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Women's obstetric and reproductive health care discourse in online forums: Perceived access and quality pre- and post-Affordable Care Act

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ABSTRACT

This corpus-based study examines women's framing of health issues in online forums (MedHelp.org, AphroditeWomensHealth.com, and Connect.MayoClinic.org) prior to, during, and after implementation of the Affordable Care Act (ACA). Since worldviews affect how women describe health issues, their discourse is both a way to see ideology indexed in the forums, as well as how that discourse has been shaped by policy. Posts were collected December 2016–April 2017 and annotated using the UAM (*Universidad Autónoma de Madrid*) Corpus Tool to examine emergent categories and compare them to three time periods: pre-, during, and post-ACA. Data within posts were coded as to the linguistic moves being made. Three frequent categories of linguistic function in the data were identified: experience-sharing, advice-requesting and offering, and rationale-offering ($N = 1268$). These linguistic moves were sub-divided into further categories (e.g., under advice requesting, a request for diagnosis), and a discourse-analytical perspective provides insight into the values indexed in each. Before ACA, forum participants cited access, fear, and a history of unhelpful medical visits as obstacles to seeking care. After implementation, obstacles cited were prior unhelpful visits, followed by access, and uncertainty regarding care-seeking appropriateness. While ACA implementation reduced lack of insurance as an obstacle to obtaining healthcare, online forums indicate that patients continue to find doctors' visits unhelpful, instead choosing to seek medical advice from the lay public. Patients' distrust of the medical profession persisted following ACA implementation. There is a need for public health initiatives to improve this relationship in order to augment health care outcomes.

1. Introduction

A main goal attributed to the Affordable Care Act (ACA) was to raise American quality of life (Shaw et al., 2014), improving access to preventative services, especially for women (Committee on Preventative Services for Women, Institute of Medicine, 2011). Before its implementation, approximately half of American women lacked access to preventative services (Robertson and Collins, 2011), a vital resource in reducing chronic disease incidence, from which women disproportionately suffer (Stolp and Fox, 2015; Wood et al., 2009) and become disabled (Lambrew, 2001). Women's increased life expectancy and complex reproductive health concerns further escalate their preventative health needs (Codispoti et al., 2008). By eliminating out-of-pocket costs for many preventative care services, the policy aimed to remove obstacles impacting women's health care access (Johnson and Fitzgerald, 2014; Rustgi et al., 2009).

Throughout this reform, mass digital communication has provided an innovative resource (Jones et al., 2015) for individuals to explore personal healthcare attitudes and practices, including issues related to women's preventative services access. Using Discourse Analysis, one can examine how online forums index individuals' perspectives, which may be examined through the lens of varying access to healthcare and coverage. Prior studies analyzing health forums have indicated that Discourse Analysis is able to bring light to the social implications of participants' interaction patterns with the healthcare system and other sectors (Giles and Newbold, 2011; Vayreda and Antaki, 2009). A discourse analytic perspective on women's health issues discussed in online discussion forums can also detect changes in such attitudes and worldviews, especially considering changes that have affected women during a period of healthcare reform.

This corpus study of health forums queries the influence of the ACA in women's perception of the healthcare system, primarily focusing on how individual women frame their health concerns pre- and post-ACA. These forums may provide an alternative source of discussion for those

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with a distrust of the medical establishment (Abrahamson and Rubin, 2012), a niche role that has been demonstrated in other studies of online discussion, specifically in the context of demographic factors such as race (Armstrong et al., 2007).

Forum threads are written in a context of a national conversation on health insurance, with increased care access proposed as a potentially impactful public health measure (Jordan and Duckett, 2014). Before implementation of the ACA, from 2000 to 2006, uninsured American women were significantly less likely to receive sexual and reproductive services (Frost, 2008). Low-income adults, especially in rural areas, increasingly travelled longer distances between 2001 and 2005 to reach emergency services (Shen and Hsia, 2010), while in urban areas, emergency departments experienced overcrowding that was increasingly unsustainable (Trzeciak and Rivers, 2003). These statistics have been attributed to a lack of access to PCPs (primary care physicians) (Morganti et al., 2013).

Despite expectations, the ACA's impact on healthcare access has been mixed. By 2014, a calculated 20 million Americans had gained insurance coverage (Blumenthal and Collins, 2014). While emergency service use decreased in California, Florida, and New York (Hernandez-Boussard et al., 2014), it increased in Illinois (Dresden et al., 2017), with gaps in coverage persisting for low-income adults (Shartzer et al., 2016). While there were reported improvements in coverage, access, affordability, and health outcomes in some demographics, such as minority populations (Sommers et al., 2014), studies indicate that the ACA expansion did not significantly increase utilization of services such as birth control, female sterilization, sexually transmitted infection counseling, and Human Immunodeficiency Virus screening (Arora and Desai, 2016) as well as cervical cancer screening (Akinlotan et al., 2017), and adults with insurance and providers have not been altering health behaviors despite the potential for increased access to advice (Hughes et al., 2019).

In this study, we evaluate the ACA climate in relation to women framing their health care experiences. Since worldviews affect the ways in which women talk about their health issues, their discourse reveals personal ideologies and how policy shapes them (Fischer, 2003). Therefore, we identified three guiding questions of the study: 1. What are the social functions of the online health forums? 2. What is the social impact of women's posts? 3. How have women changed their discourse surrounding their health on online health forums in light of ACA passage?

2. Methods

2.1. Design

Data were collected from women's health forums to form a corpus. Each post was coded as belonging to one of three ACA-related time periods, and the text within each post was tagged using theories and methods of Discourse Analysis including narrative analysis, speech acts, and conversational implicature. Three emergent categories of linguistic function were identified, and further sub-categorized by content. The resulting categorization was counted, normed, and compared to the ACA climate to determine what kinds of changes, if any, occurred in post function and topic throughout healthcare reform.

2.2. Discussion forum posts

In order to obtain forum posts relating to women's health, obstetrics, and gynecology, including highly visible women's health issues such as breast cancer and contraception, we conducted a web search for answers to common reproductive and sexual health questions (i.e., *I have pain during sex*; *I'm bleeding but had a hysterectomy*) and looked at which discussion board forums frequently appeared in search results. We chose three websites from the results that had boards specific to women's sexual, reproductive, and maternal health, and which had clear date stamps, for which most questions had responses, and in which the majority of questions and responses were posted by individuals citing a United States (US) context.

The three health related websites from which we drew online posts amounted to 252,477 posts, with MedHelp.org providing a potential of 191,767 posts, AphroditeWomensHealth.com 59,867, and Connect.MayoClinic.org 843. Personally-identifying information was not collected. This list was placed in a spreadsheet to randomly select a smaller, representative, sample that was analyzed for content applicability by visually scanning for language relevant to women's health (e.g., *abnormal*, *pain*, *discharge*, *urination*, *uterus*, *hysterectomy*, *breast cancer*, *birth*, *partum*, *bleeding*) versus content that was irrelevant (e.g., *traffic and parking*, *knee surgery*). We then used the post dates to code for healthcare climate: pre-ACA (2010 and before), ACA implementation (2011–2013), and post-ACA (2014 and after). The resulting corpus included 611 posts written between May 2005 and September 2016. This resulted in 229 pre-ACA, 171 during implementation, and 211 post-ACA posts. From these 611 posts, 1337 discourse types (from the classifications of experience, advice, and rationale) were identified. For the scope of the subsequent discourse analysis, we focus on experience-sharing, advice giving/requesting, and rationale-giving as these categories made up 1238 of 1337 discourse units.

2.3. Coding of text

Text coding has previously been used in discourse analysis of health forums (Morrow, 2006), and this corpus was annotated using the text analysis *UAM* (*Universidad Autónoma de Madrid*) *Corpus Tool* (O'Donnell, n.d.) to categorize each post for healthcare climate, and at the level of individual sections of text for the functional categories. The three emergent categories were: 1. Experience, in which the poster shares stories about experiences, 2. Advice, in which a poster requests or offers advice, and 3. Rationale, in which the poster asks for or explains the rationale of an action. Some posts contained only one category, while in others, the poster performed all three functions (see Supplementary File 1 for an example): narrating her experience, providing a rationale, and asking for advice. In such posts, each function was annotated as a separate unit.

2.4. Discourse analysis

Narrative analysis (Labov and Waletzsky, 1967; Ochs and Capps, 2001) was used to analyze the values and attitudes of stories about experiences. To identify such narratives, we looked for elements such as background, event sequence, and purpose. Temporal juncture, usually inferred by clause order, serves as the cohesive device that joins one narrative clause to the next (i.e., *discussed my pain bleeding*; *presented my rash*). An orienting statement introduces central characters and provides situational background such as time and place. A coda, or statement that returns the reader to the present, frequently closes these narratives. Finally, evaluative statements about the topics can appear throughout, answering the question, "why should we care?" This *tellability* usually derives from narratives that are unusual or remarkable, such as experiences in which symptoms and/or illnesses are understandably significant to the poster. This also occurs in narratives that portray the poster as overcoming significant challenges, such as when doctors fail their patients in some way. Figs. 2–4 in the Supplemental File show examples of experience subtypes that were analyzed using Narrative Analysis techniques.

To analyze advice discourse in the data, linguistic speech act theory (Austin, 1962) was used to draw attention to conventional performative language. To that end, we identified written acts of advice-giving or -requesting by scanning for common request structures, such as interrogatives (i.e., *Any advice*?). Requests can also be indirectly couched in a declarative statement (i.e., *Any suggestions … would be greatly appreciated*), so looking for locution (sense and reference), illocution (social action), and perlocution (effect) allowed for identification. Furthermore, giving and requesting advice may involve a suggestive verb such as *recommend*, *advise*, and *suggest* or can be structured using the conditional *I would* and modals such as *might*, *could* or *may*. The connection between linguistic structures like these and the illocution, or social action, or a request or offer, reveals the values and stances indexed by such structures. Of interest is the frequency of advice exchange as well as the advice types provided. Figs. 5–6 of the Supplemental File show examples of advice-giving and -requesting from the data.

The post's rationale was analyzed using Grice's theory of conversational implicature (Grice, 1989), which provides a systematic method for determining suggested, but not explicitly stated, entailments in the text of dialogue. In many posts, the unspoken conclusion is the social expectation that women should consult healthcare professionals regarding health concerns and not ask for online lay opinions. In each post, linguistic evidence was identified to determine if the poster was aware of the contextual social expectation of consulting medical professionals. Such entailments consisted of the rationale against seeking a professional opinion (i.e., *never mind a referral*, *I don't want to rush to the doctor just yet*). Each entailment was tagged as rationale, counted for frequency, and examined for type. Fig. 7 of the Supplemental File shows examples of a common subtype of *Rationale*, “reluctance to see a provider”.

Following post classification into the three functions of experience, advice, and rationale, there were further sub-categories within each group. For example, experience-sharing could be sub-divided into medical event stories, symptom sharing stories, and insurance situations. Types of advice included recommendations to see a PCP, specialist, free clinic, pharmacist, or to self-treat. In the rationale category, posters cited the particular reasons they chose to post on forums rather than seek advice from their doctors. Units for each subcategory were tagged, counted and examined in relation to the ACA context in an effort to identify correlations between ACA climate and discursive function. We present the results in two parts below; first, the data obtained from categorizing and quantifying using the UAM Corpus Tool, and second, the discourse analysis completed on these categories.

3. Results

3.1. Results of coding

The most common linguistic functions in the health forums were experience-sharing and advice exchange. In addition, underlying much storytelling or advice exchange was the unspoken entailment regarding use of online health forums in place of discussion with providers. The relative numbers of these categories as well as the subsequent sub-categorization is presented in Table 1.

Within the *Experience* category are three sub-types: medical event sharing, symptom sharing, and the less frequent story of insurance issues. These sub-types did not change as the ACA was implemented, though insurance stories disappeared from these forums. In 90% of medical event narratives ($N = 647$), the *tellability* of the discourse centered on the onset, symptoms, diagnosis, and treatment of a health issue without overtly evaluative language toward care. However, the other 10% contained evaluative features that revealed dissatisfaction with healthcare, features of narratives that have been found in previous research (Gordon, 2015; Hamilton, 1998). Individuals reported that “doctors didn't listen to them” (20), they received non-useful information (11), an incorrect diagnosis (9), not enough information (8), or that too little time was dedicated to the consult (2).

The second most common discursive function was advice exchange (see Table 1 above). Despite the barriers to access that existed prior to the ACA, posters' advice to seek medical attention did not appreciably change after implementation. Additionally, there was only a slight decrease in the number of posters asking for advice after the implementation of the ACA, and the rate of unofficial diagnoses provided on forums did not change. There were 444 unique instances of advice exchange, establishing this as a common forum function. Some requests for advice were specific (i.e. diagnosis, interpretation of test results, sharing personal experience, links or other resources) while others were more general (i.e., *Any suggestions*? or *Should I be concerned*?) and were usually preceded by contextual information that included a narrative.

Table 1

Discursive functions, types, and frequencies of women's posts on MedHelp.org, AphroditeWomensHealth.com, and Connect.MayoClinic.org May 2005–September 2016.

Discursive function ($N = 1337$)	Types and relative frequencies		
Share experience through narrative ($N = 647$ (51%))	Medical event narrative (71%)		
	Symptom sharing (28%)		
	Insurance issues (1%)		
Ask and give advice ($N = 444$ (33%))	Ask advice (51%)	Request for diagnosis (10%)	
		Request for outcome of similar experience (11%)	
		Request for deciding next step (10%)	
		Request for information or resources (5%)	
		Vague or other requests (15%)	
	Give advice (49%)	Suggest to see a professional (24%)	
		Suggest to try or don't try a treatment (6%)	
		Suggest to seek out nonprofessional resources (7%)	
		Offer possible diagnosis (4%)	
		Suggest to talk to someone (4%)	
		Other (4%)	
Offer and request rationale ($N = 177$ (13%))	Offer rationale (95%)	Reluctant to see a professional (53%)	Access (20%)
			Fear (8%)
			Previously unhelpful (14%)
			Unsure if care warranted (5%)
			Other (6%)
		Seeking information prior to or while waiting for appointment (35%)	
		Seeking second or alternate opinion (6%)	
		Other (6%)	
	Request rationale (5%)	No further categorization done	
Other ($N = 69$ (3%))	No further categorization done		

Rationale, which explains the reasoning for presence on the forum rather than consulting a healthcare provider, usually coordinated with sharing of experiences or requesting and giving advice. Posters' reluctance or inability to see a provider during different periods of ACA implementation (see Table 2) changed over time; the three most frequent reasons for being reluctant to see a provider pre-ACA were access, fear, and not believing a visit would be helpful. These same three reasons were also the three most frequent during ACA-implementation, but access issues moved from the first most frequent to the second most frequently cited reason post-implementation. Post-ACA, the most frequently cited reason for reluctance was that the person did not feel a visit with a provider would be helpful. Fear was cited frequently (in second position) pre- and during ACA implementation, but was not in the top three positions after implementation.

The breakdown of access issues that posters cite in their rationale are as follow: prior to ACA implementation, posters cited lack of access, fear, and a prior history of unhelpful visits as obstacles to seeking care. After implementation, the rationales cited were a prior history of unhelpful visits, followed by lack of access, and uncertainty regarding whether their health situation warranted medical care. Post- ACA, lack of access was manifested by insurance issues such as waiting for insurance card or lack of a specific coverage type, rather than a complete lack of access to the healthcare system as was found before ACA.

Table 2

Most frequent 3 reasons for being reluctant to see a provider as expressed on MedHelp.org, AphroditeWomensHealth.com, and Connect.MayoClinic.org May 2005–September 2016.

Before ACA	During implementation	After ACA
Access (insurance issues and distance)	Access (insurance issues and distance)	Already went; not helpful
Fear (of poor care or of a particular diagnosis)	Fear (of poor care or of a particular diagnosis)	Access (waiting for insurance card; coverage)
Already went; not helpful	Already went; not helpful	Not knowing whether the situation warranted a visit

3.2. Results and discussion of discourse analysis

This study's objective was to use Discourse Analysis to evaluate the ways in which women frame their health care experiences on online health forums before, during, and after ACA implementation. The most common discursive function used was sharing medical experiences (53%). This was true before the ACA and after its implementation, revealing the importance of personal narratives in women's understanding of their healthcare experiences. Narratives centered on medical events and served as a method for sharing symptoms and overcoming acute health issues. Similar to this study, the relatively moderate increase in health service utilization despite a larger increase in available healthcare services illustrates a reluctance—separate from insurance barriers—to accessing conventional care.

Examining healthcare encounter narratives provides insight into women's reluctance to seek care. Posters reported negative health care experiences such as incorrect diagnoses and treatments or unsatisfactory consults (i.e., *he literally kept his hand on the doorknob*). Through story-telling, individuals make sense of unusual or confusing circumstances, and share the lessons learned from often uncomfortable experiences. Evaluative clauses reveal a narrator's attitude toward past situations and include expressive words such as *stupid and furious*. Repetition of keys words (i.e. *confused*), ideas (i.e. *nightmare*, *terrified*), and capitalized letters and exclamation points (i.e. *EXCUSE ME*!!) are also commonly employed for emphasis.

Advice data also suggest the reasons for reluctance. A common request was for a diagnosis, a practice that presupposes that non-medical professionals could provide factual information about an individual's medical condition. Since most posters were aware of hesitancy to respond to direct requests for diagnoses, many hedged, making indirect diagnosis requests (i.e. *What could be causing this*?) or asking about experience with the symptoms or illnesses described. In response, some participants listed potential diagnoses, while others recounted their personal stories, referred interlocutors to professionals or other forum participants with similar symptoms or illnesses, or made treatment suggestions (i.e., *Get checked for fibroids*, *From my point of view*, …, *You do need to see your GYN*…).

Posters' discomfort with providing diagnoses highlights the final discursive function: providing rationale. Rationales underlie many posts and stem from an unspoken expectation that medical concerns are best addressed by healthcare practitioners. For example, the poster writing "*I can't talk to my doctor, I have no medical insurance anymore*" is not only providing two factual statements; rather the lack of insurance provides her reason for not speaking to a doctor as she is unable to pay for the consultation. Additionally, in the US, there is an assumption that there is reasonable access to care via family doctors, hospitals, and clinics. As a result, many posters feel they must justify their reason for engaging with non-medical professionals online. Responders often share this assumption and sometimes ask why the poster had not discussed their concerns with a provider. The structure of the rationale is often in the form of a because-clause (*I haven't been … because*…) and even makes reference to the underlying assumptions (*You may be wondering why I haven't been to the doctor*…).

From a public health perspective, this underlying sociocultural rationale provides insight into obstacles in accessing healthcare, real or perceived. In giving rationale, posters discussed lack of access to providers (long wait times, impacted schedule), insurance concerns, and prohibitive costs. Others acknowledged healthcare services utilization, but were seeking forum input while waiting for provider results or access. Still others noted their dissatisfaction with healthcare providers by stating they wanted a second opinion or did not see visiting the healthcare provider as a helpful option (i.e., *never mind a referral*; *i have none*…, *all i could do was go to the emergency room*, *i dont have any insurance*, *i am afraid to use it because they may cancel me*, *i'm also unemployed*, *my health insurance doesn't cover*…). Many also expressed uncertainty as to whether care was warranted. In such cases, these women used the forums as a resource to determine if their concerns warranted seeking professional advice (i.e., *how do you know when you're bleeding to death*?). Presumably, these individuals also weighed the time and financial cost of seeking out a provider before committing to the action.

The final research question considered whether the social function and conversation topics changed in relationship to ACA's implementation and how posters' questions related to the rationale function. While the social rationale for seeking out a layperson's advice and support regarding medical concerns is not affected by healthcare law, reluctance to seek medical care can be impacted by these laws. Government data corroborate the increased healthcare access during implementation. The rate of uninsured individuals dropped by 43%, between 2010 and 2015 (Obama, 2016), while the Commonwealth Fund Biennial Health Insurance Surveys (2001–2016) indicated that the number of insured women nearly doubled and the proportion of women who had difficulty obtaining healthcare dropped by nearly half. Furthermore, there was a 10% decrease in women who delayed or abstained from healthcare due to cost, and insured women were more likely to seek preventative health care services such as Pap tests and mammograms. Newly insured Americans reported being able to see their doctors within an appropriate period of time (Blumenthal et al., 2015). These decreasing barriers to care would likely be associated with a shifting rationale for not seeking healthcare, which was shown in this study. As implementation progressed, the posts indicating a lack of insurance, prohibitive distance, restrictive costs, and long appointment waiting times decreased.

Nevertheless, the narratives, advice, and rationales revealed poor healthcare experiences. This is not surprising as the Internet has opened communication channels for customer service complaints that were not convenient previously, and the quantity of evaluative discourse from forums may accordingly not be representative of overall satisfaction with women's healthcare. However, the content analysis of this dissatisfaction is of great interest to public health. Women's reluctance stemmed from concerns that doctors were unhelpful, provided poor or incomplete care, embarrassed patients, or did not provide enough time to address concerns. In addition, many complained of long periods of inactivity while they were waiting for insurance cards or test results.

This study focuses exclusively on women, a limited, yet vulnerable population targeted by the ACA. Evidence from health reform efforts predating the ACA indicates that it may take several years for researchers to accurately evaluate the success of such reform. Adequate time is also needed to determine the long-term effects of improved access for the newly insured as compared to individuals with a prior insured status. Despite these limitations, by indirectly assessing outcome measures of the ACA via online health forum postings, our research is able to initially gauge the success of the ACA.

4. Conclusion

This study's implications should be considered in the context of public opinion regarding the ACA and the continuing disconnect between healthcare providers and patients (Miaoulis Jr et al., 2009). While health insurance concerns were cited significantly less after implementation of the ACA, dissatisfaction with the provider's information, guidance, and other aspects of care did not improve with the introduction and full implementation of the reform. This discourse analytic study paid special attention to the language used by women in self-reporting healthcare issues, and those at the forefront public health initiatives must pay special attention to women's voices in order to improving their healthcare outcomes. An essential component of healthcare is *care*, and providers must redefine their provision of care to improve patient expectations and outcomes while building communication and empathy.

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Appendix A. Supplementary data

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