The Media's influence on the validity of medical information regarding Alzheimer's Disease

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ABSTRACT

This article aims to statistically analyze misinformation regarding dementia and Alzheimer's disease (AD) on the internet and discuss common trends amongst falsities. The internet is the most common source of medical information and is largely used by the general public to seek information about a condition/treatment. Dementia is one of the most searched conditions across online platforms. AD is the most common cause of dementia in the US and accounts for 75% of dementia cases. As the prevalence of AD increases, more patients turn to the media to seek information about its implications and treatments. With the increasingly important role that media plays in the field of medicine, families need to be aware of potential sources of misinformation. This paper analyzes one hundred total sources, then categorizes each source into one of three groups (with varying degrees of falsities): misleading, partially misleading, and reliable. The sources were collected using the keywords "Alzheimer's disease" and included 50 videos from YouTube and 25 recommended sources from Google and Firefox respectively (Google and Firefox are some of the most used web browsers in the USA). Subsequently, a misinformed source was thematically classified based on the type of misinformation found. To verify results, all sources were reviewed by a senior geropsychiatric consultant from London, who specializes in dementia care/treatment. [Further elaborated in 'methods' section]. The results indicate that there is systematic misinformation on the internet. It highlights the importance of patient awareness towards this issue. On this basis, it should be recommended that provider's offices alert their patients of this problem.

Introduction

In 1906, a German neurologist, named Alois Alzheimer made history by identifying the first case of what is now known as Alzheimer's Disease. His discovery was based on Auguste Deter, a 51-year-old German woman, who began to exhibit irrational behavior and severe memory loss. Her symptoms included unpredictable behavior and loss of language/fine-motor skills. She was carefully observed until the time of her death. After she passed away, Dr. Alzheimer conducted an autopsy on her brain and found misshapen clumps of protein and bundles of fibers, later identified as plaques and tangles. Though at the time, Dr. Alzheimer did not understand Auguste's cause of death, his work was later codified by his colleague Emil Kraepelin, who had officially identified the case as Alzheimer's Disease.

The most common type of dementia in the USA is Alzheimer's disease, which accounts for over 60-80% of dementia cases. However, there are over 400 types of dementia, but only 5 main dementias are prominent in the USA: alzheimer's dementia, lewy-body dementia, vascular dementia, frontotemporal dementia, and mixed dementia. There are a great variety of dementias, and each brings an onset of different symptoms. But common symptoms of dementia include memory loss, sleep apnea, language problems/trouble speaking, impaired judgment/decision making, etc. The pathology of each type of dementia differs from each other, each dementia affects a different part of the brain (thereby differing in progression and symptoms). For example, Alzheimer's disease primarily affects areas of the brain controlling memory and language function, while vascular dementia primarily affects the blood vessels supporting the brain. Each type of dementia displays relatively the same progression and is degenerative, although rates of deterioration largely depend on the patient.

Currently, there are no FDA approved disease-modifying drugs, but treatments to slow the progression of the disease and dilute symptoms have been identified. Though these drugs are not effective for treating the disease itself, they have been shown to temporally dull symptoms in some patients. Anti-depressant drugs and antipsychotic drugs have been rendered useful for symptomatic improvement. The FDA has currently approved two types of medication, cholinesterase inhibitors, and memantine. These drugs have been shown to have severe side effects including, nausea, vomiting, frequent bowel movements, etc. Drugs that are currently prescribed to dementia patients include donepezil, galantamine, memantine, and rivastigmine. These drugs are prescribed to treat patients according to the stages of dementia, for example, rivastigmine is prescribed to patients in the mid to late stages of dementia.

Alzheimer's disease and dementia have been studied for the past century by universities, pharmaceutical companies, scientists, and medical schools, but only minimal progress has been made in developing an affordable and effective cure. Due to the lack of sufficient scientific information, patients tend to rely on secondary sources (such as the media and news outlets) for scientific information. But these sources tend to be unreliable due to the lack of testing and approval from the scientific community. This potential misinformation can misguide patients and prevent them from taking certain steps/treatments towards their health. These patients also become active carriers of misinformation and may circulate false claims and misguided information about the condition, thereby negatively affecting not only themselves but several other families.

Thereby, it is crucial for patients to be aware of potential sources of misinformation. Patients must consult their primary care provider before taking/deciding any major steps/changes to their treatment or towards their health. The objective of this article is to identify potential sources of misinformation and to analyze the type and degree of falsities amongst sources.

Methods

This article analyzes one hundred sources (50 videos on YouTube and 25 videos each on Firefox and Google) for potential outlets of misinformation. The following browsers were selected due to their popularity, and high usage by US citizens. To maintain uniformity, the same search words "Alzheimer's Disease," were used in all browsers. Each video/website was analyzed for basic information such as source, publication, endorsements, etc. In order to determine which sources contained misinformation, all sources were reviewed by a senior geriatric care consultant, who specializes in dementia treatment and care. Each source that contained misinformation was further classified based on the type of misinformation it contained: treatment, disease, and prognosis. The geographical location of each was also recorded, and the video's availability (in terms of language) was analyzed.

Results

Of the 50 videos analyzed, 32% (16/50) of the videos contained misinformation. The misinformed videos were classified based on the type of misinformation they contained, into the following categories: treatment, disease, and prognosis. The majority of misinformation in the videos surrounded two categories: disease and treatment. 56% (or 9/16) of misinformed videos contained misinformation about treatment, while 44% (or 7/16) of misinformed videos contained misinformation about the disease (including early signs and diagnosis). No misinformation about the prognosis of the disease was identified in the analyzed videos, however, this does not imply that there is no misinformation surrounding the prognosis of AD. The sources/producers of the videos varied greatly. Most of the videos on YouTube were produced by research institutions. The videos produced by research institutions made up a relatively small portion of misinformed videos; 25% (or ¼). Videos produced by news outlets and independent producers made up 78% of the total videos and 75% (or ¾) of misinformed videos. Only two videos analyzed were produced by charity organizations, and they contained no misinformation. While only one video analyzed was produced in a different language (Hindi). Please refer to the appendix to see all sources identified and further classified.

A small portion of videos was also produced in different countries, approximately 10%, including India, UK, Australia, and Canada. Videos were additionally classified based on the degree of misinformation they contained, into the following three categories: misleading, partially misleading, reliable. 6% (3/50) of videos were classified as partially misleading, while the other 26% (13/50) were classified as misleading.

Reliable	Partially Misleading	Misleading
34/50	3/50	13/50

Figure 1. The table above demonstrates falsities amongst videos, by classifying each video based upon the varying degrees of misinformation found. A video was sorted as reliable when it was identified as factual and contained evidence-based reasoning. A video was sorted as partially misleading when it was identified as mostly factual, however did not contain evidence-based reasoning OR the video chose not to acknowledge/to omit particular pieces of crucial information that may otherwise be perceived as misleading. A video was sorted as misleading when it contained misinformation and lacked evidence-based reasoning.

Out of the 50 top videos on YouTube, only 10% (or 1/10) featured African Americans. African Americans are often at a higher risk for Alzheimer's disease and dementia due to genetic and environmental factors. Despite making up a significant portion of dementia cases in the US, African Americans were only featured in a small fraction of videos. Though this statistic can be attributed to many demographic factors, it is important to recognize the disparity.

Race	Fraction of videos featuring particular race	Percentage of videos featuring particular race
African American	5/50	10%
Asian	4/50	8%
Latino	1/50	2%
Caucasian/European	34/50	68%
Other/Undetermined	6/50	12%

Figure 2. The figure demonstrates the large racial disparity amongst videos, by highlighting the stark difference between racial groups featured in videos analyzed.

The misinformed videos were thematically classified based on the type of misinformation they contained (refer fig. 3). A large number of misinformed videos contained misinformation about the M.I.N.D diet (37%). The M.I.N.D diet is a commonly recommended diet for AD patients and is thought to reduce the risk of Alzheimer's Disease. However, a controversial part of this diet is the usage of alcohol as a preventative measure against dementia. Conflicting studies claim that wine may be beneficial in slowing the progression of dementia. However, two reviews of evidence conducted by Alzheimer's Disease International and the National Institute for Health Care and Excellence (NICE) have scrutinized many research studies claiming that alcohol is beneficial to dementia. Though there is no conclusive evidence that wine slows or fastens the progression of dementia, the Alzheimer's Society (UK) recommends patients avoid alcohol.

Another misinformed subject, that was repeatedly identified amongst videos was regarding the diagnosis of dementia. "The Peanut Butter Test" is a largely disputed test, which supposedly is able to diagnose Alzheimer's Disease. UF Health developed the test after noticing a disparity in the sense of smell between dementia patients and non-dementia patients. Participants were asked to smell a small sample of peanut butter from different distances under each nostril (while closing the other nostril). Researchers noted a difference in dementia patients; all dementia patients were able to smell the sample from a farther distance with their left nostril, while they were not able to smell as well with their right nostril. This study was repeated by many universities across America, but none were able to reproduce

the same results, indicating that the study may have been flawed. Many misconceptions about this test still circulate across social networking platforms (especially YouTube).

Misinformed Categories	Percentage of Misinformed videos
Diet	37.5%
Detection	18.75%
Peanut Butter Test	12.5%
Treatments	18.75%
Other	12.5%

Figure 3. The visual above categorizes misinformation, into misinformed topics and their associated statistics.
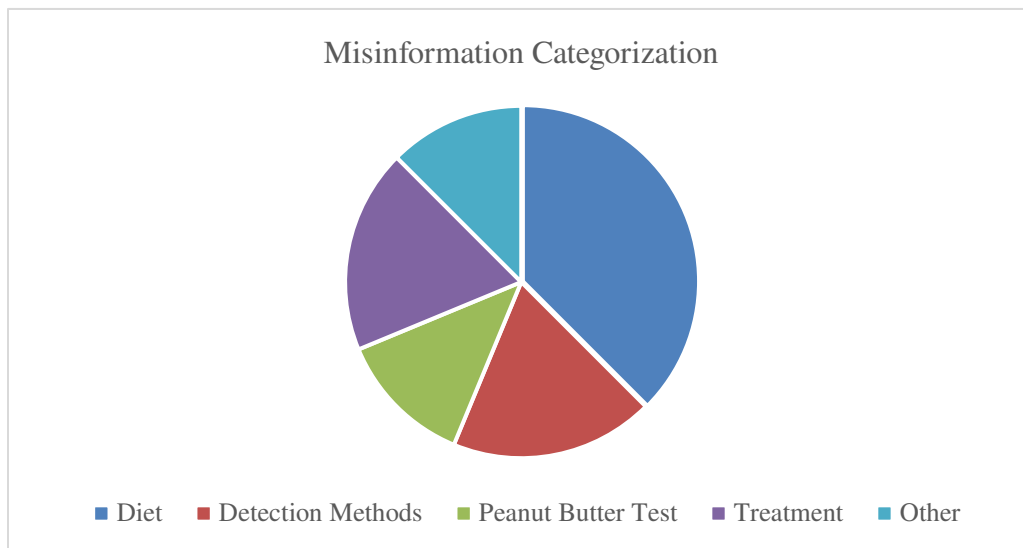

Figure 4. The visual above categorizes misinformation, into misinformed topics and their associated statistics.

The misinformed videos were sorted based on the type of misinformation they contained. Both browsers contained very little misinformation; Google was identified to have two misinformed websites, while Firefox contained three misinformed websites. However, it is important to recognize that many websites were shared between the two browsers (several of the same websites were the top 25 recommended sources in each browser). Misinformation in both browsers concerned dementia treatment/prevention. Both browsers also share similar producer breakdowns, the majority of sources on Google and Firefox are produced by research institutions, which made up respectively 48% and 56% of total sources in each browser. Unsurprisingly, sources produced by news outlets made up a significant portion of misleading sources (approximately 60%), despite only accounting for 16% of total sources amongst both browsers.

Discussion

The purpose of this study was to identify and evaluate misinformation regarding dementia and Alzheimer's Disease on media platforms. This study demonstrates that there is a large amount of misinformation surrounding the treatment/prevention of dementia. Across all platforms/browsers, the majority of misinformation identified was regarding treatment/prevention. On Firefox and Google, 100% of the misinformation identified on these browsers was regarding treatment/prevention, while on YouTube 56% of the misinformation identified on the browser was regarding treatment/prevention. The large percent of misinformation in this area may be due to a large amount of uncertainty regarding treatments for the disease. Since dementia has no approved treatment, many people turn to secondary sources and

speculation for guidance. These sources may not always be correct due to the fact that they are often not backed by scientific evidence, leaving large amounts of misinformation.

The most common rumors/falsities identified were the following: M.I.N.D diet, peanut butter diagnostic test, and the role of vitamins and supplements in the prevention of dementia. Additionally, misinformation concerning the diagnosis of the disease was found. Many tests were found online and on YouTube, which claimed to be able to diagnose dementia, after answering just a few questions. These tests did not have any disclaimers or did not provide information about the test. These tests are largely flawed since there is no accurate way to diagnose dementia, without an autopsy. Many patients take such tests and receive false negatives/positives. This is a large problem, since patients who receive a negative on such tests, may not seek medical care even if they display the symptoms of dementia. Patients must understand, the only method to diagnose dementia is to conduct an autopsy.

Of the 50 YouTube videos analyzed, many contained comments in the comment section. Several comments in each video contained information about alternative treatments for dementia. Many of these comments contained success stories, information about an alternative treatment, and name/contact information. After going through the contacts recommended on these comments, many of them linked to online stores selling vitamins and supplements. Though it cannot be assumed that the vitamins/supplements are not helpful for dementia, patients should be aware of businesses and false claims. 62% of YouTube videos analyzed contained comments on advertising or promoting another healthcare provider/alternative treatment/supplement.

Many videos claimed that the appropriate vitamins and diet can cure/prevent dementia. These videos most commonly used geographical references to hypothesize the large role of vitamins and diet in preventing dementia. One of the most common examples cited by these videos is the low rates of dementia in sub-Saharan Africa and India. Most videos emphasize that the alarmingly low rates of dementia can be attributed to dietary features. Though there is evidence that connects common Indian spices to anti-inflammatory properties, such videos fail to recognize other features that can increase/decrease one's risk of dementia; one such feature is age. Above age 65, one's risk for dementia doubles every 5 years. The average life span in sub-Saharan Africa is approximately 46 years. Due to the low lifespan, the rate of dementia significantly declines in these populations. Many videos failed to acknowledge this statistic and overlooked several environmental factors that may contribute to greater risk.

In conclusion, this research project identified sources of misinformation that are potentially harmful to patients and families. It is a growing issue in the 21st century, as the role of the media in medical care continues to expand. It is crucial that provider's offices alert their patients of this looming problem, or more dementia patients may fall prey to business tactics and false allegations of the media.

Acknowledgements

References

1. Larsson, A., Appel, S., Sundberg, C. J., & Rosenqvist, M. (2019). Medicine and the media: Medical experts' problems and solutions while working with journalists. *PLOS ONE*, *14*(9), e0220897. https://doi.org/10.1371/journal.pone.0220897

2. G, S. (2020). https://medwinpublishers.com/NNOA/NNOA16000183.pdf. *Nanomedicine & Nanotechnology Open Access*, *5*(2), 1–3. https://doi.org/10.23880/nnoa-16000183

3. Campbell, L., Evans, Y., Pumper, M., & Moreno, M. A. (2016). Social media use by physicians: a qualitative study of the new frontier of medicine. *BMC Medical Informatics and Decision Making*, *16*(1), 1. https://doi.org/10.1186/s12911-016-0327-y

4. GEORGE, D. A. N. I. E. L. R., ROVNIAK, L. I. Z. A. S., & KRASCHNEWSKI, J. E. N. N. I. F. E. R. L. (2013). Dangers and Opportunities for Social Media in Medicine. *Clinical Obstetrics & Gynecology*, *56*(3), 453–462. https://doi.org/10.1097/grf.0b013e318297dc38

5. Young, M. E., G.R., Humphreys, K. R. (2008). Medicine in the Popular Press: The Influence of the Media on Perceptions of Disease. *PLoS ONE*, 3(10), e3552.

6. https://doi.org/10.1371/journal.pone.0003552