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Satisfaction with health information communication to Multiple Sclerosis patients

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Satisfaction with health information communication to Multiple Sclerosis patients

by

Mariam A. Alrubaie

Thesis

Submitted to the College of Health and Human Services

Eastern Michigan University

in partial fulfillment of the requirements

for the degree of

MASTER OF SCIENCE

in

Clinical Research Administration

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Abstract

Multiple sclerosis (MS) is a chronic, unpredictable and crippling neuro-inflammatory disease, affecting an estimated 2.3 million individuals worldwide and 300,000 to 350,000 people in the U.S. MS is the second most costly chronic condition to treat. Given the severity of MS and its impact on patients' lives, it is important that patients feel engaged in positive, effective communications about the disease. Because of the complexity of the diagnostic process and the patients' need to adjust to life with MS, patients seek information from as many sources as possible to help them manage health needs. This study sought to investigate MS patient perceptions of their experiences with access to reliable and useful communications from various information sources, including health care professionals as well as the Internet and social media. The results showed that MS patients are critical to some extent of health care communication from both sources. Survey respondents overwhelmingly favored being able to obtain MS information from health care professionals as well as the Internet, but a large percentage of the respondents expressed some degree of dissatisfaction with health care communications provided by each.

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Introduction

Multiple sclerosis (MS) is a crippling neuro-inflammatory disease that causes mild to severe disability. MS has the following impact on Americans:

- Estimates of the number of MS patients range from 300,000 to 350,000 people in the U.S. (Foley, 2010; National Institute of Neurological Disorders and Stroke (NINDS), 2015).
- Total annual direct and indirect medical and non-medical costs for MS have been estimated to be as high as \$50,707 per patient (Trisolini, Honeycutt, Wiener, & Lesesne, 2010, p.6) and even \$54,244 (Pietrangelo & Higuera, 2015, para 17), making MS the second most costly chronic condition to treat. Only congestive heart failure is more costly.
- Approximately 200 new cases of multiple sclerosis are diagnosed each week (NINDS, 2015).
- Prevalence studies indicate that the rate of the disease has increased steadily during the twentieth century (NINDS, 2015).
- Twice as many women as men are affected, as is true of most autoimmune diseases (NINDS, 2015).
- Studies indicate that 43% to 65% of those diagnosed with MS have objective cognitive impairments that are associated with employment problems, social problems, difficulties in activities in daily living, and quality of life (Foley, 2010).

Patients who suffer from chronic illness experience communication with health care providers as a critical component of their care. Health care professionals treating MS patients includes physiotherapists, occupational therapists, and nurses as well as generalist and specialist physicians and others with whom they may have regular and frequent communication (Thorne, Con, McGuinness, McPherson, & Harris, 2004). However, health care professionals are not the patients' only information source. Given the complexity of the diagnostic process and the patients' need to adjust to life with MS, patients seek information from as many sources as possible to help them manage health needs. Increasing numbers of patients turn to the Internet to access information and support communities. In some instances, patients may be exposed to misleading or inaccurate information obtained online. Consequently, the quality of health care communication becomes increasingly important.

Typically diagnosed between ages 20 and 40, MS is a chronic and unpredictable disease, affecting the brain, optic nerves, and spinal cord. The disease affects an estimated 2.3 million individuals worldwide (National MS Society, n.d.). Because of the difficulty of diagnosis and the way that MS data is reported, no one knows the exact number of people affected by multiple sclerosis. As a result, only estimates are available regarding the prevalence of the disease. The severity of the impact of MS is however unquestioned. MS, which affects more than 1,000,000 in the western world, is the second leading cause of neurological disability in young adults, exceeded only by trauma (Barcellos et al., 2002).

Thought to be caused by the immune system attacking healthy tissue, MS symptoms include weakness, fatigue, poor coordination, loss of balance, bladder and bowel disturbances, pain, blindness and paralysis, sexual dysfunction, abnormal speech, and cognitive and emotional disturbances (Thorne et al., 2004; Trisolini et al., 2010). While the disease is not normally fatal,

it does prevent many of those affected by the disease from leading normal and productive lives (National MS Society, n.d.). Moreover, MS affects not only patients and their quality of life, but their families and society as a whole. Patients depend on health care professionals and other information sources to understand and manage their symptoms, adapt to changes in their lives, and make decisions about treatment.

The etiology of MS is not well understood, but studies tend to show genetic linkage. Haines et al. (1998) found that genetic factors play a role in susceptibility to MS. Studies showed that first, second, and third degree relatives of MS patients were at 15 to 40 times higher risk of developing MS. Twin studies and adoption studies likewise indicated increased risk for biological relatives of MS patients. Similarly, Sospedra and Martin (2005) argued the existence of a predisposing genetic trait that contributes to the development of MS. Barcellos et al. (2002) also found that complex genetic susceptibility played a significant role in MS etiology; however, the precise role of genetic factors remains unknown. The existence of so many poorly understood factors regarding MS causes and treatments contributes to the uncertainty MS patients' experience. This uncertainty also complicates their search for high quality, reliable information necessary for them to participate in health management.

Given the severity of MS and its impact on patients' lives, it is important that patients feel they engage in positive, effective communications about the disease. Therefore, health care relationships can be significant in contributing to MS patient quality of life and self-care management (Thorne et al., 2004). In general, patients can be expected to prefer to participate in shared decision-making so that optimal communication occurs between doctors and patients. In addition to collaborating in clinical decision-making, patients also typically want to strike a balance between taking over the decision-making process and leaving all decisions to the

physician. For patients suffering from chronic diseases, in particular multiple sclerosis, patient preference for significant communications has been well documented (Hamann et al., 2007). Hay, Strathman, Lieber, Wick, and Giesser (2008) noted that MS patients seek information on the Internet not to replace information provided by their physicians, but that patients were nonetheless reluctant to discuss Internet information with their physician. This reluctance highlights the dilemma MS patients' face in integrating various sources of health care information.

This study surveyed literature on health care communication for MS patients including the background and significance of miscommunication and misleading communications and new developments. In addition, the study describes the results of a quantitative survey that investigated patient perceptions concerning MS communications.

Objectives and Research Questions

This pilot study sought to investigate MS patient perceptions of their experience with accessing to reliable and useful communications from various information sources. It is the goal of this study to provide insights into how satisfied MS patients are with the information made available to them. It is significant to understand these perceptions because of their impact on overall patient health, disease management, and adherence to treatment protocols.

This researcher hypothesized that patient satisfaction, the dependent variable, would be positively correlated with health care communication from health care professionals and from the Internet and social media, the independent variables. This study used quantitative methods to investigate the relationship between patient perceptions of receiving high quality health-related information from these sources. The central research question that guided this pilot study was *what are the correlations, if any, between patient satisfaction and patient experience with obtaining health-related information from health care professionals and from social media and the Internet?*

Literature Review

A literature review reveals varying quality and reliability in health care communication for MS patients. Given that research shows that more involved patients experience better health outcomes due to increased treatment adherence and awareness, medicine is becoming increasingly more participatory to promote these outcomes (Lejbkowitz, Paperna, Stein, Dishon, & Miller, 2010). The need to find reliable and trustworthy information online regarding medical conditions exists because significant numbers of people trust the Internet for health information. In recent years surveys show that 60 to 80 percent of Americans used the Internet to find health information (Fox & Jones, 2009; Sarasohn-Kahn, 2008). By January 2008, the Internet rivaled physicians as the leading source for health information (Sarasohn-Kahn, 2008).

Research has shown a correlation between the ability to cope with MS and how well-informed the patient is. Particularly in the early phases, optimizing the information process may help the patient develop coping styles that improve adaptation to living with MS (Lode, Larsen, Bru, Klevan, Myhr, & Nyland, 2007). In addition, information seeking helps to improve the patient's confidence in the treatment received, leading to improved treatment adherence. Given that non-adherence is considered an unnecessary risk for further morbidity and mortality, and a waste of health care resources, non-adherence is an important issue in MS management. Information is therefore a significant factor in patient empowerment in decision making and optimization of therapy, leading to increased adherence (Klauer & Zettl, 2008).

In some cases the need for information can lead to increased anxiety for people with no medical training or background, as is frequently the case with individuals who believe they may be suffering from a disease or illness. Microsoft Corporation conducted a longitudinal study of

the health-related search experiences of 515 individuals. The results showed that the use of Web search engines were potentially responsible for escalating users' anxiety over medical issues (White & Horvitz, 2008). According to the *Washington Post*, the Microsoft study reported that approximately two percent of Windows Live searches were related to health topics. Nearly one-third of the 250,000 users who conducted at least one query during the study escalated their Web surfing to encompass much more serious and less common medical conditions (Butler, 2009). Problems may arise when people mistakenly believe that internet search engines can provide medical diagnostics. Horvitz (2008) argued that the challenge for Internet content providers is to improve health content in such a way that it gives more accurate results reflecting the probability and likelihood of diagnoses and that more complexities are included such as family history.

Another criticism of social media as a source of health information is that content provided by individuals may result in adverse effects or even death. In general it is assumed that low-quality information available on the Internet can cause potential harm, but the literature does not substantiate this (Deshpande and Jadad, 2009). Advocates of online health care information argue instead that social network communities tend to be very active and self-correcting. As a result, misinformation does not remain unreported or uncontested for long (Sarasohn-Kahn, 2008).

MS patients can also obtain health information from online support groups and MS patients' communities. Such organizations offer patients and their loved ones a way to search out information from around the globe, as well as from doctors and medical experts. Online communities include Healthline's Facebook page, MS Connection, MS World, the Multiple Sclerosis foundation's Facebook group, the Multiple Sclerosis Association of America, MS Voices, Daily Strength, and Patients Like Me (Holland, 2013).

In addition to seeking out support, MS patients look to the internet for information on treatments and developments. The FDA recently rejected Lemtrada, a new MS drug, on the grounds that the drug's serious risks are not outweighed by potential benefits (Doheny, 2013). According to the clinical trial watch website CenterWatch (2014), another promising treatment is the drug dimethyl fumarate approved by the FDA in March 2013. In clinical trials of more than 800 people, the drug reduced relapses from about 46 per cent for those receiving a placebo down to 27 percent.

This kind of communication is critical not only to those providing appropriate health care, but patients themselves prefer improved access to information. Study results show that MS patients prefer to participate in their treatment by being better informed. Other websites go beyond merely providing information to the MS patient by additionally supporting self-monitoring of the disease (Hatzakis et al., 2006).

Patients reported that having information about MS contributed to helping cope with the disease (Lejbkowitz et al., 2010). Hay, Strathman, Lieber, Wick, and Giesser (2008) found that most MS patients searched online for information before their first visit to an MS clinic. Research indicates this type of preparation promotes adherence to treatment.

Compared to patients with other chronic conditions, Hamann et al. (2007) found that MS patients demonstrated greater interest in participating in making medical decisions. The researchers studied patients with other chronic conditions, including schizophrenia, depression, hypertension, and breast cancer. The researchers hypothesized several possible explanations for MS patients' higher scores on the Autonomy Preference Index (API) scale. One explanation may be the increased fear of loss of control that MS patients feel. Another explanation may be that MS patients believe their treatment options are less effective. A third explanation may be the

MS trial setting in a specialized out-patient unit resulted in possible selection bias toward more patients desiring more active involvement in medical decision-making.

Research also indicates an association between duration of MS and disability with information preferences of MS patients. Recently diagnosed MS patients tended to search more for information online. As the disease grew worse, patients with longer disease duration also tended to search more (Lode et al., 2007; Wallin, Spense, & Walsh, 2000). Patients with higher disability also preferred interaction over the Internet with specialists and support groups. These patients were concerned with reading about coping approaches used by other MS patients, indicating that the Internet served a social role for them (Lejbkowitz et al., 2010). These findings highlight the importance of accessibility to online information for MS patients.

A 2014 survey of patients ($n = 1,272$) and neurologists ($n = 258$) highlights the difficulties of MS patients in obtaining health care communications. The survey determined that health care providers could help people with MS to better manage their conditions when providers better understand what their patients know or believe to be true about MS. However, survey results indicated a disconnect between patients and doctors on significant issues such as the causes of MS, adherence to treatment, and what can be done to better manage the effects of living with the disease (Strauch, 2015).

Methods

This pilot study used a self-reporting survey as the data collection instrument, the Comparison of Patient Perceptions of MS Communications Questionnaire (see Appendix A). The survey was distributed with assistance from the MS Association (MSA) of Michigan which posted the survey link on its website. The link invited MS patients who visited the MSA website to respond to the survey by clicking on a link to the web-based data collection platform by SurveyMonkey. The survey consisted of eight closed-end questions, two of which required yes or no answers, while the remaining questions asked respondents to rate items on a 5-point Likert scale. The survey did not capture demographic information. Survey items evaluated patient perceptions of communications with health care professionals compared with accessing information online using social media and the Internet. The dependent variable under investigation was patient satisfaction, while the independent variables were health care communication from health care professionals and from the Internet and social media.

Survey data was collected from MS patients on March 2, 2015. This researcher conducted a survey of individual MS patients ($n= 24$) to evaluate their perceptions of MS communications. Because of the need to reach a specific population, the study used non-probability sampling to access MS patients from individuals visiting the MSA website. This sampling strategy may have introduced self-selection bias or sampling error, causing the sample to not be representative of the target population. This sampling technique limits the ability to generalize results to a wider population.

The intent of this pilot study was to analyze the impact of health care communication by studying patient perceptions. The study was subject to limitations involving geographical location, population size, and trustworthiness of responses provided by the participants.

Limitations may also result from the individual judgment of survey participants regarding the quality of information they have accessed. Any of these factors may limit the ability to generalize study findings to the larger population. Study delimitations include the scope of survey items which may not comprise the entire patient perspective on satisfactory health care communication.

Results and Data Analysis

This researcher summarized study data using descriptive statistics. The data analysis presents results of each study question examining perceptions of patient satisfaction with health care communication and the sources of those communications, health care professionals and the Internet and social media. Because the survey link was posted on the MSA of Michigan website and respondents accessed the survey through that link, no response rate was available.

The central research question that guided this pilot study was; *what are the correlations, if any, between patient satisfaction and patient experience with obtaining health-related information from health care professionals and social media and the Internet?* The following statistics summarize results of online surveys.

Table 1 which follows shows responses to questions about the significance of health related information from health care professionals and from social media and the Internet. The table also shows responses concerning the perceived likelihood of receiving misinformation or insufficient information from these sources.

Table 1: Survey Questions 1-4

Question	Significant (%age) (n = 24)	Somewhat Significant (%age) (n = 24)	Neither Significant nor Insignificant (%age) (n = 24)	Somewhat Insignificant (%age) (n = 24)	Insignificant (%age) (n = 24)
How significant to you is communication with health care professionals regarding MS?	100.0	0.0	0.0	0.0	0.0
How significant to you is obtaining information on MS from social media and the Internet?	37.5	54.0	8.3	0.0	0.0
How likely do you believe it is to get misinformation or insufficient information on MS from health care professionals?	16.7	20.1	16.7	41.67	4.2
How likely do you believe it is to get misinformation or insufficient information on MS from social media and the Internet?	4.2	0	29.2	29.2	37.5

Table 2: Survey Questions 5-6

The following Table 2 shows the number of respondents who believe they received misinformation or insufficient information from the two sources.

Question	Yes (%age) (<i>n</i> = 24)	No (%age) (<i>n</i> = 24)
Do you believe you have received misinformation or insufficient information on MS from health care professionals?	50.0	50.0
Do you believe you have received misinformation or insufficient information on MS from social media and the Internet?	75.0	25.0

The following Table 3 shows respondents' level of satisfaction with information sources.

Table 3: Survey Questions 7-8

Question	Satisfied (%age)	Somewhat Satisfied (%age)	Neither Satisfied nor Dissatisfied (%age)	Somewhat Dissatisfied (%age)	Dissatisfied (%age)
How satisfied are you with MS treatment and access to health-related information from health care professionals? (<i>n</i> = 23)	37.5	50.0	4.2	4.2	0
How satisfied are you with MS treatment and access to health-related information from social media and the Internet? (<i>n</i> = 24)	4.2	45.8	41.7	4.2	4.2

Discussion

The results showed that MS patients are critical to some extent of health care communication in general. Patients were likely to report that obtaining information about MS was a significant concern, whether that communication occurred with health care professionals or through the use of social media and online content. The fact that 100% of respondents indicated they want such communication with health care professionals, while a slightly lower number or fewer than 91% seek this information from the Internet, highlights the value MS patients place on keeping informed. This preference would seem consistent with studies showing that patients favor more participatory disease management options. However, responses to other questions showed that MS patients' efforts to educate themselves are being thwarted. These findings support the hypothesis that MS patient satisfaction is related to the patient's ability to obtain health-related information from health care professionals and from social media and the Internet.

MS patients clearly are aware of the potential for dissemination of poor quality health care information online and in social media. Two-thirds of the respondents believe they have already received inaccurate or incomplete information from online sources, while three-quarters believe they are likely or somewhat likely get such misinformation. Given that half the respondents believed they received misinformation from health care professionals, these responses would indicate a high degree of skepticism related to any health care communication for MS patients, regardless of the source.

Clearly, in addition to desiring health care communication, MS patients also would prefer that the information they receive from medical professionals be more accurate and complete. Nearly 46% of patients were critical of information they might receive from health care

professionals. This high level of dissatisfaction may occur for a number of reasons which this study does not evaluate, but clearly this perception is cause for concern. Given that 50% of the respondents believe they have received misinformation or incomplete information in the past, these responses indicate that there is significant room for improvement. Similarity of responses to Questions 3 and 5 show consistency between the two items.

In spite of believing they have received inaccurate or incomplete information from health care professionals, nearly 88% indicated they were either satisfied or somewhat satisfied with MS treatment and access to health care information provided by health care professionals. This number is significantly higher than those respondents, 50%, indicating satisfaction with treatment and access to health care communication using social media and the Internet. It is possible that the two sources of information are best viewed as complementing each other, with MS patients benefitting from using both. While these results do not seem to indicate a strong correlation between health care communication and patient satisfaction, a number of other important variables that this study did not address may also mediate patient satisfaction. Patient satisfaction with communication from health care providers may be explained by access to treatment or perceived reasonableness of health care costs. Patient satisfaction with Internet and social media health care communication may be explained by satisfaction with access to support groups or social needs being met. This data provides health care professionals, patients, and providers of Internet content with information they can use to help positively affect MS patient care.

While this pilot study helped to validate the need for MS patients to receive high quality health-related information from health care professionals and from the Internet and social media, there are questions that could not be answered. The study design does not indicate causality, but

the findings suggest a correlation between MS patient satisfaction and health care communication. The results of the study showed several variables for future investigation that will better explain this correlation: patient interactions with health care teams, and other benefits provided by interaction on social media and with support groups are two possible variables to be examined. Additional studies with larger numbers of participants will promote the development of a better understanding of the role that health care communication plays in contributing to patient satisfaction and health management.

To contribute to the research body of expanding MS patient access to useful communication from various information sources, the following recommendations for future research include:

- A larger sample needs to be studied to yield findings generalizable to the larger population of MS patients. Given patient privacy concerns, access to a large pre-qualified database of MS patients is necessary. A survey platform such as SurveyMonkey could be used to meet requirements for security, privacy, confidentiality, and anonymity.
- Demographic information, including gender, age at diagnosis, and MS stage, should be collected.
- Surveys could include open-ended items to capture more specific information regarding inaccuracy or incompleteness of information that participants have accessed.
- A focus group of 8-10 participants could be coordinated through the MSA of Michigan to provide for more in-depth exploration of shortcomings in health care communication.
- Medical professionals, including neurologists, should be surveyed to better understand how they perceive their role in patient education and communication regarding MS disease management.

- Other factors which influence MS patient satisfaction with health care communication should be investigated to better understand correlations between access to treatment, access to support groups, and satisfaction of social needs.

The results of this survey provided insights into MS patient satisfaction with health care information available from different sources. Lejbkowitz et al. (2010) suggests that patients experience better health outcomes when they are more involved and actively participatory in choices that affect their illness and well-being. With increasing numbers of Internet users in recent years searching online for health information, it is not surprising that MS patients also seek information from the Internet and social media, as well as from health care professionals. This study showed that MS patients want more accurate and complete information not just from Internet and social media sources, but from health care professionals as well. These results highlight the importance of reliable, high-quality information from all sources if MS patient needs are to be met.

Conclusions

The following conclusions can be drawn from this study:

- Survey respondents overwhelmingly favored being able to obtain MS information from multiple sources, that is, health care professionals as well as the Internet.
- Respondents believe they have received inaccurate or incomplete information from both the Internet and health care professionals.
- The study identified the relative importance of these information sources to MS patients, who expect health care professionals to be their primary source for health-related information.
- MS patients would benefit from physicians and Internet content providers using this survey data to assess whether patient needs for accurate and reliable health information are being met.

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Appendix A: Survey Questions

(1) How significant to you is communication with health care professionals regarding MS?

1. Significant
2. Somewhat significant
3. Neither significant nor insignificant
4. Somewhat insignificant
5. Insignificant

(2) How significant to you is obtaining information on MS from social media and the Internet?

1. Significant
2. Somewhat significant
3. Neither significant nor insignificant
4. Somewhat insignificant
5. Insignificant

(3) How likely do you believe it is to get misinformation or insufficient information on MS from health care professionals?

1. Unlikely
2. Somewhat unlikely
3. Neither likely nor unlikely
4. Somewhat likely
5. Likely

(4) How likely do you believe it is to get misinformation or insufficient information on MS from social media and the Internet?

1. Unlikely
2. Somewhat unlikely
3. Neither likely nor unlikely
4. Somewhat likely
5. Likely

(5) Do you believe you have received misinformation or insufficient information on MS from health care professionals?

1. Yes
2. No

(6) Do you believe you have received misinformation or insufficient information on MS from social media and the Internet?

1. Yes
2. No

(7) How satisfied are you with MS treatment and access to health-related information from health care professionals?

1. Satisfied
2. Somewhat satisfied
3. Neither satisfied nor dissatisfied
4. Somewhat dissatisfied
5. Dissatisfied

(8) How satisfied are you with MS treatment and access to health-related information from social media and the Internet?

1. Satisfied
2. Somewhat satisfied
3. Neither satisfied nor dissatisfied
4. Somewhat dissatisfied
5. Dissatisfied

Appendix B: Human Subjects Approval Letter

EASTERN MICHIGAN UNIVERSITY

University Human Subjects Review Committee

200 Boone Hall • Ypsilanti, Michigan 48197 • Phone: 734.487.3090 • E-mail: human.subjects@emich.edu
www.emich.edu/ord (see Research Compliance)

DATE: January 12, 2015

TO: Mariem Alrubaie, MS
FROM: University Human Subjects Review Committee

PROJECT TITLE: [686787-1] Effectiveness of communications and misunderstandings of health care to Multiple Sclerosis patients and its impacts

UHSRC #: 686787-1

ACTION: ACKNOWLEDGED

Thank you for submitting your application and supporting materials for this project. The UHSRC has ACKNOWLEDGED your submission.

The following items are acknowledged in this submission:

- Application Form - UHSRC_application_2014.docx (UPDATED: 01/12/2015)
- Other - Study Checklist (UPDATED: 01/12/2015)
- Proposal - Mariem Alrubaie Research Proposal.docx (UPDATED: 11/21/2014)
- Questionnaire/Survey - Comparison of Patient Perceptions of Communications Questionnaire.docx (UPDATED: 01/12/2015)
- Questionnaire/Survey - Survey informed Consent.docx (UPDATED: 11/21/2014)
- Training/Certification - 3citiCompletionReport4439759.pdf (UPDATED: 11/21/2014)
- Training/Certification - 2citiCompletionReport4439759.pdf (UPDATED: 11/21/2014)
- Training/Certification - 1citiCompletionReport4439759.pdf (UPDATED: 11/21/2014)

If you have any questions, please contact the UHSRC at human.subjects@emich.edu or 734-487-3090. Please include your project title and UHSRC number in all correspondence with this committee.