

Quality of Medical Advice for Chronic Pain on Social Platforms

Kaitlin Light Costello
Rutgers University
New Brunswick, NJ, USA
k.costello@rutgers.edu

ABSTRACT

Chronic pain is a stigmatized condition, and many patients report that it is difficult to get information from healthcare providers. As a result, some patients go online to exchange health information on social platforms, but the type and quality of this information is unknown. In this mixed-methods study, comments on a chronic pain platform were inductively analyzed and a typology of medical advice was developed. Subsequently, the alignment of this advice with evidence in the medical literature was assessed by systematically searching for relevant systematic reviews or meta-analyses. Five types of advice were present: over-the-counter remedies, prescription drugs, illicit substances, seeing a different healthcare provider, and lifestyle changes. No evidence was available for 33.9% of the advice, but 33% had at least low support in the literature. 7.8% was harmful. Contributions from this study include a general typology of medical advice online, a methodological approach for assessing the quality of such advice, and several recommendations for future research.

KEYWORDS

Health informatics; Information quality; Internet

ASIS&T THESAURUS

Credibility; Medical science; User generated content

BACKGROUND

Chronic pain is experienced by over 50 million people in the United States, and the CDC notes that is one of the most common reasons for visiting the doctor in the country (Dahlhamer, 2018). Unlike acute pain, which acts as a signal, chronic pain has no apparent biological value, and its severity and evolution depend on multiple factors (Institute of Medicine, 2011) although it must persist for at least three months to be classified as chronic (IASP Task Force on Taxonomy, 1994). Chronic pain lowers quality of life and can cause depression, anxiety, job loss, social isolation, and in some cases, suicide (Institute of Medicine, 2011). Because its etiology is often difficult to pinpoint, it has historically been treated as a psychopathological issue (Katz, Rosenbloom, & Fashler, 2015). This is also because pain is inherently subjective, and its severity and impact is often difficult or impossible for people to articulate (IASP Task Force on Taxonomy, 1994). As a result, it can be difficult for patients to obtain treatment (Werner & Malterud, 2003). Stigma and disbelief from doctors are both commonly reported by patients (De Ruddere & Craig, 2016).

Stigma is an information problem (Goffman, 1963), and it is associated with information poverty (Lingel & Boyd, 2013). Information poverty is a theoretical framework wherein marginalized individuals are deprived of helpful sources of information; as a result, they may exhibit self-protective behaviors, such as secrecy, while interacting with information (Chatman, 1996). People with chronic pain are often information impoverished partly because healthcare providers, who work within a system that prioritizes objective indicators of illness, may discount patient narratives or label patients with pain as difficult or untrustworthy due to epistemic privilege (Buchman, Ho, & Goldberg, 2017). The resulting information poverty may lead some with chronic pain to seek out information online (Hasler & Ruthven, 2011). People with stigmatized conditions are more likely to use the Internet for health information, either in lieu of or to supplement information from providers (Berger, Wagner, & Baker, 2005). While surveys of patients in pain clinics indicate that up to 40% of them use the Internet for health information (Corcoran, Haigh, Seabrook, & Schug, 2010), this percentage is likely higher in the overall population of chronic pain patients.

People with chronic pain may use a variety of social platforms to exchange information and support (Newhouse, Atherton, & Ziebland, 2018). Social platforms allow those with chronic pain to connect with one another, exchange health information, and make sense of their illness experience (Merolli, Gray, & Martin-Sanchez, 2014). On Tumblr, for example, these discussions often include the difficulty of communicating about chronic pain with clinicians (Gonzalez-Polledo, 2016).

However, one long-standing concern about patients using the Internet for health information is the quality of that information (Eysenbach, 2005). On websites with no social component, information about chronic pain is generally of low quality (Bailey, LaChapelle, LeFort, Gordon, & Hadjistavropoulos, 2013). Such studies typically assess quality via readability scores, and may combine readability with scales that measure factors like formality of content and the site's design (Zhang, Sun, & Xie, 2015). However, quality is not analogous with readability, and the quality of user-generated health information found on social platforms is often not directly addressed in the literature: "As more people began to contribute health information online, [there is an] urgent need to understand the quality of user-generated content" (Zhang et al., 2015, p. 2082). This article, therefore, addresses the following research questions:

RQ1: What medical advice is given for chronic pain on social platforms?

RQ2: Is this advice aligned with evidence in the medical literature?

METHODS

The data reported on in this article are part of a larger grounded theory study with multiple sources of data, including 3 separate interviews using semi-structured and structured techniques and 1 home visit observation session with seven individual participants, all diagnosed with chronic pain conditions, that took place in 2016-2017. During their interviews, almost all of the participants mentioned multiple online support groups that they visit for information about chronic pain. For theoretical sampling purposes, the 25 most popular posts from the forum mentioned most frequently were inductively analyzed over time in order to iteratively develop a codebook (Saldaña, 2015). These codes were refined and categorized progressively during three rounds of individual coding and peer-debriefing sessions (Lincoln & Guba, 1985). The six resulting codes are mutually exclusive and exhaustive. The codes were then applied to 1,346 comments made in 100 randomly-selected threads posted between 2014 and 2017; a second coder analyzed a subset of 237 of these comments in order to determine intercoder reliability using Cohen's kappa for each category. This article reports only on the comments offering medical advice ($\kappa=.86$), defined in the codebook as *information or advice about specific medications for pain, medical treatments for chronic pain, or alternative methods of treatment for pain*.

Each comment containing medical advice was assessed to determine the pain condition in question and the advice being offered for that condition (condition/advice pairs), in alignment with the PICO format commonly used in evidence-based medicine (Schardt, Adams, Owens, Keitz, & Fontelo, 2007). Comments that offered multiple pieces of advice were labeled with multiple pairs; for example, if a comment recommended the poster try pain relief cream or a TENS unit for back pain, it was labeled with both "Pain relief cream + back pain" and "TENS + back pain." These pairs were identified and inductively sorted into categories to develop a typology of advice by the research team, and disagreements were reconciled via discussion.

The Cochrane Library and MEDLINE (Ovid) databases were searched up to 15 February 2019 for systematic reviews or meta-analyses for each individual condition/advice pair. Only systematic reviews and meta-analysis were included as they represent the gold standard used for evidence-based medical practice (Munn, Stern, Aromataris, Lockwood, & Jordan, 2018). Systematic reviews typically report evidence quality ratings using the GRADE approach, which specifies the level of quality of the evidence and the effect of the treatment. In this study, the extended abstract, summary of findings, and/or plain language summaries were analyzed and the effect of the treatment or intervention in question and the quality of the evidence was recorded using the following scale: No review exists, Insufficient evidence available for

recommendation, Harms outweigh benefits, Unsupported, Low support, Moderate support, and Supported. (Condition/advice pairs labeled as "insufficient evidence available for recommendation" returned relevant systematic reviews, but the reviews found that there was not sufficient literature available to make a recommendation.)

To address both research questions, percentages are reported to facilitate comparison, as in Byström (2002). Assessing the statistical significance of the findings was not appropriate due to the small sample size. Many threads contain multiple comments advising the same treatment; for example, a thread about trigeminal neuralgia, a facial nerve disorder, may contain five comments advising gabapentin, a nerve pain medication. Because repetition is one way that users form credibility assessments on social health platforms (Costello, 2016), redundant entries were counted multiple times when carrying out analyses.

RESULTS

RQ1: What medical advice is given for chronic pain on social platforms?

There are 173 comments containing medical advice, and 218 total instances of advice in the sample. Most comments contain only one piece of advice, but 45 comments present between 2 and 5 pieces of advice, with a mode and median of 2 per comment. There are 113 original condition/advice pairs in the data; 73 (64.6%) of these appear only once, and 40 (35.4%) are repeated. The mode of repeated advice pairs is 2. Two pieces of advice are repeated nine times. Commenters rarely provide links to outside resources as evidence; instead, they discuss their personal experiences with treatments or simply offer advice without giving contextual information. The two most common pieces of advice are to ingest a cannabinoid product ($n=27$) or to apply heat ($n=26$). As it is against the rules of the forum to buy or sell products, no comments offering treatments for sale were present in the dataset.

There are five types of medical advice present; Table 1 reports their proportions.

Advice type	n (%)
OTC remedies	80 (36.7%)
Prescription drugs	63 (28.9%)
Illicit substances	33 (15.1%)
HCPs	21 (9.6%)
Lifestyle	21 (9.6%)

Table 1. Types of advice and their proportions.

Over-the-counter (OTC) remedies, such as using an anti-inflammatory drug; or applying heat or ice, muscle patches, a TENS unit, braces, or pain relief cream.

Prescription drugs or surgical treatments. Often, brand names (e.g., Lyrica, Gabapentin) are mentioned, but sometimes more general prescription treatments like "steroids" or "muscle relaxers" are advised. Surgical

treatments mentioned include decompression surgery and gamma knife procedures.

Illicit substances. Marijuana and cannabinoid derivatives are overwhelmingly represented in this category, although other illicit substances are occasionally mentioned (e.g., kratom).

Seeing another type of healthcare provider, including those who practice “alternative medicine,” such as acupuncture and chiropractic; physical therapists and massage therapists are also present in the data.

Lifestyle changes, including exercise, yoga, diet, meditation, and psychotherapy.

RQ2: Is this advice aligned with evidence in the medical literature?

Table 2 shows the proportion of types of evidential support for given advice. Percentages are reported out of the total instances of advice in the sample (n=218). No systematic reviews or meta analyses were found for about a third of the advice instances (33.9%). Perhaps surprisingly, only 7.8% of the advice was harmful; a great deal more of it showed at least low support (33% total, combining low, moderate, and supported advice).

Evidential support	n (%)
No review exists	74 (33.9%)
Insufficient evidence	35 (16.1%)
Harms outweigh benefits	17 (7.8%)
Unsupported	20 (9.2%)
Low support	20 (9.2%)
Moderate support	30 (13.8%)
Supported	22 (10.1%)

Table 2. Evidential support for advice.

A contingency table (Table 3) showing the distribution of evidential support by evidence type suggests some findings for further exploration. For example, harmful advice given in this sample is either about prescription drugs or illicit substances, and, illicit substances are the only type of advice for which no strong support was found. There was also no unsupported advice regarding illicit substances.

	OTC	Drugs	Illicit	HCP	Life.
No review	15.1%	10.1%	6.4%	—	2.3%
Insufficient	8.7%	1.8%	1.8%	2.8%	1.0%
Harms	—	3.7%	4.1%	—	—
Unsupport.	1.8%	4.1%	—	2.3%	1.0%
Low	3.7%	1.4%	1.8%	2.3%	—
Moderate	4.6%	4.6%	1.0%	.5%	3.2%
Supported	2.8%	3.2%	—	1.8%	2.3%

Table 3. Evidential support according to advice type.

DISCUSSION

This study makes several contributions to our understanding of advice quality in online social platforms for chronic pain. First, we provide a general typology of the type of advice

offered; in future work, this typology could be tested for its transferability to other conditions. Future research could also assess differences in amount of advice types between different medical conditions in order to determine whether, for example, stigmatized conditions are more likely to garner advice about illicit substances when compared with non-stigmatized conditions, or if certain types of conditions have a higher likelihood of having low- or high-quality medical evidence available about them on social platforms.

Sixty-six percent of the advice on this platform has enough corresponding evidence for a systematic review or meta-analysis to exist; of these reviews, half of them have enough evidence for claims about treatment to be made. The level of harmful advice is lower than one might expect, especially given the level of pessimism regarding health misinformation on social platforms in both the popular media (e.g. Warraich, 2018) and the scientific literature (Lau, Gabarron, Fernandez-Luque, & Armayones, 2012). However, statistical analyses were not undertaken on this data due to the small sample size. A larger dataset would allow for more sophisticated statistical analyses to be carried out between and among the identified types of evidence and levels of evidential support, offering more robust conclusions.

This study also makes a methodological contribution by presenting a way to assess the quality of medical evidence on social platforms using measures of quality offered by evidence-based medicine. It may be possible to automate some or all of the techniques used in this study (e.g., identifying condition/advice pairs) in order to assess health information quality on social platforms in real-time. Similar efforts have been used to automatically identify users who are likely to share health misinformation (Ghenai & Mejova, 2018), but identifying the quality of advice itself in real-time has several advantages that are also worth pursuing.

CONCLUSION

In this study, comments on a chronic pain platform were inductively analyzed and a typology of five types of medical advice was developed. Advice quality was assessed by creating condition/advice pairs and searching for relevant systematic reviews. No evidence was available for 33.9% of the advice, and 33% had at least low support in the literature. 7.8% was harmful. Our findings offer a general typology of medical advice, methods for assessing health information quality on social platforms, and recommendations for future research.

ACKNOWLEDGMENTS

Thanks very much to the participants who spent time with me and who provided insight in the initial phase of this study. This research was partly made possible by a Rutgers SC&I Grant for Individual Faculty Research.

REFERENCES

- Bailey, S. J., LaChapelle, D. L., LeFort, S. M., Gordon, A., & Hadjistavropoulos, T. (2013). Evaluation of Chronic Pain-Related Information Available to Consumers on the

- Internet. *Pain Medicine*, 14(6), 855–864.
<https://doi.org/10.1111/pme.12087>
- Berger, M., Wagner, T. H., & Baker, L. C. (2005). Internet use and stigmatized illness. *Social Science & Medicine*, 61(8), 1821–1827.
<https://doi.org/10.1016/j.socscimed.2005.03.025>
- Buchman, D. Z., Ho, A., & Goldberg, D. S. (2017). Investigating Trust, Expertise, and Epistemic Injustice in Chronic Pain. *Journal of Bioethical Inquiry*, 14(1), 31–42. <https://doi.org/10.1007/s11673-016-9761-x>
- Byström, K. (2002). Information and information sources in tasks of varying complexity. *Journal of the American Society for Information Science and Technology*, 53(7), 581–591. <https://doi.org/10.1002/asi.10064>
- Chatman, E. A. (1996). The impoverished life-world of outsiders. *Journal of the American Society for Information Science*, 47(3), 193–206.
[https://doi.org/10.1002/\(SICI\)1097-4571\(199603\)47:3<193::AID-ASI3>3.0.CO;2-T](https://doi.org/10.1002/(SICI)1097-4571(199603)47:3<193::AID-ASI3>3.0.CO;2-T)
- Corcoran, T. B., Haigh, F., Seabrook, A., & Schug, S. A. (2010). A Survey of Patients' Use of the Internet for Chronic Pain-Related Information. *Pain Medicine*, 11(4), 512–517. <https://doi.org/10.1111/j.1526-4637.2010.00817.x>
- Costello, K. L. (2016). Impact of patient-provider communication on online health information behaviors in chronic illness. *Proceedings of the Association for Information Science and Technology*, 53(1), 1–10.
<https://doi.org/10.1002/pra2.2016.14505301060>
- Dahlhamer, J. (2018). Prevalence of Chronic Pain and High-Impact Chronic Pain Among Adults — United States, 2016. *MMWR. Morbidity and Mortality Weekly Report*, 67. <https://doi.org/10.15585/mmwr.mm6736a2>
- De Ruddere, L., & Craig, K. D. (2016). Understanding stigma and chronic pain: a-state-of-the-art review. *Pain*, 157(8), 1607–1610.
<https://doi.org/10.1097/j.pain.0000000000000512>
- Eysenbach, G. (2005). Patient-to-patient communication: Support groups and virtual communities. In D. Lewis, G. Eysenbach, R. Kukafka, P. Z. Stavri, & H. B. Jimison, *Consumer Health Informatics: Informing consumers and improving healthcare*. Retrieved from <http://www.springerlink.com/content/v30740q33p124747>
- Ghenai, A., & Mejova, Y. (2018). Fake Cures: User-centric Modeling of Health Misinformation in Social Media. *Proceedings of the ACM on Human-Computer Interaction*, 2(CSCW), 58.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity* (1st ed.). New York: Simon & Schuster.
- Gonzalez-Polledo, E. (2016). Chronic Media Worlds: Social Media and the Problem of Pain Communication on Tumblr. *Social Media + Society*, 2(1), 2056305116628887.
<https://doi.org/10.1177/2056305116628887>
- Hasler, L., & Ruthven, I. (2011). Escaping information poverty through internet newsgroups. *Fifth International AAAI Conference on Weblogs and Social Media*.
- IASP Task Force on Taxonomy. (1994). *Classification of chronic pain: Descriptions of chronic pain syndromes and definitions of pain terms* (2nd ed.; H. Merskey & N. Bogduk, Eds.). Seattle: International Association for the Study of Pain Press.
- Institute of Medicine. (2011). *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. Retrieved from <http://www.ncbi.nlm.nih.gov/books/NBK91497/>
- Katz, J., Rosenbloom, B. N., & Fashler, S. (2015). Chronic Pain, Psychopathology, and DSM-5 Somatic Symptom Disorder. *Canadian Journal of Psychiatry. Revue Canadienne de Psychiatrie*, 60(4), 160–167.
- Lau, A. Y. S., Gabarron, E., Fernandez-Luque, L., & Armayones, M. (2012). Social Media in Health — What are the Safety Concerns for Health Consumers? *Health Information Management Journal*, 41(2), 30–35.
<https://doi.org/10.1177/183335831204100204>
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry* (1st ed.). Sage Publications, Inc.
- Lingel, J., & Boyd, D. (2013). “Keep it secret, keep it safe”: Information poverty, information norms, and stigma. *Journal of the American Society for Information Science and Technology*, 64(5), 981–991.
- Merolli, M., Gray, K., & Martin-Sanchez, F. (2014). Therapeutic Affordances of Social Media: Emergent Themes From a Global Online Survey of People With Chronic Pain. *Journal of Medical Internet Research*, 16(12). <https://doi.org/10.2196/jmir.3494>
- Munn, Z., Stern, C., Aromataris, E., Lockwood, C., & Jordan, Z. (2018). What kind of systematic review should I conduct? A proposed typology and guidance for systematic reviewers in the medical and health sciences. *BMC Medical Research Methodology*, 18.
<https://doi.org/10.1186/s12874-017-0468-4>
- Newhouse, N., Atherton, H., & Ziebland, S. (2018). Pain and the Internet: Transforming the Experience? In *Painscapes* (pp. 129–155). Springer.
- Saldaña, J. (2015). *The coding manual for qualitative researchers* (3rd edition). Los Angeles, CA: SAGE Publications Ltd.
- Schardt, C., Adams, M. B., Owens, T., Keitz, S., & Fontelo, P. (2007). Utilization of the PICO framework to improve searching PubMed for clinical questions. *BMC Medical Informatics and Decision Making*, 7(1), 16.
<https://doi.org/10.1186/1472-6947-7-16>
- Warraich, H. (2018, December 20). Opinion | Dr. Google Is a Liar. *The New York Times*. Retrieved from <https://www.nytimes.com/2018/12/16/opinion/statin-side-effects-cancer.html>
- Werner, A., & Malterud, K. (2003). It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors. *Social Science & Medicine*, 57(8), 1409–1419.
[https://doi.org/10.1016/S0277-9536\(02\)00520-8](https://doi.org/10.1016/S0277-9536(02)00520-8)
- Zhang, Y., Sun, Y., & Xie, B. (2015). Quality of health information for consumers on the web: A systematic review of indicators, criteria, tools, and evaluation results. *Journal of the Association for Information Science and Technology*, 66(10), 2071–2084.
<https://doi.org/10.1002/asi.23311>