

RISKS AND BENEFITS OF SELF DIAGNOSIS USING THE INTERNET

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SELF-DIAGNOSIS USING THE INTERNET

Abstract*Risks and Benefits of Self-Diagnosis Using the Internet*

As technology use increases, self-diagnosis using a symptom checker on the World Wide Web has become a topic of discussion in the health field. Given that many in the United States continue without access to medical care, it is becoming common practice for patients to self-diagnose using information sought on the internet. Health literacy of internet health information is a concern, especially among vulnerable populations, such as immigrants and those without access to health insurance.

The aim of this study is to understand the phenomenon of self-diagnosis using the internet as a source of health information among a convenience sample of Salem State University students (N= 150). A survey instrument was used to examine the following: perception of accurate health information sought throughout the internet; follow-up with primary physicians, how much trust is placed in internet self-diagnosis, and how often participants use the internet to self-diagnose. Data was analyzed using thematic coding methods.

The internet provides us with access to information, yet among those seeking health-related information, there is a concern that critical health information can either be misinterpreted, unreliable or both. Self-diagnosis using the internet is a particular concern if patients are using the internet in the place of a physician. Results from this study can inform healthcare professionals about college faculty, staff and student perceptions regarding use of the internet to self-diagnose prior to seeing a primary physician, as well as inform future study of this phenomenon.

Keywords: internet, self-diagnosis, risks, college students, faculty, staff, perceptions, use

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Introduction

The internet provides us with access to information, yet among those seeking health-related information, there is a concern it can be misinterpreted, unreliable or both. Self-diagnosis using the internet is a particular concern if patients are using the internet in the place of a physician. Results from this study can inform healthcare professionals about college faculty, staff and student perceptions regarding use of the internet to self-diagnose prior to seeing a primary physician, as well as inform future study of this phenomenon. With the Internet growing over the years, it has led to much advancement in our society. Having access to a wealth of knowledge whenever we turn on our computers can be helpful in so many ways. Now, the answer to any question can be found at the type of a few keys and click of a button. But, with this wealth of information comes consequences. Health information is in abundance on the World Wide Web, providing people with the opportunity to explore their health from the comfort of their homes. Unfortunately, not everyone is qualified to be seeking out their own potential diagnoses from web databases. Those who are undereducated in both reading and computer technology can be led astray. Not only could they misdiagnose themselves, but they could also attempt to treat themselves. Western medicine has been around for longer than evidence-based hospital treatment, but it is not always as effective or safe.

The majority of the population have access to the Internet on a daily basis. There are computers at home, at work, and in schools. As the Internet has grown, it has led to great accomplishments. Being able to type in your symptoms in a symptom checker and get a list of results can help people get a slight grasp on what their condition might be. There has been extensive research on the use of online databases directed towards help, but not much has been done on what happens after the search.

It is hypothesized that those who find negative results on their internet searches will not seek help from their primary care provider. Also, it is hypothesized that eighty percent of those who take the survey handed out will have engaged in health seeking information on the Internet.

Literature Review

Defining the Act (of online diagnosis)

Humans have a desire to find answers to their problems, or their ailments in this case. A person suffering from a sore throat may Google it and find any number of answers to their problems, and there may be satisfaction or an increased worry. “For patients, medical diagnosis is the gateway to the sick role that legitimizes suffering and departure from normal social roles as appropriate and blameless” (Copelton & Valle, 2009, p. 625). In short, giving a name to the beast makes it more bearable and easier to cope with. Copelton and Valle (2009) found that people that engage in self-diagnosing may visit their physician afterwards so they can hear what they may have to say about the presenting symptoms. In further research, there is hope to find out whether individuals engaging in internet self-diagnosis will seek professional medical treatment afterwards. There is this idea that having a legitimate answer to the suffering is what makes people feel better. Having a diagnosis, regardless of whether it is self-found or determined by a medical professional, can bring relief to the individual.

Perceived Benefits

Ideally, websites such as WebMD, Mayo Clinic, and other symptom search engines can determine whether the questionable symptoms could imply a serious problem or whether they are unsupported (White & Horvitz, 2009). Searching for symptoms on the internet can be beneficial when preparing for a doctor’s visit. It can calm a person to have an idea what could be

going on before stepping into the doctor's office. It can give a person the resource to take part in their own health. People can use the internet to understand possible conditions before seeing their doctor, spend as much as they want asking questions, and better understand what the doctor is discussing about their health (Luger, Houston, & Suls, 2014). If a doctor is not great about translating medical jargon to a layperson, this person can use the internet to understand more about their disease. Anyone with access to a computer has access to the information it holds, and with the number of internet users increasing, there is more access to health information.

One great benefit is that “the Internet has the potential to increase health information access in remote areas and to otherwise under-served populations” (Cline & Haynes, 2001, p. 675). Not everyone has access to, or can afford to have a regular doctor. The Internet has provided many advantages to our ever-growing world, and this is one of them. More people can have access to health information and be able to identify risks or signs that someone might need further medical attention.

Perceived Risks

Unfortunately, there is more research about the negatives and risks of internet self-diagnosis than benefits. Mentioned earlier, everyone who has access to the internet, has access to a symptom checker. On the other side of that, anyone with access to a computer with Internet and the ability to edit websites can add to health information displayed on the web (Hardy, 1999). The question remains, how accurate is the information that is out there? The worry is that people are coming up with the wrong answers about their health and this is hurting them, not helping.

There is a wealth of knowledge about western medicine on the Internet. Unfortunately, there can be serious interactions between eastern and western medicine. Health related search

engines do not differentiate between material provided by a medical health professional and those who could be promoting western medicine over evidence-based (Hardy, 1999). There is treatment out there that can be sought without a medical professional. Many use western medicine, or alternative treatments to treat their diseases or symptoms. One concern is that those seeking health information on the Internet may not understand the information presented to them correctly and try treatments that can harm them instead of going to visit their primary care provider (Cline & Haynes, 2001). Now, there is an online market of pharmacies that can send an individual medications without a prescription. Medications like Viagra (which carry a stigma of shame to some) can be bought online. Unfortunately, “online purchase of drugs...[is] something that can pose a threat to people’s health due to over-consumption, dangerous products, medicinal interactions, etc.” (Benigeri & Pluye, 2003, p. 384).

There are over seventy thousand websites boasting information related to health (Cline & Haynes, 2001) leading to a large database of medical knowledge at any Internet- users fingertips. Determining which are accurate, and which could lead a person astray is one of the dangers. “A spokesman from the U.S. Department of Health and Human Services warned, ‘trying to get information from the Internet is like drinking from a firehouse, and you don't even know what the source of the water is’” (Cline & Haynes, 2001, p. 677). Cline and Haynes (2001) have determined that over half of health information on the internet is unsound.

When seeking material online, parents caring for their children at home with fevers found that only nine percent of websites offered accurate information (Cline & Haynes, 2001). This point offers a great deal of information about treatment. Even if an individual knows what the problem may be, the treatment options offered online may not be accurate or even safe. Those who do not work in the medical field and understand the medical field may have a hard time

distinguishing between facts and ideas. Individuals can be led astray by the information they are led to on the Internet, and they may have a hard time distinguishing between fact and fiction.

Mental health is another avenue where the Internet can be dangerous. Mental health is growing and becoming more accepted throughout the community. However, the Internet could be involved in “validation of serious psychiatric disorders as ‘normal’” (Cline & Haynes, 2001, p. 681). Having a mental illness is nothing to be ashamed of, but like most other medical conditions, they cannot be ignored. They need to be diagnosed and treated so the individual can return back to optimal health.

“Internet use is strongly connected to socio-economic status” because not everyone can afford to have constant access to a computer or the Internet in which to search their symptoms (Benigeri & Pluye, 2003, p. 382). Because of this, there are “increasing social disparities in health” (Benigeri & Pluye, 2003, p. 382). The general population does not understand medical jargon. Also, “difficulty with technical terms and the required reading skill level is also a problem” (Benigeri & Pluye, 2003, p. 383). Medical terms can be intimidating to one who has never heard them, and they can confuse many. Internet has been described as “dangerously confusing to clients” and with the amount of misleading information it makes sense to be confused (Hardy, 1999, p. 827). “People with the greatest health needs have low information access due to lower health literacy levels” (Benigeri & Pluye, 2003, p. 383). English medical websites generally require high school level or greater reading ability, meaning that those without a high school education (or greater) are likely to interpret health information incorrectly. Benigeri and Pluye concluded that “for educated people who know how to find useful information on the Internet regarding self-care and disease prevention, and who also know how to deal with the health care system, the Internet holds great promise”, but outside of that

population, health seeking on the information could be dangerous (Benigeri & Pluye, 2003, p. 384).

Defining “Cyberchondria”

Searching a headache on the Internet can either lead you to a serious condition, such as brain tumor, or a non-serious condition such as caffeine withdrawal. The ability to differentiate between the two possible diagnoses can illuminate anxiety levels and education of the individual. Obviously, there are more headaches caused by caffeine withdrawal than a brain tumor, but evidence shows that the more common diagnosis is severe. Although not a widely adopted term, “cyberchondria” explains the irrational tendencies of those who use the internet for self-diagnosis in a negative way. “Cyberchondria” is used in reference to the unsupportable assumption that an individual’s symptoms inevitably mean a diagnosis of a severe disease (White & Horvitz, 2009). Escalations from common symptoms to mistaken diagnoses and treatments are the danger with the wealth of information on the Internet. It can lead to unnecessary anxiety and a rise in healthcare bills due to trips to the health provider’s office. Although not an official diagnosis, it pertains well to this situation in that individuals who are seeking answers to their medical symptoms may find themselves thinking they have a serious medical condition.

Peterson (2012) said that “cyberchondria” (the web- related hypochondria) is escalating as the use of the internet becomes integral in daily life. The fear is that those who are engaging in online websites and finding a result they feel fits their symptoms are not going to their doctor after. Peterson found that the brains of “cyberchondriacs” and gamblers have similar tendencies to be unrealistic and illogical. When researching symptoms online, if the first two suggested

symptoms for a condition match, the “cyberchondriac” brain believes the third matches as well (even if this is not true).

Methods

Design

This study consists of a literature review on defining the act of using the internet to self-diagnosis, perceived benefits of that act, perceived risks of that act, and defining the term “cyberchondria”. It also included a qualitative survey study using a convenience sample of Salem State University (SSU) students, faculty, and staff (N=122). Once the survey was created on Survey Monkey, it was distributed online. In addition to social media, it was sent through several email databases, reaching a large population of students including (but not limited to) the honors, nursing, and psychology department. All grade levels and any department at SSU could take part in the survey; this was to attain the largest population and obtain as many results as possible.

Data Collection and Analysis

One hundred and twenty- two surveys were submitted. The correlation between those who internet self-diagnosed and those who went to see their primary care provider was assessed. Thematic coding methods were used to analyze the qualitative data resulting from the surveys.

Aim

The aim of this survey was to better understand the incidence of internet self-diagnosis. It also encouraged the participant to be aware of their own online tendencies when it came to their health, and what they do with that health information.

Purpose Statement

The purpose of the study was to evaluate the impact of the internet on health care as it pertained to a certain population. Hopefully, through the gathering of this information, medical health professionals could better understand where their patients are getting their information. Learning about the internet search habits of patients can help nurses better understand how to explain things to their patients and opens up communication about healthy and unhealthy online activity as it pertains to symptomology

Ethical Considerations

Before any research was conducted, a sample survey was approved by Salem State University's Institutional Review Board. Participants were asked to read and accept a disclosure statement before beginning the questionnaire. They were expected to read the statement and decide for themselves if they wish to partake in the survey. No penalty resulted from opting out of taking the survey. Before and after completing the survey, the participant was able to continue with their normal day. Participants were students, staff, and faculty at Salem State University. There were no exclusions for participants, any department could participate. There was minimal risk to participants and minimal benefits.

Research Results

Results

The results of the survey are presented in Figure 1 and Figure 2. The goal was to collect 150 surveys, and 122 were collected. There was a healthy mix of ages, with the greatest amount aged 21-25 (the age of most college students). Forty-six percent of the responses were from seniors at Salem State University. Ninety-one percent of the responses were female. When asked whether the individual used the internet for health advice (questions number 6), forty-one percent agreed and twenty-eight percent strongly agreed. When asked about the reliability of health

information on the internet (question number 7), forty- five percent were neutral and twenty-nine percent agreed it was reliable. When asked if they consulted the internet before seeing their primary care physician (question number 8), fifty percent agreed and nineteen percent strongly agreed. When asked if they consult with their doctor after their internet results (question number 9), twenty percent strongly agreed and forty percent agreed. When asked if they informed their doctor about their use of the internet in their health (question number 10), thirty- two percent agreed and thirty-one percent disagreed. When asked if they ever diagnosed using only the internet (questions number 11), thirty- four percent agreed and twenty- eight percent disagreed.

The results show that the data was skewed because the majority of the responders were female and seniors at Salem State University. They also showed that those who use the internet to find health information believe it is reliable, when the data shows it is not. It was determined that the majority of people use the internet to understand their medical condition before seeing their doctor, but the majority still went to the doctor after their results. The data showed that half of the responders told their doctor they used the internet before their visit, and half did not. The data also showed that about half of the responders diagnosed only using the internet, and half disagreed.

Understanding the behavior of those who use the internet related to their health can help doctors understand their patient's perspective. Health care providers can direct their patients to accurate information located online, or they can better teach their patient about the disease or problem they may be having. This data can help medical health professionals understand their patient's use of self- diagnosis using the internet (Figure 1; Figure 2).

Discussion

One lesson that health professionals can take away from this research is understanding that the behavior is occurring. The data from the current research, and past research that was assessed found that there is a large amount of the population that internet self-diagnose. Evaluating how patients go about this behavior and if they are conducting themselves in a healthy manner is important to evaluate. In this way, medical professionals (such as doctors and nurses) can provide guidance toward healthy internet behavior that can help them, not hurt them.

Another lesson health professionals can take away from the research is that their patients may have questions they are not taking the time to answer. Nurses, doctors, and therapists want their patients to lead healthy lives and one way to encourage that is to reassure the asking of questions. Patients may not understand medical jargon used when describing their condition, and instead of asking their doctor what it means, they may consult the internet (that may or may not be correct).

A question that was raised during the research process was regarding health care and economic status. Maybe patients are not going to see the doctor because they do not have a primary care provider or because they do not have insurance, or cannot afford the copay. When considering this, internet self-diagnosis makes sense because it gets an answer without having to spend more money. In further research, it would be interesting to assess if there are health seekers on the internet that are doing it because they do not have many other options available to them.

Encouraging the use of health professionals could reduce the use of internet self-diagnosing. Patients may feel that they cannot go to their primary health provider or a nurse because they would be bothering them or they do not understand what they are saying. Patients

should be encouraged to have an open, healthy relationship in order to promote the best way of life.

A significant limitation in the conduction of this survey was sample size. A sample (N=122) of students, faculty, and staff was drawn from Salem State University's population. The results found that the majority were both female and seniors. Almost all participants had a primary care provider. Considering both of these facts, it is clear that the data was skewed. It did not contain as many older adults, males, or those who did not have access to a primary care provider.

The results show that half of people with a primary provider use the internet instead of consulting their doctor, which is important for primary health professionals to know. If patients are using the internet for their health needs, they could be led astray or engage in unhealthy behavior. Health professionals need to appreciate this behavior so they can help to improve health information and health literacy for their patients. They can do this by taking the time to answer their questions or direct them to accurate online health information.

Conclusions

One hundred twenty two surveys were completed at Salem State. From the conduction of this survey, it has been found that there is a high incidence of internet self-diagnosis occurring among students, staff, and faculty, although female senior students made up a larger portion of the study population. Similar survey studies should be conducted in the future in order to compare results across studies, especially if a different population were examined. The questions included in the survey were directed at evaluating if self-diagnosis using the internet occurred, and if it did, was there involvement with a primary care physician after the use of the internet. It can be concluded that more investigation needs to be done in this area of research. This behavior

will only grow as the internet becomes more readily available to us. We need to understand how it is being used related to self-diagnosis, promote the positive actions, and discourage the negative ones.

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Tables and Figures

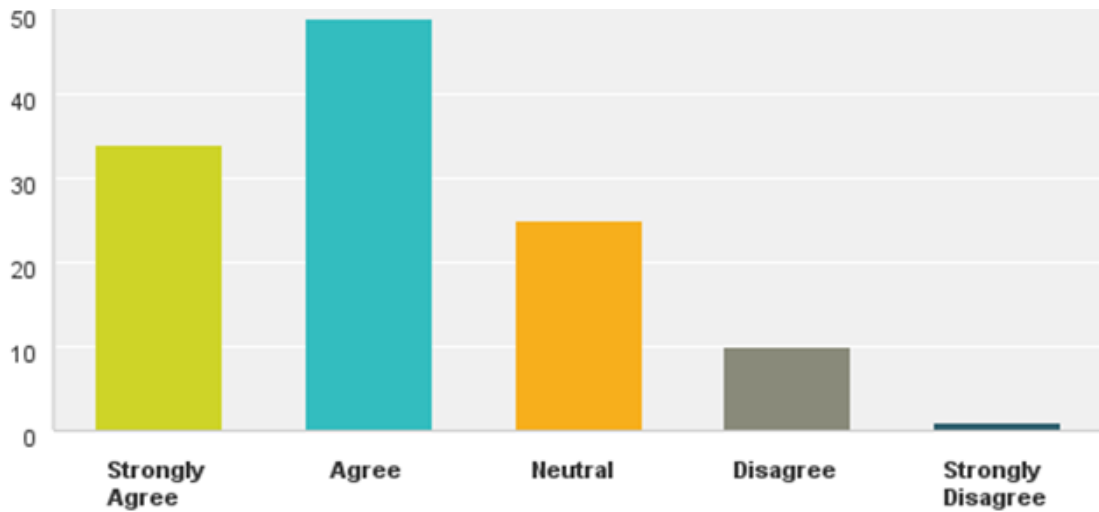


Figure 1

Figure 1 shows the answers to the question of whether the participant regularly used the internet for health advice.

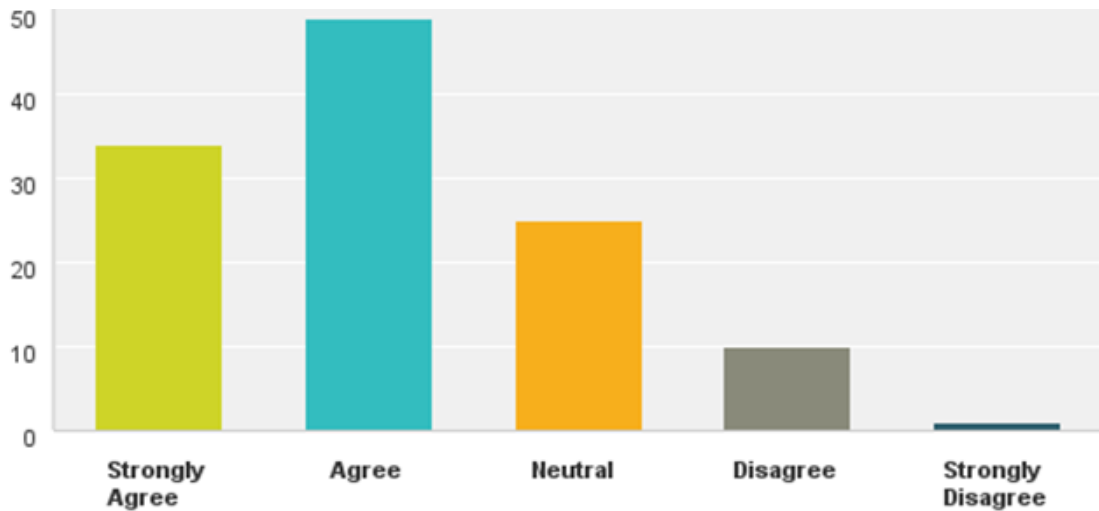


Figure 2

Figure 2 shows the answers to the question of whether participants self-diagnosed their health problems solely using the internet, rather than seeing a health care professional.