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Online public reactions to frequency of diagnostic errors in US outpatient care

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Abstract

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Background—Diagnostic errors pose a significant threat to patient safety but little is known about public perceptions of diagnostic errors. A study published in *BMJ Quality & Safety* in 2014 estimated that diagnostic errors affect at least 5% of US adults (or 12 million) per year. We sought to explore online public reactions to media reports on the reported frequency of diagnostic errors in the US adult population.

Methods—We searched the World Wide Web for any news article reporting findings from the study. We then gathered all the online comments made in response to the news articles to evaluate public reaction to the newly reported diagnostic error frequency (n=241). Two coders conducted content analyses of the comments and an experienced qualitative researcher resolved differences.

Results—Overall, there were few comments made regarding the frequency of diagnostic errors. However, in response to the media coverage, 44 commenters shared personal experiences of diagnostic errors. Additionally, commentary centered on diagnosis-related quality of care as affected by two emergent categories: (1) US health care providers (n=79; 63 commenters) and (2) US health care reform-related policies, most commonly the Affordable Care Act (ACA) and insurance/reimbursement issues (n=62; 47 commenters).

Conclusion—The public appears to have substantial concerns about the impact of the ACA and other reform initiatives on the diagnosis-related quality of care. However, policy discussions on diagnostic errors are largely absent from the current national conversation on improving quality and safety. Because outpatient diagnostic errors have emerged as a major safety concern, researchers and policymakers should consider evaluating the effects of policy and practice changes on diagnostic accuracy.

Keywords

diagnostic error burden; public perceptions

Introduction

Errors of diagnosis pose a significant threat to patient safety [1–3]. Most diagnostic error research has been focused on the identification and reduction of errors from the medical perspective [4–9]. There are limited data from patients' perspectives [10]. Consequently, it is unknown how the public perceives and reacts to the issue of diagnostic errors, commonly referred to as misdiagnosis in the media. Perceptions and misperceptions of diagnostic errors can shape public opinion about the nature of the problem of diagnostic errors and can influence policy makers who might be able to address the problem. Traditionally, surveys and interviews have been used to assess this type of data. However, recently, online commentary has been used to assess public perceptions for health issues, such as influenza and vaccines [11–14]. This platform offers commenters an interactive space to anonymously post opinions and participate in discussions [15]. To date, no studies have analyzed online commentary to explore perceptions of diagnostic error.

A 2014 study estimated that diagnostic errors affect 1 in 20 US adults per year; [16] or approximately 12 million adults per year in outpatient settings. Being the first estimate of its kind, this study was widely discussed in the lay press. We used this opportunity to conduct

an exploratory qualitative analysis of online public perceptions of the reported frequency of diagnostic error in the US adult population.

Methods

We searched the World Wide Web and conducted a qualitative analysis of online comments made in response to the media coverage related to the study. The study was considered exempt from Institutional Board Review.

Data set

The study was released on April 17, 2014 in *BMJ Quality & Safety* [16] and garnered national media attention. Search terms included a combination of “Hardeep Singh” (study’s lead author), “12 million diagnostic errors”, and “1 in 20 US adults”. We identified 25 online articles reporting on the error frequency, including an op-ed written by one of the authors [17]. Thirteen websites had public comments available up to August 31, 2014, all of which were included. There were a total of 289 anonymous comments, ranging from 1 to 79 comments per site. Forty-eight comments (16.6%) were excluded due to lack of relevance to the research objective or because they contained derogatory language, involved commenters insulting each other or the author, or involved discussions of unrelated topics (e.g. gun control). The remaining 241 comments were subsequently analyzed.

Table 1 lists online media outlets and the number of comments, conversations and individual commenters included in the study. We did not have access to any demographic information but some commenters identified themselves as physicians or other health care providers (n=31) or patients (n=67); identities of 64 commenters were unclear.

Data analysis

We conducted a qualitative content analysis [15, 30] of the 241 included comments. All commenters and conversations within the discussion boards selected for the study were examined and copied verbatim into Word documents. The coding team (TDG, GG, and VM) familiarized themselves with all data and created an initial code book. All comments were independently coded by two reviewers (GG and VM) in Atlas TI and any newly emergent categories were added to the code book. The data sets were merged, reviewed for disagreements, and resolved by the first author (TDG, an experienced qualitative researcher) by including all appropriate codes or the most accurate code. Codes that conveyed similar meanings or ideas were combined to form new categories. To maintain anonymity, commenter user names were excluded.

Results

Overall, there were few comments made regarding the frequency of diagnostic errors. However, in response to the media coverage, 44 commenters shared 54 personal experiences of diagnostic errors. Additionally, commentary centered on diagnosis-related quality and safety of care in the US as affected by two emergent categories: (1) US health care providers (n=79; 63 commenters) and (2) US health care reform-related policies (n=62; 47

commenters), most commonly the Affordable Care Act (ACA) and insurance/reimbursement issues.

Personal experiences related to diagnostic errors

Forty-four commenters shared personal experiences they had with diagnostic errors including patients who shared their own or their relatives' experiences and health care providers who shared colleagues' experiences. Overwhelmingly, patients and their relatives expressed fear and anger and told stories of symptoms being dismissed by their physicians or healthcare teams. For example, one patient shared the following (paraphrased to maintain anonymity):

I was misdiagnosed. I had continuing chest pain following gallbladder removal. Pain occurred after eating as if I had not had my gallbladder removed. The surgeon referred me to a gastroenterologist doctor after an upper endoscopy did not reveal any problems. The gastroenterologist told me that if I kept this up I would be an addict and I needed to get over it and go back to work! I am a health care professional. My colleague, a physician, finally asked my surgeon to refer me to another gastroenterology specialist after significant weight loss. Finally, I was diagnosed with chronic smoldering pancreatitis. It was not all in my head.

Despite the anger and fear, there were some commenters who sympathized with physicians by acknowledging that doctors are capable of mistakes. For instance, a patient wrote (paraphrased to maintain anonymity),

My mother was misdiagnosed for several weeks. She was diagnosed with things such as the flu and kidney infection. She was sent home despite continuing to becoming increasingly ill. By the time a cardiologist diagnosed endocarditis, IV antibiotics were not able to stop the infection. She died in surgery. I was infuriated that had it been caught sooner, she may have survived. But doctors are human and they're going to miss things sometimes. I just wish I didn't need to lose my mom in order to learn that tough lesson.

Another commenter, whose symptoms were misdiagnosed as an allergy, wrote, "Not blaming the doctor at all, because he had seen those exact symptoms so many times that he was certain it was an allergy. This just happened to be the one time in a hundred when it wasn't".

A few respondents (n=4) were self-identified physicians or other health care providers who shared stories of diagnostic errors. They tended to include reasons for diagnostic errors such as lack of knowledge or failure to perform appropriate histories and physical exams, competing incentives, or the limitations of the practice of medicine.

"Everyone looks retrospectively at these cases with 20/20 hindsight but try living it in the ER. These doctors are working hard under conditions most people would find unbearable. We are always aware that we may be sending someone home to their death because clinical judgment/tests etc. are not perfect".

Perceptions of US health care providers

Commenters expressed strong feelings, both positive and negative, about the quality and safety of care in the US. Specifically, commenters indicated mixed perceptions of the physician's role in care. Positive comments (n=31; 24 commenters, one physician, two health care providers) acknowledged the complicated diagnostic process and tended to focus on the notion that physicians are human and therefore not immune to making mistakes. For example, one commenter wrote

“What I find interesting is that medicine is one of the only professions that people are not allowed to make mistakes in. We are all human. We have all made mistakes in our jobs. But physicians, PAs, NPs, pharmacists, and nurses are never allowed to make an error. The stakes may be higher, but the PRACTICE of medicine is not an easy thing”.

Negative comments (n=48, 39 commenters, three health care providers) tended to express anger and criticize physician knowledge and ethics. As an example, a commenter wrote

“I am convinced that there are way too many doctors with nonexistent diagnostic skills. Three times now I have told patients that they were in heart failure and they needed to go back to their doctors and DEMAND a cardiac workup”.

Another wrote, “DOCTORS are very uninformed... the longer out of school, the more antiquated the knowledge”. As might be expected, many of these commenters expressed anger towards physicians as related to diagnostic errors. For instance, “Only profession that can literally KILL you and still get paid!”

Some commenters indicated that physicians are dismissive of patients' symptoms and questions. One commenter expressed, “Shocker! I'm an RN and Physicians seem to be quick to dismiss and hand out ice cream cones to move on to the next \$\$\$”. Another wrote, “When explaining symptoms to them they make a snap judgment. If you ask a question they get angry”. Finally, some commenters expressed a loss of trust, based on their personal interactions with physicians and the health care system, “Wrong diagnosis and no diagnosis have undermined my trust in the medical profession as a whole. And, I am not alone”.

The role of current US health policy

Overwhelmingly, commenters had negative perceptions of current US health care policy as it relates to diagnostic errors and quality and safety of care (n=62; 47 commenters). Policy concerns were generally focused on the impact of the Affordable Care Act (ACA). Many commenters issued warnings that the ACA will only exacerbate error rates; however, few indicated how this might occur. Examples include: “If you think this is bad, then just wait until the Obamacare environment settles in. Errors will probably triple or quadruple...”, “Not to worry, Obamacare is on the scene. Take two aspirin and call back your health care provider next year. Good luck, Mr. and Mrs. America”; “Oh pitiful us! If you think it is bad now (which it is not), give it about 2 years with Obamacare. Doctors are retiring in droves...”.

Both patients and health care providers articulated frustration over interactions with insurance companies as an added complication in the diagnostic process. A physician commenter said, “Can’t help but wonder how many important diagnoses-especially cancers-get delayed past the point of effective treatment, thanks to back-and-forth battles and phone tag games with the insurance companies”? A patient commenter also remarked on the problematic relationship between physicians and insurance companies as it relates to the practice of medicine. “It doesn’t help that insurance companies are often the ones dictating how much time a physician can spend with a patient... Most doctors I know would relish more time with their patients, if only reimbursement wasn’t so bad, and reduced nearly every year”.

Despite the generally negative tone, some commenters held expectations that the ACA would positively impact care. “Pay our health care providers the good wages they deserve, but take the obscene profits out of it. The ACA is but a small step in the right direction. We need major changes, and it is not going to happen with our current system”.

Discussion

We analyzed online commentary to media reports on newly reported frequency of diagnostic errors in the US adult population in order to gain insight into public perceptions of diagnostic error. While methods to analyze online news media commentary to explore public perceptions of health issues have only recently emerged [11–14, 31], we found they provided useful insights into patients’ perceptions of diagnostic errors.

We found an absence of alarm at the frequency or potential harm related to diagnostic error. Those that did comment suggested that the rate of error reported was probably a conservative estimate. Indeed, a little over one-fourth of the individual commenters shared personal stories of diagnostic errors either experienced by themselves, family members, or colleagues. This awareness may be an indicator of patients’ increasing willingness to participate in patient safety and engage in diagnostic error improvement activities.

We also found that the public had substantial concerns about the impact of the ACA and other reform initiatives on diagnosis-related quality and safety of care, with many fearing additional decline. Resentment towards the ACA may be due in part to the timing of the release of the diagnostic error frequency study. On April 1, 2014, President Barack Obama announced that 7.1 million consumers enrolled in care through the ACA marketplaces [32]. During this time a number of media reports were simultaneously released criticizing the value of the ACA. Furthermore, on April 10, 2014, Kathleen Sebelius, Health and Human Services Secretary, resigned her position related to issues with the ACA marketplaces, which further triggered national media coverage of the ACA.

Health care reform initiatives as well as evaluations of quality and safety related to these reforms are not specifically focused on diagnosis related issues. Moreover, what long-term effect the ACA will have on improving diagnosis is unknown. Due to the emerging concern related to outpatient diagnostic errors [33], researchers and policymakers should investigate the effects of changes in policy and practice on diagnostic accuracy. Unfortunately, policy

issues around diagnostic errors are understudied and underdeveloped and are largely absent from the current national conversation on improving quality and safety [34].

This study has several limitations. We collected online, publicly available data which does not include demographic details. We do not expect those who comment on media websites to be representative of the US population. The online comments included in this study reflect spontaneous, unsolicited opinions unaffected by researchers or the research process. Despite the lack of generalizability, the opinions contextualized the diagnostic process within current health care reform initiatives, thus showing the need for more policy-related conversations related to diagnosis. Since our study was completed, selected issues related to diagnosis such as reimbursement for cognitive work, have been recently highlighted in the recent Institute of Medicine report on “Improving Diagnosis in Health Care” [8].

In conclusion, we found that some members of the public have substantial concerns about the impact of the ACA and other reform initiatives on the diagnosis-related quality and safety of care. Because outpatient diagnostic errors have emerged as a major safety concern, researchers and policymakers should consider evaluating the effects of policy and practice changes on diagnostic accuracy.

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Table 1

Media websites included in the study.

Online media outlet	Comments (n=241)	Conversations ^a (n=92)	Individual commenters ^b (n=162)
<i>The Wall Street Journal</i> [17]	67	39	35
NBC News [18]	62	22	33
Medscape [19]	36	0	34
Newser.com [20]	24	14	17
CBS News [21]	15	7	9
DailyMail.com [22]	14	9	13
Fox News [23]	7	1	6
Reuters News Agency [24]	6	0	5
RT Network [25]	3	0	3
U.S. News & World Report [26]	2	0	2
<i>Medical News Today</i> [27]	2	0	2
LiveScience.com [28]	2	0	2
<i>Modern Healthcare</i> [29]	1	0	1

^aConversation is defined as an initial comment that other individuals replied to resulting in a conversation between two or more people.

^bDetermined by unique user names.