

Thematic Analysis of Migraine Stakeholders Using Online Artifacts

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Abstract

What are stakeholder perspectives in migraine? How do stakeholders like clients/patients, caregivers, and providers communicate about their views and goals? The foregoing questions are part of an approach to management of chronic conditions called Health Co-Inquiry. This method promotes person-centered care, stakeholder activation, evidence-based practice, and integrated care. A primary objective is to improve outcomes through mutual respect and cooperation. How can we discover the views of stakeholders? I used a unique, bifurcated method to assess them. Online posts served as a source of data, collected via a WebCrawler. In cooperation with my supervisor, I evaluated themes at websites related to migraine. In addition, I used word frequency data from the WebCrawler. Prevailing themes were providing information, giving support, looking to peers and providers for assistance, and advertising products/services/clinical trials.

Introduction

Migraine is identified as a disabling condition among adults, and chronic migraine is among the top 20 disabling conditions, globally according to the World Health Organization (2001, 2004). There has been much research about migraine triggers, potential causes, and treatments. However, there are less data about the experiences of migraineurs. There is even less research on Health Co-Inquiry in migraine i.e., stakeholder collaborations between persons with migraine, caregivers, and health providers. This study was designed to help identify some of the key narratives across stakeholder roles in chronic migraine. Using a bifurcated method, I conducted thematic inductive analyses of publicly available, online stakeholder narratives about migraine. In addition, I compared those results to data from a WebCrawler that is designed to count word frequency data at the same websites and create word clouds (pictorial representations of the relative frequencies of keywords). Overall, the experiences of stakeholders in migraine share some traits, although themes related to "seeking information" and "suffering" seem more prevalent in patient/client and caregiver posts.

The Health Co-Inquiry approach identifies the perspectives of those involved with migraines. Gaps in stakeholder communication are detrimental to a migraineur's plan of care and goals. Such loop holes in person-centered care require attention and further research. Chronic diseases are consistently disabling conditions that demand the teamwork of all stakeholders. Previous research indicated that billions of dollars and millions of days of productivity were lost through chronic migraine (Smith, 2001). Teamwork is needed so that each member communicates with another e.g., physicians talking to care givers, caregivers talking to migraineurs, and physicians talking with other medical professionals. Regardless of fault, research indicates that less than enough education on migraines is given in medical schools which may cause inaccurate physician-client communication (Minen, Loder, Tishler, & Silbersweig, 2015). Progress has been made over 14 years. However, Smith (2001) recognized a lack of physician and patient education, and just three years ago the same statement was made by Minen et al. (2015). Recognition of subjective themes across migraineurs, caregivers, and health providers can reveal faulty processes in the management of migraines. Honest and thorough stakeholder communication promotes cooperation, and can enhance current or future approaches to migraine from each perspective involved. Seifert and Seifert (2017) termed such approaches as "Health Co-Inquiry" which involves evidence-based practice, patient-centered care, and patient activation. Essentially, the approach towards migraineurs should be specific to the individual (understanding their unique context and needs). Care centered on the client also means the activation of the migraineur, his or her caregivers, health service providers, peers, and all those potentially involved. Proper chronic health care management requires staying up to date on the status of the client, advancements in medical knowledge, and clear constant communication with the other stakeholders. Using the bifurcated method, thematic analysis was conducted to find common personal narratives across websites. Research was conducted to identify congruencies between stakeholder perspectives using online resources.

Methods

The current study utilizes a web crawler with a bifurcated method to analyze quantitative and qualitative data. Information is gathered from public forums online. See Figure 1. The WebCrawler searched URLs that were gathered from four big name search engines: Google, Bing, Yahoo, and Ask. Qualitatively, the content of the URLs was analyzed, and common themes were identified across provider, client or patient, and caregiver postings (Hatch, 2002). The WebCrawler yielded quantitative data (i.e., frequencies of keywords for which it was directed to search). It also produced qualitative data (pictorial word clouds to indicate relationships between words). Thematic analyses and WebCrawler results were then compared. The research protocol was reviewed and approved by the Malone University Institutional Review Board.

Figure 1. Bifurcated Method Model

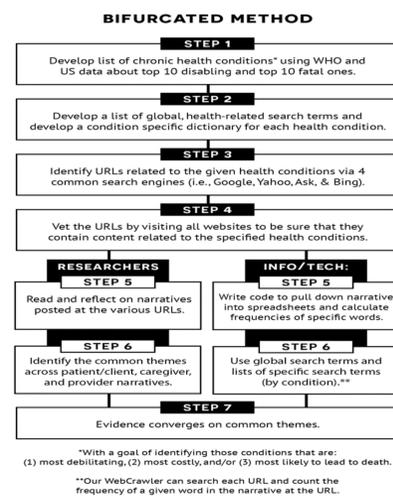
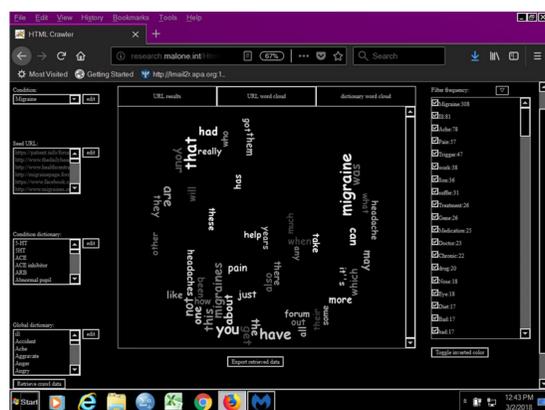


Figure 2. Word Frequency Word Cloud



Results

I conducted this research project using the Co-Health Inquiry bifurcated method with qualitative and quantitative analyses. Out of a pool of data links, ten were randomly selected. Dr. Seifert and I separately thematically analyzed the sample links. We identified and compared common qualitative themes across stakeholder domains. Key narratives were then cross-examined with the quantitative word frequencies of each URL. General themes across stakeholder domains were seeking help, seeking information (on diagnosis, treatment, and research), distribution of misleading information, and seeking suggestions.

Client/Patient Seeking an app or product	Caregiver/Family Seeking (technical/medical) information	Provider Providing up-to-date information	Organization/Agency Providing up-to-date information	Researcher Providing information about diagnosis	Employer Seeking information about disability accommodations
Posting on specialized forums of peers (like one for equestrians, one for cannabis users), but specifically posting about migraine	Seeking suggestions (interactive medicine...)	Providing up-to-date resources	Providing up-to-date resources	Providing information about treatment	Ergonomics/person-environment interactions
Seeking help and information, specifically from peers, whether on a specialized site or not	Seeking help	Providing information about diagnosis	Providing information about diagnosis	Providing information about clinical trials	
Venting (migraine interrupts, non-rmp without a ub not understand)		Providing information about treatments	Providing information about research	Providing information about research results	
Testimonials (e.g. about things that work and that don't work)		Providing information about selling products			
Disseminating misinformation (perhaps unintentionally)		Disseminating misinformation (perhaps unintentionally)	Hiding "Ah-ha!!" information, perhaps to deceive?	Disseminating information that seems false while obfuscating researcher identities & contact information	

URL
http://www.topix.com/forum/health/migraine
http://migrainetalk.forumotion.co.uk/
http://www.migraine.org.uk/get-advice/
https://www.physicsforums.com/threads/the-four-stages-of-migraine-305792/
https://www.dinet.org/forums/topic/27868-anybody-else-have-an-intractable-migraine/
https://www.chronoforse.com/forum/archive/index.php/t-318339.html
https://ergoweb.com/forums/topic/treatment-of-light-induced-migraine-headaches-in-the-office/
https://forum.grasscity.com/threads/migraines-453628/
https://cassiopea.org/forum/?topic=17971.0
https://exchanges.webmd.com/migraines-and-headaches-exchange

The top 20 word frequencies in the 10 sample websites were cross-analyzed stakeholder domains. The terms of the condition specific dictionary were assigned specific stakeholder involvement. The top 20 word frequencies, and the associated stakeholders were compiled. Then the sum of the sample's top 20 word frequencies were calculated into ratios to the sum of the sample's total word count. Word frequency data is shown in the WebCrawler Word Frequency chart. Research was associated with all 20 terms, client/patient in 19, caregiver/family and provider in 17, employers in 12, and organizations/agencies in 11. Quantitative and qualitative data were compared for discussion.

Word Frequencies from WebCrawler

Word	Frequency within URLs	Percentage of Total Words	Relevant Domains
Migraine	308 : 21,183	1.50%	All
ill	81 : 21,183	0.38%	All
Ache	78 : 21,183	0.37%	All
Pain	57 : 21,183	0.27%	Client/Patient, Caregiver/Family, Provider, Researcher
Trigger	47 : 21,183	0.22%	All
Work	38 : 21,183	0.18%	Employer, Client/Patient, Caregiver/Family, Researcher
Son	36 : 21,183	0.17%	Client/Patient, Caregiver/Family, Employer, Researcher
Suffer	31 : 21,183	0.15%	Client/Patient, Caregiver/Family, Provider, Researcher
Treatment	26 : 21,183	0.12%	All but Employer
Gene	26 : 21,183	0.12%	Provider, Researcher
Medication	25 : 21,183	0.12%	All
Doctor	23 : 21,183	0.11%	All but Agency/Organization and Employer
Chronic	22 : 21,183	0.10%	All
Drug	20 : 21,183	0.09%	All
Nose	18 : 21,183	0.09%	Client/Patient, Provider, Researcher
Eye	18 : 21,183	0.09%	All
Diet	17 : 21,183	0.08%	Client/Patient, Caregiver/Family, Provider, Researcher
Bad	17 : 21,183	0.08%	All
bad	17 : 21,183	0.08%	All
Aura	17 : 21,183	0.08%	Client/Patient, Researcher

Discussion

Most narratives at the URLs we analyzed are from clients/patients. These are the people at the forefront of migraine suffering. There is a common desire to talk about their migraines and testimonies, which makes one think this may be due to the nature of migraine and suffering. They also seek information. Another prominent group of those posting online about migraine is caregivers/family, who seek help, suggestions, and information. Perhaps, looking for medical and technical information online is related to poor communication with and education by providers with whom they interact. This is a question for further investigation. A third key stakeholder group is also present online: Providers. However, their focus appears to be on giving information, selling products, and seeking clients/patients. All in all, researchers and organizations/agencies have an online presence, too.*

*Other important facts in our data: 28 thematic narratives, 6 stakeholder domains, 20 about migraine information, 4 of those 20 seemed to carry some false information.

Limitations

This is the second use of the WebCrawler in the bifurcated method. Thus, there are a few bugs yet to be worked out. For example, "nose", "ill", and "ace" appear to have been counted when they were stand-alone words and when they were found within words. Hopefully, additional programming will alleviate this parsing issue.

References

- Minen, M. T., Loder, E., Tishler, L., & Silbersweig, D. (2016). Migraine diagnosis and treatment: A knowledge and needs assessment among primary care providers. *Cephalalgia*, 36(4), 358-370. doi:10.1177/0333102415593086
- Seifert, L.S., & Seifert, C.A. (2017). Multi-method Health Co-Inquiry: A case illustration for persons with chronic illness, caregivers, providers, and researchers. *Current Psychology*. doi: 10.1007/s12144-017-9676-7
- Smith, T. (2001). Pitfalls in migraine diagnosis and management. *Clinical Cornerstone*, 4(3), 26-70.