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Accessing disease information via smartphones: A senile macular degeneration investigation in over-65-year-old patients

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Abstract

Aim: To investigate how frequently over-65-year-old senile macular degeneration (SMD) patients use smartphones and the Internet for disease information, as well as to evaluate website readability and information quality.

Material and methods: There were 400 SMD patients who were followed up on at a retina clinic. SMD was defined as the presence of >5 hard drusen or >1 125 µm soft drusen in the macula, and scar or subretinal fluid compatible with SMD. Face-to-face interviews were used to gather demographic data, including age, gender, educational level, smartphone use, and whether patients researched SMD in Google, YouTube, or other websites. Two experienced ophthalmologists blindly evaluated 32 Google websites and 37 YouTube videos using Ateşman and Bezirci-Yilmaz readability formulas, as well as JAMA and DISCERN indexes.

Results: The average age of the patients was 75.0±6.6 years, and 37.3% owned a smartphone. Legally blind patients (40.5%) used smartphones less frequently for Internet searches (p<0.001). As educational level increased, patients became more active in searching diseases electronically. The JAMA score in texts was 0.8±0.4, while it was 0.7±0.6 in videos (p=0.654). The DISCERN score was 35.1±6.2 and 33.2±10.3 in texts and videos, respectively (p=0.347). Smartphone use decreased with age (OR=0.896, 95% CI: 0.859-0.934), but not with legal blindness (OR=0.756, 95% CI: 0.458-1.245).

Conclusion: Improved quality and reliability of internet websites and video information, more emphasis on informative audio recordings and videos for people with low vision, and easily readable Internet websites could all have a positive impact on patients' adherence to treatment.

Key words: google, information, internet, readability, senile macular degeneration, smartphones, youtube videos

Introduction

Over the last decade, smartphones, personal computers, laptops, tablets, and other information and communication technology-related devices have grown in popularity and use. This has allowed people to accomplish a variety of tasks more quickly and safely [1,2]. Indeed, studies on eliminating health disparities are being conducted as a result of these innovations [3]. While the devices used in the health system were previously designed to be used by health professionals, technological advancements have brought the use of technology to the forefront in order to obtain information about people's health and conduct necessary research [4].

The elderly population in the USA is expected to exceed 72 million by 2030, and the global elderly population is expected to reach 1.6 billion by 2050, implying that health problems will become more prevalent as the population ages [5,7]. A significant proportion of the elderly population is gradually embracing technology, and smartphone use among the elderly is on the rise [8]. It is anticipated that the elderly, who are thought to have difficulty accessing health services, will attempt to obtain health information via smartphones in the future. Given the increasing use

of smartphones, the potential for internet use to improve the health of older adults is quite high, particularly given projected population growth.

Many studies have been conducted to determine the readability of text on websites that appear on the screen based on Google searches [9,10], which patients rely on as the most popular internet search engine for information [11]. Moreover, YouTube, the second most visited website on the Internet, is gaining traction as an information source [12]. In 2020, 2.1 billion users watched over one billion hours of video on YouTube, and more than 500 hours of new videos were uploaded every minute [13]. Parallel to all of this, 74% of adults in the USA use YouTube [14], with its popularity owing to the fact that it is free to use on devices such as laptops and smartphones, with the latter accounting for 70% of all visits [15]. Matter of fact, numerous ophthalmology studies analyzing YouTube videos have been published [16,17].

This study aimed to determine how frequently senile macular degeneration (SMD) patients over the age of 65 use smartphones and the Internet for disease information, as well as which websites they frequently use as a source of information. It also aimed to investigate the readability and information quality of Internet websites, as well as to evaluate the data in terms of demographics such as age, gender, educational level, and frequency of smartphone use.

Material and methods

Study design and data collection

This study followed the ethical principles outlined in the Declaration of Helsinki and was approved by the Afyonkarahisar Health Sciences University Ethics Committee Institutional Review Board, with the approval code and date 2022/315. It included SMD patients who were being monitored in the retina clinic of a tertiary hospital by two experienced ophthalmologists (MD and IEA). SMD was defined as the presence of >5 hard drusen or >1 125 μm soft drusen in the macula, as well as scar or subretinal fluid compatible with SMD.

Face-to-face interviews were used to collect data about the patients' age, gender, education level, and smartphone use when they came in for examination. Data was also collected about whether or not patients searched the Internet for SMD information and, if so, which Google, YouTube, or other websites they visited

Inclusion and exclusion requirements

The inclusion criteria were that the patients' cognitive level be at a level where they could come to the ophthalmology clinic independently or with a relative and be examined and answer the questions asked. Those with severe dementia and difficulties understanding the questions were barred from participating in the study. SMD patients with a visual acuity of <20/200 in the well-sighted eye were regarded legally blind [18].

Readability formulas

The Ateşman readability formula takes into account factors such as the number of words in sentences and the number of syllables in words before calculating a score [19]. Scores of a) 90-100 indicate that the text is readable with as little as four years of education, b) 80-89 between 5th-6th grades, c) 70-79 between 7th-8th grades, d) 60-69 between 9th-10th grades, e) 50-59 between 11th-12th grades, f) 40-49 between 13th-14th grades, and g) 30-39 indicate that the text is readable with 16th grade education. The Bezirci-Yilmaz formula, on the other hand, directly determines which education level the text is readable for [20]. The text is readable for primary school if 1-8 points are present, high school if 9-12 points are present, and undergraduate education if 12-16 points are present.

Internet website readability level assessment

The study included the first 50 websites that appeared on the screen after the search term "senile macular degeneration" was entered into the Google search engine on July 01, 2022. Duplicate websites or websites with information in a different language were not studied. The Ateşman [19] and Bezirci-Yilmaz [20] readability formulas, which are two distinct readability formulas with established validity and reliability in Turkish, were used to assess the information on 32 websites.

YouTube video information quality assessment

The first 50 videos that appeared on the screen after entering "SMD" into the YouTube search bar were included in the study. Again, duplicate videos and content broadcast in a different language were excluded from the study, leaving 37 videos for assessment. Two experienced ophthalmologists (MD and IEA) blindly evaluated the first 32 Google internet websites and 37 YouTube videos using the Journal of the American Medical Association (JAMA) [21] and DISCERN [22] indexes, which are used to measure the quality of health-related information on the Internet. The following parameters were investigated: a) broadcasting duration (the number of days the videos have been broadcast since their upload), b) views count, c) viewing rate (the number of views divided by the broadcasting duration), d) video duration, and e) likes and comments count.

JAMA index

The JAMA index is used to evaluate health-related website content. This index calculates a general score by assigning 0 or 1 points for authorship, bibliography, patent rights, and timeliness.

DISCERN index

The DISCERN scoring system was developed to objectively assess the quality of health-related publications by patients, physicians, and internet information providers. It contains a clear statement of the information's objectives, a list of sources, balanced and unbiased information, and an overall scoring table on the advantages and disadvantages of treatments (Table 1). Each question is assigned a score of 0 to 5, and the total DISCERN score ranges from 16 to 80. A score of 63-80 is considered excellent, 51-62 good, 39-50 moderate, 27-38 poor, and 16-26 very poor.

Data analysis

SPSS (PAWS Statistics, Version 18, Chicago IL) was used to conduct the statistical analysis. Categorical variables are shown as percentages and frequencies in descriptive statistics results, while continuous variables are shown as mean and standard deviation. The chi-square test was used to compare categorical variables. The conformity of continuous variables to normal distribution was assessed using skewness and kurtosis values, and it was discovered that they exhibited normal distribution characteristics. To compare normally distributed continuous variables, the Student's t test was employed. The inter-rater reliability analysis employed the intraclass correlation

Table 1 The DISCERN scoring system

1.	Are the objectives of the information provided clear?	1-5
2.	Does the information provided achieve its objectives?	1-5
3.	Is the information provided relevant to the objectives?	1-5
4.	Is it clear which sources of information were used to provide the information?	1-5
5.	Is it clear when the information used or reported in the publication was produced?	1-5
6.	Is the information provided balanced and unbiased?	1-5
7.	Does it contain details of information sources?	1-5
8.	Does the information given refer to areas of uncertainty?	1-5
9.	Is it explained how each treatment works?	1-5
10.	Are the benefits of each treatment explained?	1-5
11.	Are the risks and side effects of each treatment explained?	1-5
12.	Is it explained what will happen if no treatment is given?	1-5
13.	Is the impact of treatment options on overall quality of life explained?	1-5
14.	Is it explained that there may be more than one possible treatment option?	1-5
15.	Does the information provided provide support for joint decision making?	1-5
16.	Assess the overall quality of the publication based on the responses to all questions.	1-5

coefficient (ICC). An excellent fit was defined as an ICC value greater than 0.80. Comparisons were made in the statistical analysis using the evaluators' average scores. After statistical analysis, the Multinominal Logistic Regression test was used to evaluate variables and confounding variables that revealed statistically significant differences. Logistic regression results are presented as odds ratio (OR) and 95% confidence interval (95% CI). Statistical significance level was accepted as $p<0.05$.

Results

There were 194 (48.5%) females and 206 (51.6%) males. The mean age was 75.0±6.6 years. 64% of the participants had only completed primary school. 40.5% were legally blind. There were 37.3% of the smartphone users. 11.8% of participants used smartphones to search for SMD-related information, with 9% using Google to search for Internet websites and 2.8% watching YouTube videos (Table 2).

Table 2 Demographic characteristics of the patients.

Parameters	n (%)
Educational level	
Illiterate	71 (17.7)
Primary school	256 (64.0)
High school	33 (8.3)
University	40 (10.0)
Legal blindness	
Absent	238 (59.5)
Present	162 (40.5)
Smartphone use	
No	251 (62.7)
Yes	149 (37.3)
Information source	
Never searched	353 (88.2)
Google	36 (9.0)
YouTube	11 (2.8)
Total	400 (100.0)

n=Number of participants, %=Percent

Legally blind SMD patients had significantly lower frequency of smartphone use and a history of SMD-related Internet searching ($p<0.001$). Patients were more active in searching their disease on the Internet as their educational level increased (Table 3).

The readability level of 32 SMD-related Internet websites was 11-12, with an average of 54.1±6.8 points, according to the Ateşman readability formula. The Bezirci-Yilmaz formula determined that the websites were readable with an education level of 11-12 years, corresponding to an average of 11.7±2.1 points. The website written in the easiest to read format was readable after 7 years of education, while the website written in the most difficult to read format was readable after 17 years of education.

The average duration for SMD-related YouTube videos was 453±547, with 136±317 likes and 5.4±12.7 comments. The average broadcasting duration, view count, and viewing rate were 1548±1011 days, 21079±51841, and 17.8±40.2, respectively.

The correlation between the JAMA (ICC=0.824) and DISCERN (ICC=0.994) scores for the websites and YouTube videos of both ophthalmologists was determined to be "excellent." The JAMA score in written text on websites was 0.8±0.4, while in YouTube videos it was 0.7±0.6 ($p=0.654$). The DISCERN score in written text on websites was 35.1±6.2 points and 33.2±10.3 points in YouTube videos ($p=0.347$). Longer videos received high JAMA and DISCERN index scores, and factors such as likes, comments, and view count were found to be unrelated to the JAMA and DISCERN scores.

The logistic regression analysis revealed that smartphone use decreased with age (OR=0.896, 95% CI: 0.859-0.934). Legal blindness, on the other hand, was not associated with smartphone use (OR=0.756, 95% CI: 0.458-1.245). As educational levels rose, so did the use of smartphones (Table 4).

Discussion

Access to information in medicine has made significant progress since the 1990s, thanks to advances in information technology [23]. In fact, the term "e-health" first appeared at that time, and access to health-related information in the electronic environment has grown in popularity ever since [24]. Several studies on the use of smart technology products show that the elderly are becoming more adaptable to changing technology [25,26].

Furthermore, the aging population and widespread use of smartphones are widely acknowledged to be becoming increasingly important in general society. The elderly's use of smartphones and similar devices increases their possibility of benefiting from smartphones in getting disease information, given that they are more likely to experience many health problems as they age. In medicine, it is a critical issue based on health literacy that the elderly population, which is bombarded with information from a variety of sources, particularly the physicians they are examined by, access accurate information about their diseases while their treatments continue. After all, research on the use of smartphones in this field has been conducted in order to assess treatment compliance and symptoms, to aid in treatment management, and to determine health literacy [27,28].

The current study has a high power with 400 SMD patients, and the findings can be generalized globally. Smartphones were used by 37.3% of the patients, and 11.8% searched the Internet for SMD-related information. While 9% of the patients used Google, 2.8% searched the Internet and attempted to obtain SMD-related information via YouTube videos. A small

Table 3 Legal blindness and educational status in relation to smartphone use and Internet search

Legal blindness	Educational level				Total	P value
	Illiterate	Primary school	High school	University		
	n, (%)	n, (%)	n, (%)	n, (%)	n, (%)	
			Smartphone use			
No	No	27 (84.4)	93 (61.2)	4 (18.2)	7 (21.9)	131 (55.0)	<0.001
	Yes	5 (15.6)	59 (38.8)	18 (81.8)	25 (78.1)	107 (45.0)	
Yes	No	36 (92.3)	73 (70.2)	6 (54.5)	5 (62.5)	120 (74.1)	0.015
	Yes	3 (7.7)	31 (29.8)	5 (45.5)	3 (37.5)	42 (25.9)	
			Senile macular degeneration-related Internet search			
No	No	31 (96.9)	139 (91.4)	16 (72.7)	15 (46.9)	201 (84.5)	<0.001
	Yes	1 (3.1)	13 (8.6)	6 (27.3)	17 (53.1)	37 (15.5)	
Yes	No	39 (100.0)	100 (96.2)	8 (72.7)	5 (62.5)	152 (93.8)	<0.001
	Yes	0 (0.0)	4 (3.8)	3 (27.3)	3 (37.5)	10 (6.2)	

n=Number of participants, %=Percent

Table 4 Logistic regression analysis of smartphone use by age, legal blindness, and educational level.

Parameters	B	S.E.	Wald	P value	OR	95% CI for EXP (B)	
						Lower	Upper
Age (Years)	-0.110	0.021	27.070	0.000	0.896	0.859	0.934
Legal blindness present *(Reference: no legal blindness)*	-0.280	0.255	1.209	0.272	0.756	0.458	1.245
Educational level *(Reference: illiterate)*			35.762	0.000			
Primary school	1.314	0.412	10.175	0.001	3.721	1.660	8.342
High school	2.593	0.554	21.915	0.000	13.365	4.514	39.572
University	2.741	0.533	26.412	0.000	15.499	5.449	44.080
Constant	7.860	1.576	24.867	0.000	2590.587		

proportion of SMD patients used the Internet to learn about their diseases.

As patients' educational levels rise, so does their use of smartphones, and they become more active in searching their disease on the Internet. Expectedly, SMD patients with legal blindness had significantly lower rates of smartphone use and a history of searching their disease on the Internet. In contrast, the logistic regression analysis revealed that legal blindness was unrelated to smartphone use, and that smartphone use increased gradually as education level increased. Even if they were legally blind, patients with a high educational level were just as effective at using smartphones as those with good vision but low education. These patients appeared to benefit from smartphones, which allow them to listen to a text aloud while also enlarging the image to some extent. After all, education seems to be a powerful tool for overcoming a wide range of challenges, including legal blindness.

When the readability level of 32 SMD-related Internet websites was assessed, the Ateşman readability formula revealed that it required an education level of 11th to 12th grade with an average of 54.1±6.8 points. Furthermore, Internet websites were readable with an education level of 11-12 years, corresponding to an average of 11.7±2.1 points in the Bezirci-Yilmaz formula. In one study, the readability level and information quality of 12 frequently clicked websites containing SMD information were evaluated using JAMA scoring, revealing that the websites were readable with 11-12 years of education and the information quality was low [29]. Despite being for Internet websites in a different language, these results were comparable to ours. The JAMA and DISCERN scores for the current study also indicated low quality information, putting it in line with the literature. Longer videos had higher JAMA and DISCERN index scores, and it was revealed that factors such as the number of likes and comments, as well as view count, were unrelated to the JAMA and DISCERN index scores. This demonstrated that expert-approved videos containing more accurate information were unrelated to patient-favored videos. Patients are unable to select videos with more accurate information. Thus, it appears that patients are very likely to receive incorrect information since broadcasting on YouTube does not require expertise.

To our knowledge, no research on SMD videos on YouTube has been published. We can assume that many people use YouTube to learn more about this particular disease, based on the fact that the videos in the current study were viewed by an average of 21079±51840 people. Despite this, the JAMA and DISCERN scores indicated that the information in these videos was of poor quality. As a result, both text on Internet websites and YouTube videos may not be regarded as platforms where patients could obtain healthy and reliable information about SMD. Even if adults over the age of 65 with SMD use these websites as a source of information infrequently today, we anticipate that smartphone use among the elderly will increase in the future. Conducting relevant studies in this area, as well as preparing high-quality videos and written texts for the public's access to healthy and reliable information by various non-governmental medical organizations, particularly ophthalmological societies, could be beneficial in increasing patients' adherence to treatment.

Medicine can no longer be limited to simply examining patients and providing disease information. Depending on where they practice, physicians should be partly or entirely responsible for providing accurate information to patients through medical associations or individually through the Internet. Otherwise,

since no specialized knowledge is required to publish videos or prepare informational texts in this field, increased viewing of videos created by unqualified individuals who may mislead patients in order to generate advertising revenue by generating a large number of clicks and who promise healing with unlikely treatments may become a public health issue.

Our study has a significant limitation in that patients were asked if they had done direct Internet searches for information on their own. It should be noted that patients' relatives, particularly those younger than themselves, might well be researching the disease and inadvertently passing on incorrect information to the elderly patients. Furthermore, despite the fact that the current study included 400 patients and the results were evaluated using power analysis generalizable to the global population, it was conducted with Turkish patients using Turkish-written materials. Large-scale multi-racial and multi-lingual studies conducted in different geographic locations may yield more clinically and ethically significant results.

Conclusion

As the elderly population grows, so does smartphone use. As a result, the elderly who have been diagnosed with SMD are expected to use the Internet more frequently for disease information. Therefore, the Internet websites should be easy to read; more emphasis should be placed on informative audio recordings and videos for individuals with low vision; and, if necessary, the quality and reliability of the information on these websites should be improved by having it prepared by experts. Otherwise, patients' adherence to treatment may be jeopardized, and improperly prepared Internet websites and YouTube videos may become a public health issue.

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