Understanding and Learning from Patient Testimonials in Online Communities

Introduction

In October of 2018, a twitter hashtag #DoctorsAreDickheads began trending after a youtube blogger named Stevie Boebi released a video discussing her years of medical gaslighting and dismissal but eventual diagnosis of Ehlers-Danlos Syndrome. Other social media users that predominantly identified as women, people of color, and people with psychiatric conditions used the hashtag to express their own histories of medical dismissal. The hashtag has been part of a larger discussion of implicit bias and stigma amongst physicians that prevents them from providing adequate medical care to patients with marginalized identities (access Aleshire, Ashford, Fallin-Bennett, & Hatcher, 2018; Ayerbe et al., 2018; Dehon et al., 2017; Fitzgerald & Hurst, 2017). #DoctorsAreDickheads exposes the ways that our cultural rhetorics of normative health have material consequences for those most vulnerable to (cis)sexism, fatphobia, and stigma against mental illness.

On September 24th, 2018, JAMA Pediatrics published an opinion piece by Peter Louis Loper Jr, MD, entitled "The Electronic Health Record and Acquired Physician Autism" (Loper, 2018b). In this editorial, Dr. Loper blames deteriorations of physician-patient interactions on an autistic-like state caused by a prioritization of maintenance of the Electronic Health Record (EHR) over engaging with patients with the attention they deserve. Dr. Eric Topol shared the piece via twitter to over 100k followers. It has since been re-tweeted and recirculated very widely. When challenged for publishing the article via letters to the editor, Loper doubled down, using the full text of the DSM-5 criteria for autism to justify his metaphor (Loper, 2018a). Public perceptions of autism as a problem in general, and as a deficit of empathy and compassion in specific, are at the heart of the pervasive stigma and discrimination Autistic people face on a daily basis. This stigma and pathologization underlies many, if not all, of our experiences with bullying, trauma, abuse, and our risk for falling victim to filicide (Botha & Frost, 2018; Cassidy, Bradley, Shaw, & Baron-Cohen, 2018). This case reveals that the stereotype is also widespread in the medical field during the treatment of patients.

Autistic patients are exactly those which are so often vulnerable to patient-physician miscommunication. Many Autistic people are both autistic and have one or more chronic condition to manage (Davignon, Qian, Massolo, & Croen, 2018). In fact, due to disproportionate unemployment (Shattuck et al., 2012), histories of trauma, and experiences of invalidation by medical staff, many Autistic people struggle to even access adequate healthcare (Zerbo et al., 2018).

This paper will be a qualitative analysis of patient testimonials under the #DoctorsAreDickheads hashing, exploring what it reveals about inadequacies in the current paradigm of medical service

provision for people of color, women-identifying and patients with psychiatric conditions. Social media is revealed to be a powerful way of getting this message across, which is why the testimony that is provided on different social media will form the base of the analysis. One article used a sample of 491 tweets using the hashtag "doctorsaredickheads" showing the power of social media as a platform for public expression, as well as underlined the power dynamic that exists between patients and physicians. Additionally, it highlighted intersectionality as leading to further problems in the healthcare industry. (Access Sharma, A. E., Mann, Z., Cherian, R., Del Rosario, J. B., Yang, J., & Sarkar, U., 2020).

The narratives of mental health stigma present in the experiences of patients and the attitudes toward them exhibited by physicians on social media, as well as qualitative data on physician attitudes toward the patients will be used in this study. It will conclude with recommendations for physician-patient collective steps towards countering this issue. By forming authentic connections to patients, physicians can liberate themselves from the domination of implicit bias and transform their care ethic to the benefit of all.

Methods

Social media including Twitter, Reddit, and other public discussion forums were used to share information about the conditions of medical service provision in the United States. While there are some studies of this public data, no studies have previously been used used to specifically contextualize publicly available discourse using a qualitative analysis of detailed interviews, which will be done for the purposes of this study.

This study will involve 7 data samples. The first sample includes the top 50 publicly available threads on Twitter under the hashtag #DoctorsAreDickheads. The second sample includes the top 50 publicly available threads on Twitter under the hashtag #PatientsAreDickheads. The third sample includes the first 20 publicly available Reddit threads concerning #DoctorsAreDickheads. The fourth sample will include the first 20 publicly available Reddit threads concerning #PatientsAreDickheads. The fifth sample will be a collection of editorials on the #DoctorsAreDickheads Moment. The sixth sample will be a publicly distributed Qualtrics Survey soliciting participation from people who identify as chronically ill and who remember the #DoctorsAreDickheads moment. The seventh sample will be a publicly distributed Qualtrics Survey soliciting participation from people who identify as physicians and who remember the #DoctorsAreDickheads moment.

Samples 1-5 will be analyzed and any direct quotation the researchers wish to use in publication must be consented to by the original poster. The original account owner will be notified of the context and content of their intended quotation and asked for their permission, wherein the risks of direct quotation of publicly available content in research will be outlined. If this consent is

denied or cannot be acquired, the direct quotation cannot be used and the researchers must use a paraphrase or find a different source to quote. This extra post-consenting process is a necessary reform in research ethics with online content.

A specific consent process will be undertaken for direct quotation of public content. This includes the following steps:

1. Original account handle is contacted via direct message in the relevant platform. These platforms use spam filters, and so a user may view our request without us knowing, and may decide whether to respond.

2. If account info also has an associated email address, we will send the request to this address. We will do this because account holders may no longer be active on the platform. We are trying to give everyone equal opportunity to reject consent AND to give it, as some people really do want their testimony's shared.

3. The request message will read as follows: "Hello, I am a researcher at Purdue University. I am working on research relating to the #DoctorsAreDickheads Hashtag on social media. Our team would like to use public content that you wrote as a direct example. If you do not respond, or if you say no, we will respect your privacy and will not include direct quotation of your work in our publications. The quote we would like to use and the context in which it is shared is shown below. If you agree to be quoted, or if you have any questions, please let us know. If you agree, we will give you a form to sign. This form will bind us to sharing your content only in the context we have discussed with you. This form is meant to protect you from our inappropriate use of your words. Thank you for your consideration."

Samples 6 and 7 involve the same study procedures with differing survey and interview questions. The study procedures include the following:

1. Participants are recruited through online flyers shared on social media asking for participation from people who a) remember the #DoctorsAreDickheads moment and b) identify either as a physician or as a chronically ill person

2. Interested participants take a short qualtrics survey in which they confirm they meet the participation criteria, answer some questions about their experiences with the moment, and opt-in to future contact for scheduling an interview. The survey will remain open for 1 month.

3. Up to 10 participants from each sample (total of 20) will be randomly selected from those who opt-in to interview for a 1-hour video interview conducted over zoom. This interview will take place 2 to 4 weeks after the survey has closed.

A maximum number of survey participants identifying as chronically ill will be a cap of 250 participants, and it will be the same for participants identifying as physicians: 250. A maximum of interview participants identifying as chronically ill will be 20 from the original 250, and participants identifying as physicians will be 20 from the original 250.

The study involves no more than minimal risk associated with any private conversation about experiences with giving or receiving medical care. Some participants may find describing their past poor experiences with medical care distressing, and are encouraged to discontinue participation at will, and are recruited on the basis of their willingness to share these experiences. Although the only foreseeable risk is breach of confidentiality, being identified as a participant in a survey about this topic is not more risky than their initial participation in public online discussions.

Understanding the patient and physician discourses around patient physician interactions may help us identify systemic dysfunctions in care that impact both patient experience and physician working conditions. A risk of discomfort is mitigated by 1) freedom to withdrawal and 2) recruitment based on the participants' willingness to discuss negative experiences.

Results

1. Twitter

The analysis of discussions on Twitter revealed the nature of patient-physician interactions as well as their experiences under the hashtags #doctorsaredickheads and #patientsaredickheads. This helped unveil dynamics within this realm. Several tweets of the 50 samples that were taken attempted to elucidate the inherent power that physicians possess within the healthcare system. The power dynamic was illustrated in various tweets, highlighting how it often influences the nature of patient care and communication. People who had been diagnosed with chronic and painful conditions in 10% of the sample top 50 tweets asked the physicians to put themselves in the shoes of the patient, asking them to be them. If physicians were unhappy with the way that their appointments with patients, it was simply a bad day at work. But if patients left unhappy, it could mean the difference between life and death.

Physicians felt attacked by the hashtag #doctorsaredickheads, with some tweeting that calling all doctors dickheads is not a constructive way to raise grievances. A counter-narrative emerged, as posted by physicians, in the form of the hashtag #PatientsAreDickheads, demonstrating a response from individuals who hold positions of power within the medical field. This response firstly further highlights the presence of a power imbalance which a aper argues is a direct result of societal norms (Greco, 2020), as well as reveals underlying issues in physician care. One tweet succinctly pointed out that the issue did not lie with either physicians or patients; it was the fault of the medical model. The model focuses on treating as many patients as possible, which aims to address the growing demands of healthcare, but also raises questions about the quality and personalization of patient care, a vital aspect that emerged prominently from the patient narratives.

A constructive way that three two of the tweets from the sample chose to broach this topic was by asking what doctors could do better to understand their patients and communicate with them better. This effort on the part was met well by patients who were happy that doctors were attempting to understand their perspective.

2. Reddit

Exploring patient narratives on Reddit provided deeper insights into the lived experiences of individuals interacting with the healthcare system. Through the analysis of publicly available Reddit threads, various challenges faced by patients while get diagnoses of their conditions are revealed. Their narratives additionally illuminated the emotional toll of inadequacies in communication, misdiagnoses, and dismissive attitudes exhibited by some healthcare providers. It also provided a platform on which physicians could express their feelings on various subreddits on the #doctorsaredickheads and #patientsaredickheads hashtags.

One physician expressed how complicated medicine and patient care is, including a mixture of societal factors, insurance companies, and more complicated issues with the patients. Another physician shared a feeling of being burned out after following the hashtags. They explained that currently, medical schools are placing a higher emphasis on communication and rapport, as well as ensuring patient participation in their decisions. There is also training with treatment of vulnerable populations, which wasn't the case when they were a student in medical school. This shows a positive trend in the education and training of future physicians, providing hope for the future of patients. Additionally, a subreddit shares the opinion that patients need to be reminded of their right to refuse certain treatments, and what a doctor says is not the final word.

3. Editorials

Our analysis, beyond social media platforms, encompassed editorials that surrounded the #DoctorsAreDickheads movement. One of prominence was an opinion piece written by Dr. Peter Louis Loper Jr. It raised debate about the influence of electronic health records on physician-patient interactions. This editorial, while focusing on the issue of physician attention and engagement, also shed light on the other challenges that exist within the healthcare system, in particular within the context of patient care and empathy.

These editorials help promote dialogue within the medical community about the dynamics of patient-physician interactions, showcasing a growing awareness of the need for improved communication and patient-centered care. The discussion sparked by these editorials further underscores the significance of examining patient narratives and experiences to inform comprehensive changes within the healthcare ecosystem.

4. Survey and Interviews

The results of the study are currently limited, due to pending survey and interview data (Samples 6 and 7). This was a result of time constraints due to the time taken for the IRB to be approved. This portion of the study, involving the voices of chronically ill patients and physicians, which will help create a more comprehensive and integrated view of the challenges faced by patients, and the impact of the hashtags will be carried forward by the team and added to this paper as soon as samples 6 and 7 are collected.

Conclusion

The narratives published on social media are effective instruments for comprehending the complex dynamics of patient-physician interactions within the healthcare system in a society that is becoming more and more connected through digital platforms. This study examined the extensive array of patient testimonies shared on social media using the hashtag #DoctorsAreDickheads, applying light on the difficulties people, especially those with marginalized identities, encounter. An understanding of the intricate interaction of power dynamics, communication problems, and systemic concerns emerged through a thorough research of Twitter tweets, Reddit posts, and professional editorials.

Our Twitter research revealed the power dynamics at play in the healthcare system and the sway doctors have over patient care and communication. Notably, the rise of counter-narratives like #PatientsAreDickheads highlighted the necessity for an extensive revision of healthcare paradigms, placing a strong emphasis on individualized care and meaningful patient-physician interactions.

We were able to delve more deeply into the lived realities of people managing healthcare difficulties by investigating social media posts. Improved patient-physician interactions are urgently needed to be given the emotional toll that poor communication and dismissive attitudes have on patients. Physician viewpoints on Reddit platforms highlighted how healthcare grows more complex, which helped create a more complete awareness of the issues at hand.

Editorials by reputable medical professionals helped shed light on the impact that electronic health records have on interactions between doctors and patients. These editorials sparked a conversation amongst various medical professionals, prizing the value of compassion and patient-centered care (Kaba, 2006).

While these analyses add to our present understanding, the survey and interview data which will be collected are additional sources of information that will provide us a more complete picture of

patient and physician experiences. These samples, 6 and 7, have the potential to increase our comprehension of the difficulties experienced by patients and healthcare professionals, enabling a more inclusive conversation.

The deep value of patient testimonies in online forums as important sources of insight into healthcare issues is highlighted by this study. Additionally, it emphasizes the relevance of empathy, effective communication, and patient-centered care within the healthcare ecosystem by diving into the narratives of disadvantaged individuals and contrasting them with medical perspectives. In addition, the crucial and volatile role of diagnosis is stressed, as it is important to help affirm patients' disabilities (Morrison, 2019). The advocation of the development of genuine connections, the elimination of hidden biases, and the advancement of care ethics are advised, with the ultimate goal of moving toward a healthcare paradigm that empowers everyone and gives everyone a voice. By working together, we hope to create a world in which patient tales, including the use of social media as a manner for them to share their feedback, serve as catalysts for progress (Vogel, 2019) and the actual issue at hand is targeted; the way physicians are taught and required to treat their patients.

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