38	3	Misleading	1	Unreliable	2	Partially Comprehensive
VD 15	Animation: Age-Related Macular Degeneration	National Eye Institute, NIH (professional org)	641	00:43	6,312	8	1	Useful	2	Partially Reliable	2	Partially Comprehensive
VD 16	Understanding Age-Related Macular Degeneration	Penn Medicine (professional uni)	1,733	51:29	16,225	53	5	Useful	2	Partially Reliable	2	Partially Comprehensive
VD 17	Eye Disease Age Related Macular Degeneration	Preserve Mac Forte (profit org)	1,422	05:47	42,308	41	3	Useful	5	Reliable	5	Comprehensive
VD 18	Photodynamic Therapy for Age-related Macular Degeneration	Bennett & Bloom Eye Centers (professional clinic)	2,184	06:05	5,901	7	0	Misleading	1	Unreliable	2	Partially Comprehensive
VD 19	Video Illustration of Age-related Macular Degeneration (AMD)	OptelecUS (profit company)	3,046	00:23	90,814	27	5	Misleading	1	Unreliable	2	Partially Comprehensive
VD 20	Treating age-related macular degeneration - Ghezal Beliakoff	SENS Foundation (Research org)	664	19:28	1,549	12	0	Useful	4	Partially Reliable	2	Partially Comprehensive
Average			1,197	09:47	20,001	57.25	1.7		2.65		2.80	
Max			3,046	52:06	90,814	364	6		5		5	
Min			0	00:23	21	0	0		1		1	

Table 1: Results from first 20 videos displayed on the first page.

Evaluation of you tube vidoes for Age-Related Macular Degeneration (AMD)-- a Warning Sign !								
SR	Name	Uploader	Number of days since upload	Duration	Views	Likes	Dislikes	Evaluation Useful Misleading Irrelavant
VD 01	Understanding Age-Related Macular Degeneration (ARMD)	mdconversation (Profit website)	1,036	12:00	8,213	35	0	Useful
VD 02	Age-Related Macular Degeneration (AMD)	BayerTVinternational (profit compnay)	669	02:12	9,173	16	0	Misleading
VD 03	Age-Related Macular Degeneration	eyehealthaz (independent user)	1,451	05:26	15,911	13	2	Misleading
VD 04	Age-Related Macular Degeneration (AMD)	geteyesmart (professional org)	1,814	04:28	6,857	13	1	Useful
VD 05	Progression of wet Age-Related Macular Degeneration	AngioOrg (nonprofit organization)	1,310	03:02	24,839	85	6	Useful
VD 06	Treatments For Age-Related Macular Degeneration	MonkeySee (Non profit website)	645	03:02	4,102	16	0	Useful
VD 07	Genetic Testing for Inherited Non Age-Related Macular Degeneration	Mayo Clinic (Non profit medical care)	0	08:39	21	0	0	Irrelavant
VD 08	Dry Age-Related Macular Degeneration (Dry AMD)	mdconversation (Profit website)	1,036	05:09	4,098	8	0	Useful
VD 09	Age Related Macular Degeneration Symptoms	AMDResearcher (independent user)	2,240	01:25	21,254	13	2	Useful
VD 10	Dietary Prevention of Age-Related Macular Degeneration	NutritionFacts.org (Non profit org)	139	04:22	10,760	364	3	misleading
VD 11	Age-related Macular Degeneration (A.M.D.)	Distinctive Voices (professional org)	656	52:06	1,379	5	0	Useful
VD 12	Wake up and SEE - Age Related Macular Degeneration (AMD)	AngioOrg (nonprofit organization)	446	02:15	75,363	53	0	Useful
VD 13	Dietary Prevention of Age-Related Macular Degeneration	NutritionFacts.org (Non profit org)	694	04:51	33,996	338	3	Misleading (repeated)
VD 14	If I Had Wet Age-related Macular Degeneration (AMD)	Insidermedicine (educational website)	2,106	02:57	20,943	38	3	Misleading
VD 15	Animation: Age-Related Macular Degeneration	National Eye Institute, NIH (professional org)	641	00:43	6,312	8	1	Useful
VD 16	Understanding Age-Related Macular Degeneration	Penn Medicine (professional uni)	1,733	51:29	16,225	53	5	Useful
VD 17	Eye Disease Age Related Macular Degeneration	Preserve Mac Forte (profit org)	1,422	05:47	42,308	41	3	Useful
VD 18	Photodynamic Therapy for Age-related Macular Degeneration	Bennett & Bloom Eye Centers (professional clinic)	2,184	06:05	5,901	7	0	Misleading
VD 19	Video Illustration of Age-related Macular Degeneration (AMD)	OptelecUS (profit company)	3,046	00:23	90,814	27	5	Misleading
VD 20	Treating age-related macular degeneration - Ghezal Beliakoff	SENS Foundation (Research org)	664	19:28	1,549	12	0	Useful
Average			1,197	09:47	20,001	57.3	1.70	
Max			3,046	52:06	90,814	364	6	
Min			0	00:23	21	0	0	

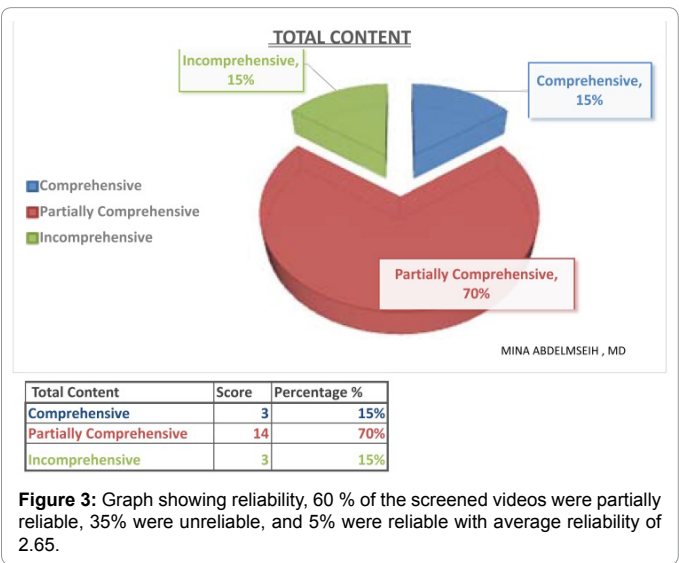
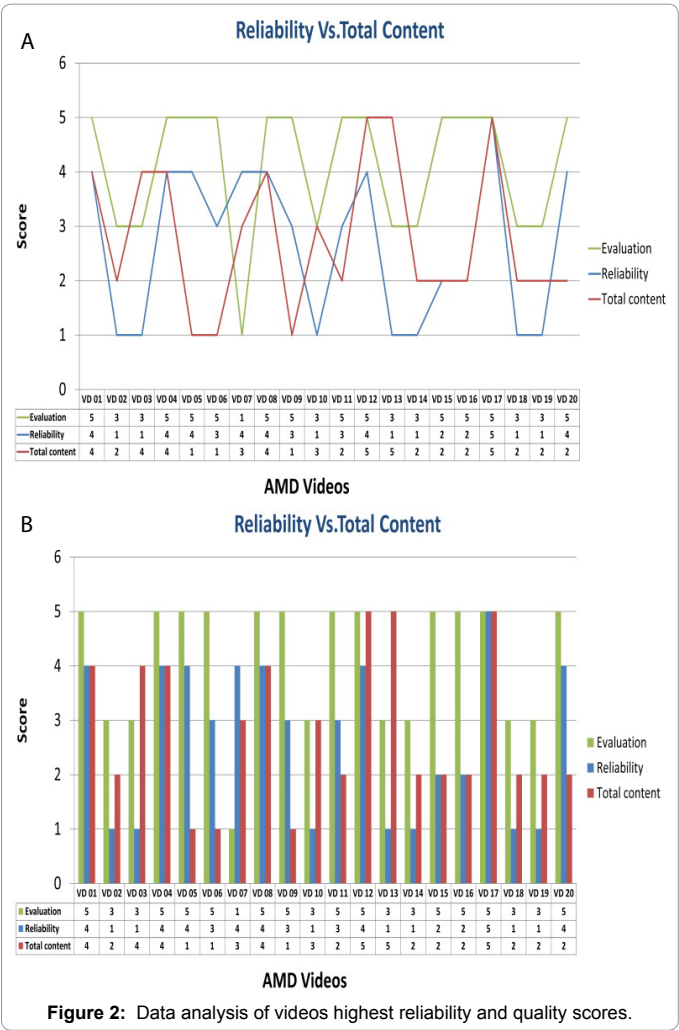
Table 2: Results from first 20 videos classified based on their content as useful, misleading or irrelevant.

Evaluation of you tube vidoes for Age-Related Macular Degeneration (AMD)-- a Warning Sign !									
SR	Name	Uploader	Clear and achieved aims	Reliable sources of information	balanced unbiased information	Additional sources of information	Areas of uncertainty	Total reliability score	Reliability
									Reliable Partially Reliable Unreliable
VD 01	Understanding Age-Related Macular Degeneration (ARMD)	mdconversation (Profit website)	1	1	1	1	0	4	Partially Reliable
VD 02	Age-Related Macular Degeneration (AMD)	BayerTVinternational (profit compnay)	0	0	1	0	0	1	Unreliable
VD 03	Age-Related Macular Degeneration	eyehealthaz (independent user)	0	0	0	1	0	1	Unreliable
VD 04	Age-Related Macular Degeneration (AMD)	geteyesmart (professional org)	1	1	1	0	1	4	Partially Reliable
VD 05	Progression of wet Age-Related Macular Degeneration	AngioOrg (nonprofit organization)	1	1	1	0	1	4	Partially Reliable
VD 06	Treatments For Age-Related Macular Degeneration	MonkeySee (Non profit website)	1	1	1	0	0	3	Partially Reliable
VD 07	Genetic Testing for Inherited Non Age-Related Macular Degeneration	Mayo Clinic (Non profit medical care)	0	1	1	1	1	4	Partially Reliable
VD 08	Dry Age-Related Macular Degeneration (Dry AMD)	mdconversation (Profit website)	1	1	1	0	1	4	Partially Reliable
VD 09	Age Related Macular Degeneration Symptoms	AMDResearcher (independent user)	1	0	1	1	0	3	Partially Reliable
VD 10	Dietary Prevention of Age-Related Macular Degeneration	NutritionFacts.org (Non profit org)	0	0	0	1	0	1	Unreliable
VD 11	Age-related Macular Degeneration (A.M.D.)	Distinctive Voices (professional org)	1	1	1	0	0	3	Partially Reliable
VD 12	Wake up and SEE - Age Related Macular Degeneration (AMD)	AngioOrg (nonprofit organization)	1	1	1	1	0	4	Partially Reliable
VD 13	Dietary Prevention of Age-Related Macular Degeneration	NutritionFacts.org (Non profit org)	0	0	0	1	0	1	Unreliable
VD 14	If I Had Wet Age-related Macular Degeneration (AMD)	Insidermedicine (educational website)	0	0	0	1	0	1	Unreliable
VD 15	Animation: Age-Related Macular Degeneration	National Eye Institute, NIH (professional org)	0	1	1	0	0	2	Partially Reliable
VD 16	Understanding Age-Related Macular Degeneration	Penn Medicine (professional uni)	0	1	1	0	0	2	Partially Reliable
VD 17	Eye Disease Age Related Macular Degeneration	Preserve Mac Forte (profit org)	1	1	1	1	1	5	Reliable
VD 18	Photodynamic Therapy for Age-related Macular Degeneration	Bennett & Bloom Eye Centers (professional clinic)	1	0	0	0	0	1	Unreliable
VD 19	Video Illustration of Age-related Macular Degeneration (AMD)	OptelecUS (profit company)	0	0	0	1	0	1	Unreliable
VD 20	Treating age-related macular degeneration - Ghezal Beliakoff	SENS Foundation(Research org)	1	1	1	1	0	4	Partially Reliable
Average								2.65	
Max								5	
Min								1	

Table 3: Analysis of length of video, time since upload, video popularity and likability.

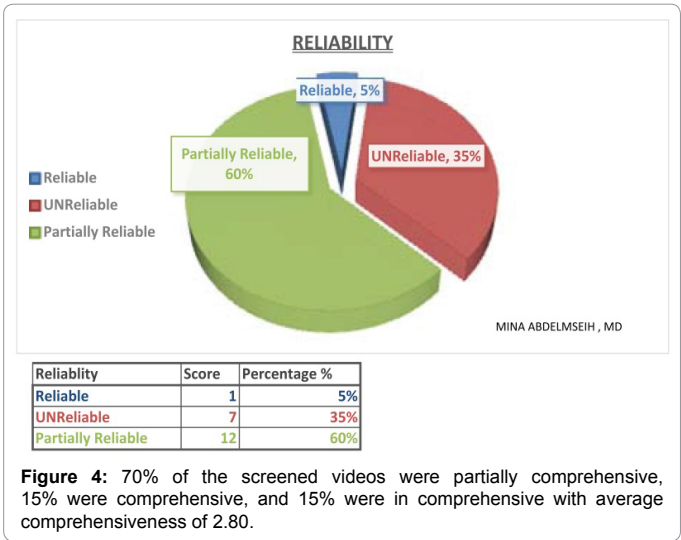
Evaluation of you tube vidoes for Age-Related Macular Degeneration (AMD)-- a Warning Sign !									
SR	Name	Uploader	Epidemiology	pathogenesis	clinical features	diagnostic tests	Treatment	Total content score	Total content
									Comprehensive InComprehensive Partially Comprehensive
VD 01	Understanding Age-Related Macular Degeneration (ARMD)	mdconversation (Profit website)	1	0	1	1	1	4	Partially Comprehensive
VD 02	Age-Related Macular Degeneration (AMD)	BayerTVinternational (profit compnay)	0	1	1	0	0	2	Partially Comprehensive
VD 03	Age-Related Macular Degeneration	eyehealthaz (independent user)	1	1	1	0	1	4	Partially Comprehensive
VD 04	Age-Related Macular Degeneration (AMD)	geteyesmart (professional org)	1	1	1	1	0	4	Partially Comprehensive
VD 05	Progression of wet Age-Related Macular Degeneration	AngioOrg (nonprofit organization)	0	1	0	0	0	1	InComprehensive
VD 06	Treatments For Age-Related Macular Degeneration	MonkeySee (Non profit website)	0	0	0	0	1	1	InComprehensive
VD 07	Genetic Testing for Inherited Non Age-Related Macular Degeneration	Mayo Clinic (Non profit medical care)	1	0	0	1	1	3	Partially Comprehensive
VD 08	Dry Age-Related Macular Degeneration (Dry AMD)	mdconversation (Profit website)	1	1	1	0	1	4	Partially Comprehensive
VD 09	Age Related Macular Degeneration Symptoms	AMDResearcher (independent user)	0	0	1	0	0	1	InComprehensive
VD 10	Dietary Prevention of Age-Related Macular Degeneration	NutritionFacts.org (Non profit org)	1	1	0	0	1	3	Partially Comprehensive
VD 11	Age-related Macular Degeneration (A.M.D.)	Distinctive Voices (professional org)	0	0	1	0	1	2	Partially Comprehensive
VD 12	Wake up and SEE - Age Related Macular Degeneration (AMD)	AngioOrg (nonprofit organization)	1	1	1	1	1	5	Comprehensive
VD 13	Dietary Prevention of Age-Related Macular Degeneration	NutritionFacts.org (Non profit org)	1	1	1	1	1	5	Comprehensive
VD 14	If I Had Wet Age-related Macular Degeneration (AMD)	Insidermedicine (educational website)	0	1	0	0	1	2	Partially Comprehensive
VD 15	Animation: Age-Related Macular Degeneration	National Eye Institute, NIH (professional org)	0	1	1	0	0	2	Partially Comprehensive
VD 16	Understanding Age-Related Macular Degeneration	Penn Medicine (professional uni)	0	1	1	0	0	2	Partially Comprehensive
VD 17	Eye Disease Age Related Macular Degeneration	Preserve Mac Forte (profit org)	1	1	1	1	1	5	Comprehensive
VD 18	Photodynamic Therapy for Age-related Macular Degeneration	Bennett & Bloom Eye Centers (professional clinic)	0	1	0	0	1	2	Partially Comprehensive
VD 19	Video Illustration of Age-related Macular Degeneration (AMD)	OptelecUS (profit company)	0	1	1	0	0	2	Partially Comprehensive
VD 20	Treating age-related macular degeneration - Ghezal Beliakoff	SENS Foundation (Research org)	0	1	0	0	1	2	Partially Comprehensive
Average								2.80	
Max								5	
Min								1	

Table 4: The rating scale, rated on a 5-point scale ranging from No to Yes.



Discussion

Driven by a desire for a more active role in healthcare decision making, patients with chronic diseases are increasingly using the World



Wide Web to learn more about their diseases and possible treatments [21].

YouTube is one such very popular, open-access, video-sharing website hosting an increasing number of clips on diagnosing, treating, and preventing illnesses [22,23].

Recent studies have shown that three-quarters of individuals seeking health information on the Internet “never,” “hardly ever,” or only “sometimes” check the source of information [24].

In recent years many studies have been discussed reliability of you tube videos for many health diseases. In this study utility of these videos for online visitors was evaluated, and videos uploaded by nonprofit organizations or universities were found to be more useful. I assume that using simple language provides with interesting animations and further work will increase patient education and enhance his understanding.

My study declared that you tube material is a poor source for accurate information regarding AMD diseases and treatment. Therefore, accessible videos are not helpful enough for patients seeking for more detailed information on the treatment of AMD.

The current assessment of YouTube videos material is overall insufficient.

Assessing the quality of information on AMD on YouTube; it was found that 60% of the videos were useful for patients with AMD. Nonprofit professional organizations and university channels were the best sources of information. Thirty-five percent of the screened videos on AMD were misleading, providing scientifically unproven or inaccurate information based on currently available scientific evidence.

In Summary, reliable comprehensible you tube videos edited by professional persons or organizations, which will attract the attention of the patients, may enhance their knowledge about AMD diseases frequently seen in USA. Further work is always preferred to determine whether available information on YouTube can play an important role in patient care other than insufficient education about the disease and its management. While videos available on the Internet may be an additional educational tool available for patients, ophthalmologists

should be familiar with specific resources to help guide and teach their patients to ensure best results [25] and to avoid false or inaccurate information, potential dangers and intricacies.

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