Cerrahpaşa Med J 2023; 47(1): 77-80 ORIGINAL ARTICLE

Evaluation of Parkinson's Disease Treatment Information in Internet

Gözde Baran

Department of Neurology, Marmara University Pendik Training and Research Hospital, İstanbul, Turkey

Cite this article as: Baran G. Evaluation of parkinson's disease treatment information in internet. *Cerrahpaşa Med J.* 2023;47(1):77-80.

Abstract

Objective: The aim of this study is to determine the quality of the information presented on the websites about "Parkinson's Disease Treatment" and "Parkinson's Disease Surgery" and their role in patient information by evaluating the DISCERN® scores and author classification of the researched websites.

Methods: The search words were determined as "Parkinson's disease treatment (PDT)" and "Parkinson's disease surgery (PDS)" from Google®. The first 30 websites were evaluated with the DISCERN® instrument.

Results: A total of 60 websites were analyzed with 2 different searches with the keywords. When section 1 results were evaluated, the purposes of 2 (7.1%) websites in the Parkinson's disease treatment group and 2 (6.7%) websites in the Parkinson's disease surgery group were clear and understandable. When section 2 results were evaluated, 3 websites (10.7%) in the Parkinson's disease treatment group and 10 websites (33.3%) in the Parkinson's disease surgery group explained all treatment methods. When the section 3 results were evaluated, 3 (10.7%) websites out of 28 websites in the Parkinson's disease treatment group and 3 (10%) websites out of 30 websites in the Parkinson's disease surgery group were found to be useful and appropriate sources of information, based on the answers to all other questions.

Conclusion: To prevent patients from accessing misleading information on the internet and to prevent information pollution, it is recommended to monitor websites and to rely more on websites containing information from health professionals.

Keywords: Parkinson's disease, Internet, information pollution, Parkinson's disease surgery, Parkinson's disease treatment

Introduction

Parkinson's disease (PD) is a neurodegenerative disorder of dopaminergic neurons in the substantia nigra.[1] About 0.3% of the general population is affected and is more common in men than in women.[2]

An increasing number of healthcare professionals and patients use the Internet to obtain guidance and support on health-related issues and to access health information. Many websites provide health-related information, and this number is growing day by day.[3] Around 77% of patients do research on their health before meeting with their doctor.[4]

Although it helps patients to have better information about health, make clearer decisions about their diseases, strengthen their trust in their physicians, and increase their compliance and satisfaction, it can also lead to information pollution and misleading and incorrect information.

The aim of this study is to determine the quality of the information presented on the websites about "Parkinson's Disease Treatment" and "Parkinson's Disease Surgery" and their role in patient information by evaluating the DISCERN® scores and author classification of the researched websites.[5]

Material and Method

The search words were determined as "Parkinson's disease treatment (PDT)" and "Parkinson's disease surgery (PDS)" from Google®, which is a widely used search engine all over the world, and they were searched in Turkish.[6] Key terms for the research were chosen by considering the words that an outpatient with limited medical knowledge could search for on the internet about the disease. A study on Google data flow and traffic showed that the first 30 results listed in the search result collected 97.4% of all traffic in the average search.[7] Based on the results of this study, 30 websites obtained with PDT and PDS keywords were examined in detail for the study. Video sites were excluded. Websites were classified as physician, news, healthcare, personal, and unidentified according to their authors (Table 1). After classification, websites were evaluated using the DISCERN® instrument[5] (Table 2).

The DISCERN® instrument consists of 15 key questions and an overall qualification assessment. The questions are organized into 3 parts: The first part is about the evaluation of reliability and consists of 8 questions. It helps to decide whether the information can be trusted as a source of information about treatment options. Part 2 is about whether sufficient and detailed information is given about treatment options and consists of 7 questions. Third part consists of the evaluator's overall qualification rating at the end of the instrument. Each question is scored from 1 to 5. The researcher, who evaluates the site according to each question, determines the appropriate score from 1 to 5. Question 16 is about the total score and reliability of the site (Table 2). Each site was independently scored by the observer.

Statistical Analysis

In this study, Statistical Package for the Social Sciences 23.0 (IBM SPSS Corp., Armonk, NY, USA) was used as the statistical analysis program. Statistical analysis was performed using descriptive statistics (mean, standard deviation) and Mann–Whitney *U* test. A P value of $<.05$ was considered as statistically significant.

Received: September 27, 2022 **Accepted:** October 29, 2022
Publication Date: December 8, 2022
Corresponding author: Gözde Baran, Department of Neurology, Marmara University Pendik Training and Research Hospital, İstanbul, Turkey
e-mail: drgozdebaran@gmail.com
DOI: 10.5152/cjm.2022.22032

Table 1. Website Author Classification

Author	Definition
Healthcare	Websites affiliated with a government or private healthcare facility
News	Websites affiliated with organizations dealing with news
Personal	Non-physicians with no institutional or organizational affiliation
Physician	Individual physicians with no healthcare facility affiliation
Unidentified	Dead links or otherwise unidentifiable websites

Results

A total of 60 websites were analyzed with 2 different searches with the keywords "Parkinson's disease treatment (PDT)" and "Parkinson's disease surgery (PDS)." Since 2 websites could not be accessed in the PDT group, the evaluation was made over 28 websites.

Table 2. The DISCERN® Instrument

Discern Questions
Section 1: Is the publication reliable?
Question 1: Are the aims clear?
Question 2: Does it achieve its aims?
Question 3: Is it relevant?
Question 4: Is it clear what sources of information were used to compile the publication (other than the author or producer)?
Question 5: Is it clear when the information used or reported in the publication was produced?
Question 6: Is it balanced and unbiased?
Question 7: Does it provide details of additional sources of support and information?
Question 8: Does it refer to areas of uncertainty?
Section 2: How good is the quality of information on treatment choices?
Question 9: Does it describe how each treatment works?
Question 10: Does it describe the benefits of each treatment?
Question 11: Does it describe the risks of each treatment?
Question 12: Does it describe what would happen if no treatment is used?
Question 13: Does it describe how the treatment choices affect overall quality of life?
Question 14: Is it clear that there may be more than one possible treatment choice?
Question 15: Does it provide support for shared decision-making?
Section 3: Overall rating of the publication
Question 16: Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices

Table 3. Distribution of Website Authors

Author (n = 58)	PDT (n = 28)	PDS (n = 30)
Physician (n = 2)	1	1
News (n = 26)	13	13
Healthcare (n = 12)	8	4
Health Institution (n = 12)	4	8
Unidentified (n = 6)	2	4

PDS, Parkinson's disease surgery; PDT, Parkinson's disease treatment.

Among the 28 websites in the PDT group, 8 (28.6%) were healthcare, 13 (46.4%) were news portals, 4 (14.3%) were personal, 1 (3.6%) physician, and 2 (7.1%) were in the unidentified group. Among the 30 websites in the PDS group, 4 (13.35%) were healthcare, 13 (43.3%) were news portals, 8 (26.7%) were personal, 1 (3.3%) physician, and 4 (13.35%) were in the unidentified group (Table 3). In both groups, news portals were found to be the most common among the first 30 results.

When section 1 results were evaluated, the purposes of 2 (7.1%) websites in the PDT group and 2 (6.7%) websites in the PDS group were clear and understandable. In the PDT and PDS groups, there were moderate deficiencies in 3 (10.7%) and 13 (43.3%) websites, and serious and comprehensive deficiencies in 23 (82.2%) and 15 (50.0%) websites, respectively. It was determined that 14.6% of the -websites in the PDT group and 43.3% of the websites in the PDS group provided information directly related to the subject. While 2 (7.1%) of the websites in the PDT group indicated the source and date of use for the content, none of the websites in the PDS group provided a source. While the websites in the PDT group were found to be unbiased at the rate of 68%, the websites in the PDS group were found to be unbiased at the rate of 43.3%. It was observed that none of the websites in both groups contained data on additional support and information resources. Again, it has been observed that 1 website in each group contains information on areas that remain unclear on the subject.

When section 2 results were evaluated, 3 websites (10.7%) in the PDT group and 10 websites (33.3%) in the PDS group explained all treatment methods and their mechanism of action. One (3.5%) website in the PDT group and 3 (10%) in the PDS group explained the benefits of all treatment modalities in detail. In each of the 2 groups, 1 website explained the treatment risks. While no website in the PDS group addressed the issue of how the process would be in the absence of treatment, 1 website (3.5%) in the PDT group did. The effect of treatment on quality of life was clearly explained at a rate of 3.5% in the PDT group and 6.7% in the PDS group. It has been clearly stated that there may be more than 1 treatment option at a rate of 14.2% in the PDT group and 10% in the PDS group. The information content about making a joint decision with the physician, patient's relatives, or health professionals about the treatment method was determined as 7.1% and 6.7% in the PDT and PDS groups, respectively.

Considering the section 3 results, in the evaluation made according to the answers to all other questions, 3 websites in the PDT and PDS groups were determined as useful and appropriate information sources.

In the PDT group, the mean score of section 1 was 1.89 ± 0.83, section 2 mean score was 1.54 ± 0.73, and section 3 mean score

was 1.68 ± 0.98. In the PDS group, section 1 mean score was 1.89 ± 0.66, section 2 mean score was 1.91 ± 0.72, and section 3 mean score was 2.17 ± 0.98. No significant difference was observed between the DISCERN® scores and the authors' groups in the sections in the PDT group ($P > .05$). However, DISCERN® scores obtained in sections 1 and 3 in the PDS group were significantly lower in the websites in the unidentified group ($P < .05$). Although there is no significant difference in section 2, it can be considered that there is a strong relationship ($P = .073$).

Discussion

The rapid development of the Internet started with the widespread use of personal computers and the increase in the use of the Internet,[8,9] which triggered an unprecedented information revolution.[10] Research on the disease and treatment methods are mostly done after diagnosis and are aimed at obtaining more detailed information about the disease.[11] However, the increase in the number of websites may result in accessing false, misleading, and dangerous information from uncontrolled resources.[12] As a result, people can reach misleading information about their diseases and treatment methods. Especially in recent years, health institutions where device-assisted treatments for Parkinson's disease can be applied have become widespread. The frequency of research on this subject and the frequency of bringing it to the agenda have also increased. For this reason, although the level of awareness of this subject in society is not low, some patients ask questions about getting information about the surgery when they first get the diagnosis of Parkinson's disease, while it is seen that some patients have no knowledge about this issue even in the advanced stages. Samanci et al[13] stated that anyone can provide information to the Internet and present their health-related experiences without any filtering or editorial control regarding accuracy. For this reason, it is very important for patients to reach accurate and reliable sources about their diseases and treatment processes in terms of their compliance with the treatment in the follow-up process and their correct orientation in the decisions to be made.

Google® was found to provide 67.5% of global search queries in 2014. It ranks first in searches with a usage rate of approximately 94.9% in Turkey.[6,13]

In our study, no significant difference was observed between the DISCERN® scores and the authors' groups in the PDT group sections ($P > .05$). Contrary to expectations, the reliability of websites belonging to physicians and health services was not found to be higher. It has been observed that the content of these sites is mostly for promotional and advertising purposes. However, DISCERN® scores obtained in sections 1 and 3 in the PHA group were significantly lower in the websites in the unidentified group ($P < .05$). Although no significant difference statistically was observed in section 2, it can be considered that there is a strong relationship ($P = .073$). When the section 3 results were evaluated, 3 (10.7%) out of 28 websites in the PDT group and 3 (10%) out of 30 websites in the PDS group were found to be useful and relevant sources of information, based on the answers to all other questions. It was observed that all the websites that were considered reliable were healthcare-related sites in the PDT group, while 2 were related to healthcare in the PDS group, and 1 was a personal site belonging to a medical doctor. This result shows that most of the first 30 websites that we come across when researching to obtain information from the Internet in both groups have serious deficiencies in their content. Studies evaluating the reliability of low back pain and lumbar disc surgery websites have similarly found that websites are largely of low-to-moderate quality and are less likely to provide useful information.[13,14]

Videos on YouTube, one of the largest video-sharing sites, also have shortcomings in reliability and corporate surveillance. Various studies have evaluated YouTube videos posted by health institutions, consistently reporting a lack of reliable and helpful videos.[15,16] In a study in which YouTube videos about deep brain stimulation were analyzed using the DISCERN® analysis method, it was found that only 24% of the videos scored above 3 on the DISCERN® scoring scale. In addition, in the study, they determined that health institutions would not increase the quality of medical information on YouTube if they published non-reviewed videos.[17]

The Internet is the easiest and fastest way for patients to access information. As stated by Greene et al.[18] physicians can act as guides to help patients find reliable material by accepting internet use. Discussing the information discovered on the Internet will encourage patient education and thus increase the patient's willingness to participate in decision-making processes. In order for patients to obtain reliable and comprehensive information and to stay away from advertising and guiding information, reliable websites should be created and these sites should be ranked higher in the search engine.

The Internet is an easily and quickly accessible source of information for PDT and PDS, but it poses a danger to patients and physicians because they often contain inaccurate, incomplete information and does not cite sources. Information pollution disrupts the patient–physician relationship and leads to unfulfilled expectations and communication problems. Brochures, booklets, and websites created by health professionals and associations should be the first choice of patients for information security.

Ethics Committee Approval: Ethics committee approval is not required as the study is an internet study.

Informed Consent: Since the study is an internet study, consent is not required.

Peer-review: Externally peer-reviewed.

Declaration of Interests: The author declare that they have no competing interest.

Funding: The author declared that this study has received no financial support.

References

1. Ding W, Ding LJ, Li FF, Han Y, Mu L. Neurodegeneration and cognition in Parkinson's disease: a review. *Eur Rev Med Pharmacol Sci*. 2015;19(12):2275-2281.
2. Fahn S. Description of Parkinson's disease as a clinical syndrome. *Ann N Y Acad Sci*. 2003;991:1-14. [CrossRef]
3. Grandinetti DA. Doctors and the Web. Help your patients surf the Net safely. *Med Econ*. 2000;77(5):186-188, 194-186, 201.
4. Chi-Lum B. Friend or foe? Consumers using the Internet for medical information. *J Med Pract Manage*. 1999;14(4):196-198.
5. Charnock D, Shepperd S, Needham G, Gann R. DISCERN®: an instrument for judging the quality of written consumer health information on treatment choices. *J Epidemiol Community Health*. 1999; 53(2):105-111. [CrossRef]
6. *Net Applications: Market Share Statistics for Internet Technologies*; 2014. Available at: http://www.netmarketshare.com.
7. *Chitika Insights: the Value of Google Result Positioning*; 2013. Available at: http://info.chitika.com/uploads/4/9/2/1/49215843/chitikainsights-valueofgoogleresultspositioning.pdf.
8. Eng TR, Maxfield A, Patrick K, et al. Access to health information and support: A public highway or a private road? *JAMA*. 1998;280(15): 1371-1375

9. Pew Research Center. *More Online, Doing More: 16 Million Newcomers Gain Internet Access in the Last Half of 2000 as Women, Minorities, and Families with Modest Incomes Continue to Surge Online*; 2001. Available at: http://www.pewinternet.org
10. Jadad AR, Gagliardi A. Rating health information on the internet: navigating to knowledge or to Babel? *JAMA*. 1998;279(8):611-614. [CrossRef]
11. Pew Research Center. *The Online Health Care Revolution: How the Web Helps Americans Take Better Care of Themselves*; 2000. Available at: http://www.pewinternet.org.
12. Cline RJ, Haynes KM. Consumer health information seeking on the internet: the state of the art. *Health Educ Res*. 2001;16(6):671-692. [CrossRef]
13. Samanci Y, Çelik SE. Low back pain and Internet: Infopollution. *Turk Neurosurg*. 2017;27(5):804-808. [CrossRef]
14. Atci IB, Yilmaz H, Kocaman U, Samancı MY. An evaluation of internet use by neurosurgery patients prior to lumbar disc surgery and of information available on internet. *Clin Neurol Neurosurg*. 2017; 158:56-59. [CrossRef]
15. Samuel N, Alotaibi NM, Lozano AM. YouTube as a source of information on neurosurgery. *World Neurosurg*. 2017;105:394-398. [CrossRef]
16. ReFaey K, Tripathi S, Yoon JW, et al. The reliability of YouTube videos in patients education for Glioblastoma Treatment. *J Clin Neurosci*. 2018;55:1-4. [CrossRef]
17. Tripathi S, ReFaey K, Stein R, et al. The reliability of Deep Brain Stimulation YouTube videos. *J Clin Neurosci*. 2020;74:202-204. [CrossRef]
18. Greene DL, Appel AJ, Reinert SE, Palumbo MA. Lumbar disc herniation: evaluation of information on the internet. *Spine (Phila Pa 1976)*. 2005;30(7):826-829. [CrossRef]