Similarity as a credibility cue in online support groups for chronic kidney disease

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ABSTRACT
Patients with lifelong health conditions such as chronic kidney disease (CKD) may search for health information online throughout the course of their illness. On the Internet, patients may encounter patient peers in online support groups (OSGs) focused on their particular chronic illness. We currently know very little about how patients assess the credibility of information posted by other patients in OSGs.

This poster examines this issue, presenting data from a grounded theory study on health information seeking and personal health information disclosure in OSGs for CKD. The poster describes how patients use similarity as a credibility cue. The data demonstrate that information on OSGs is assessed differently than information presented on static websites, extending our notions of how users assess trustworthiness and credibility online. These findings also extend our understanding of how users make these judgments on the Internet by describing the development of criteria assessments over time, relative to the illness experiences of the seeker. This poster also highlights the importance of shared experience when judging trustworthiness in OSGs, a concept that has received little attention in the literature to date.

Keywords
Credibility, health information seeking, online support groups

INTRODUCTION
Patients living with lifelong health conditions often search for information about their health throughout their illness trajectory (Johnson & Case, 2012). Many patients are increasingly turning to the Internet for health information (Fox & Duggan, 2013). Both static and interpersonal resources, including OSGs focused on specific chronic illnesses, are available online. However, research on credibility assessments of online information focuses on static information resources (e.g., Metzger, 2007). We currently know very little about how patients assess the credibility of information found in OSGs or on the broader social web. There is also a dearth of studies that focus on “real users, in real situations, dealing with real issues of relevance” (Saracevic, 2007, p. 2141).

The few studies on credibility assessment on the social web rely on survey data (Morris, Counts, Roseway, Hoff, & Schwarz, 2012) or on public discussions of credibility being held in online forums themselves (Savolainen, 2011), providing a limited picture of how users judge quality and credibility in social websites like OSGs. Discussing these issues with users who participate in online forums, particularly in the context of OSGs for chronic illness, is necessary in order to develop a more complete understanding of the phenomenon.

This poster attempts to address these gaps in the literature by presenting a portion of data collected as part of an ongoing study, “Investigating information seeking and disclosure in online support groups for chronic kidney disease” (University of North Carolina – Chapel Hill IRB #13-1952). CKD was chosen as it is a non-stigmatized, incurable, life-long condition requiring a great deal of treatment decision-making from the patient. Individuals with CKD, therefore, grapple with issues of both health information-seeking and illness disclosure as part of their everyday lives (Ormandy, 2008).

METHODS
The data presented in this poster were gathered as part of a larger grounded theory study examining health information seeking and personal health information disclosure online. In grounded theory, there is no central research question or hypothesis; instead, a process or behavior is explored in detail, and multiple facets of interest emerge and evolve as the research progresses (Glaser & Strauss, 1967). This poster describes one of the many themes identified in this dataset: how participants use similarity as a method of assessing credibility and relevance of information posted in OSGs by other patients.

There are two main sources of data: semi-structured interviews and forum posts made to one of three OSGs for CKD. Ten individuals, all between the ages of 50 and 70, diagnosed with CKD, and using various treatment
modalities (see Table 1 for more detailed participant information), were recruited using public messages posted by the researcher on the three OSGs. 18 total interviews have been conducted to date. Each interview lasted, on average, 97 minutes. The interviews resulted in 29.1 total hours of audio, which were transcribed by the researcher and coded in NVivo 10. At the time of transcription, a pseudonym was randomly assigned to each participant using random-name-generator.info. With permission, posts made to the OSGs by 9 of the 10 participants were harvested using import.io; the researcher harvested all posts from users with less than 250 posts and purposefully sampled posts from participants with more than 250 posts. These were also coded in NVivo 10. At the completion of the second interview, participants were sent a $75 gift card as a token of appreciation for their time.

Data were analyzed qualitatively using grounded theory methods (Charmaz, 2014). The researcher began by coding line-by-line, actively describing the data in the interviews and on the forums; then, the codes were grouped into thematic categories and focused codes were created to describe those categories. As new data were collected, new codes were compared to the focused codes, merging the new analysis with the extant analysis – this is known as the constant comparative method. Memos were also written throughout the analysis process, tracking the development of codes over time. These memos also alerted the researcher to several questions about the process of evaluating other patients as information sources; to fill these gaps, theoretical sampling in the form of adding new questions to the interview guide for some of the later participants was carried out. Data analysis was performed for the codes presented in this poster until theoretical saturation, or the absence of new themes in the data, was reached.

RESULTS AND DISCUSSION
Participants use many different cues to assess the credibility of statements made and information found in OSGs, including the level of detail in posts, their recency, the author’s tone, whether the information had a clear source, the author’s length of membership on the forum, their posting frequency, and similarities between the author and the searcher. This poster focuses on similarity as a cue for credibility. Data on the remaining cues will be presented in future work and is available upon request.

A recurring theme in the data is the notion of finding people “like me” specifically with respect to the CKD experience. It is important to note that there is not necessarily a “typical” illness trajectory for people diagnosed with CKD, although patients generally progress from pre-diagnosis with symptoms to renal replacement therapy (dialysis and/or transplant) to a period of stability that may be followed by a decline that is punctuated by further bouts of stability in a life-long pattern (Jablonski, 2004). Furthermore, not everyone experiences all of these events in their illness, and the rate of CKD progression varies widely. For example, Brent had 10 years to prepare for dialysis, while Steve began dialysis the same day he was diagnosed.

Because CKD treatments are highly individualized – as Gretchen puts it, she tries to intimate a tone of “This applies to me, it might not apply to you” in her posts – information provided by people who share illness similarity is more relevant and seen as more credible to participants. Illness similarity is assessed in four domains: etiology of CKD, current stage of CKD, treatment choice(s), and the rate of progression throughout the illness. Brent describes the phenomenon: “One of the profiles that I naturally gravitate to are those folks that do reveal that they have PKD. Because I’ve got a lot more in common with them than with people with diabetes…. I pay closer attention to those folks and their various postings.” The notion of illness similarity is closely related to Rogers’s (2003) concept of homophily, wherein people tend to communicate with people who are similar to themselves. Similarity may be a way of assessing cognitive authority (Wilson, 1983): if an author has enough

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Current treatment</th>
<th>No. years on OSG</th>
<th>Posting amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joan</td>
<td>Transplant (deceased donor)</td>
<td>6</td>
<td>High (&gt;1000)</td>
</tr>
<tr>
<td>Nina</td>
<td>Transplant (living donor)</td>
<td>2</td>
<td>Low (&lt;100)</td>
</tr>
<tr>
<td>Brent</td>
<td>Home hemodialysis</td>
<td>1</td>
<td>Medium (250-500)</td>
</tr>
<tr>
<td>Amy</td>
<td>Fistula placed for in-center dialysis</td>
<td>N/A</td>
<td>Lurker (0)</td>
</tr>
<tr>
<td>Steve</td>
<td>Fistula placed for in-center dialysis</td>
<td>4.5</td>
<td>High</td>
</tr>
<tr>
<td>Travis</td>
<td>In-center dialysis</td>
<td>2</td>
<td>Low</td>
</tr>
<tr>
<td>Gretchen</td>
<td>Peritoneal dialysis</td>
<td>2</td>
<td>High</td>
</tr>
<tr>
<td>Sherri</td>
<td>Recently diagnosed</td>
<td>&lt;1</td>
<td>N/A</td>
</tr>
<tr>
<td>Candice</td>
<td>Recently diagnosed</td>
<td>&lt;1</td>
<td>Low</td>
</tr>
<tr>
<td>Jacob</td>
<td>In-center dialysis</td>
<td>3</td>
<td>Medium</td>
</tr>
</tbody>
</table>

Table 1: Participant information (listed by date of first interview).
in common with the seeker, the seeker is able to assess whether or not the information they share in common is accurate. This may allow seekers to more readily trust information that is shared by the author that the seeker did not yet know.

In contrast, Amy describes how the absence of illness similarity prevents her from sharing information in the forums: “A lot of the questions? I’ve not been in their situation. So, talking to people on dialysis, I don’t have that experience. I don’t know much more than I’m sorry you’re going through this, kind of stuff. And, too, my journey into kidney disease came from a whole atypical background. Most people are diabetic and have high blood pressure…. I don’t have the same symptoms, and don’t quite understand all the stuff they’re going through. I don’t know how much my two cents would really make a difference.” Sharing similar knowledge has been related to credibility in prior research; for example, Woudstra and van den Hooff (2008) found four quality-related factors in selecting people as information sources, including topic knowledge and perspective – both factors that are related to, but are not the same as, similarity.

Not only do participants seek information from people with shared illness experiences; they also seek information from users who are farther along in their illness trajectory, a process labeled future forecasting by the researcher. Gretchen explains: “That information was very relevant to me. Because I could see other people’s problems, I wasn’t having that problem yet, but I was aware of it and could keep an eye open for it.” Future forecasting is discussed in more detail in an upcoming article.

Many participants described difficulties finding patients with similar experiences in the OSGs, often due to poor search functionalities available on the sites. Travis explains: “I don’t have diabetes. I don’t have lupus. I don’t have PKD.... Weeding through all that? It took a long time.” One way that participants dealt with this problem was to evaluate signature lines. Some users on the forums include signatures that are automatically added to the end of every comment they make; in the two OSGs examined that facilitate this practice, these signatures nearly always include bulleted, dated lists of the most important events in the user’s illness trajectory as defined by the user, which Joan calls their “kidney history” (see Figure 1). By carefully examining available signature lines, participants were sometimes able to quickly identify what to read and what to skip. Amy succinctly describes the process: “As I’m reading, I’ll glance down and think, ‘That’s not worth even trying to read in depth.’” In this way, the signature line is an illness vitae that acts as a credibility badge for users, allowing quick individual assessments of the potential relevance and credibility of the content of specific comments. Signatures therefore function as a heuristic for evaluating credibility in OSGs (Metzger, Flanagin, & Medders, 2010).

Illness vitae also highlight the role that time plays in credibility assessments on social websites: users build up a reputation over time and through experience with the illness, and this reputation impacts whether or not their posts are seen as credible. Furthermore, illness vitae and their use on the forums are related to the concept of opinion leaders, trusted individuals who are influential in specific fields and who demonstrate competence in a given topic or profession (Rogers, 2003). It is also similar to concept of author reputation offered by Savolainen (2011), although the notion of building a reputation over time is not addressed in his work.

Participants also describe looking for patients who share a similar “lifestyle,” either by living in the same geographic area, having similar careers, or sharing hobbies. This is particularly important because as Joan explains, “[Dialysis modality choice] is really a lifestyle choice.” Steve, an avid camper, provides a detailed description of trusting information from another camper while discussing dialysis modality choices: “He went, ‘Yeah, you’re probably making the right decision for you….’ He didn’t have, as they say, a horse in the race, but it was coming from somebody I respected and who I thought I could trust. It’s nice to have a second opinion from somebody who knows what they’re talking about, not an amateur!” He finds this information particularly trustworthy because the person sharing it has similar lifestyle demands of their dialysis modality.

In addition to assessing similarities in illness and lifestyle, participants often mentally noted users who repeated what they knew, or who shared information that was congruent with their own knowledge. For example, Amy searches for information that “goes along with what I know about. I don’t say I know everything, but when I’m reading something, if it’s like, yeah, I can go along with that, I can trust that person.” Steve notes that when he asked a question about a specific experience he had with his nephrologist, “something you would just think would be completely off the wall,” other users shared similar experiences with him – and gave him tips on what to do next. “They said, ‘Oh yeah, that happened to me. Ask this, this, and this. And I would go in and ask those three questions, and those were exactly the questions I needed to ask.” Steve’s ability to verify that his experience was not unique made the rest of the information provided by other users seem more credible and useful to him.

Participants do not necessarily judge all posts by similar users as credible, however. As Travis notes, “I’m kind of still leery, because these are people with kidney problems. They’re not professionals.” Instead, participants draw from

Figure 1: Example illness vitae
a wide variety of sources, selectively applying similarity as a credibility cue when they feel it is relevant for them and their current needs. Nina expounds on this: “When you go to [an OSG], there’s somebody who’s actually gone through this. Now, that doesn’t mean that your experience is going to be the same. But that is someone who went through it... there’s a lot of relevance to my own life there, just reading what people are doing, and what they recommend.” Therefore, it is evident that the information found in OSGs is not, as Amy states, “the Bible for ‘this is what I should be doing.’ I just use it for basis, to examine what’s going on in my life.” While similarity is an important cue for credibility, participants apply it flexibly and selectively as they search for information in OSGs. This matches findings from McKenzie’s (2003) examination of cognitive authority assessments made by expectant mothers of twins, where participants applied flexible and versatile definitions of authority and credibility to different sources and in different contexts.

In fact, many participants saw the information they got on the forums as a jumping-off point for future searches. Participants universally discussed the importance of, in Gretchen’s words, “crosschecking” information they found online, a process Jacob calls “finding multiple points of agreement.” Crosschecking validates the credibility of information found in a particular source or posted by a particular individual in an OSG. Travis explains: “I’m not just going to jump into something just because somebody says, ‘Oh, I tried this and it worked.’ Like I said, before I do that, I’d rather – as Reagan used to say – ‘Trust and verify.’” Crosschecking occurs both online and offline and will be addressed in a future article.

CONCLUSION

The findings presented in this poster demonstrate that similarity is often used as a marker of information credibility in OSGs for CKD. Similarity assessments are greatly aided by the employment of illness vitae, often included as signature lines by many users on the forums. This work contributes to our understanding of how people gauge the credibility of information found on the social web, stressing the intersubjectivity of credibility assessments online and highlighting the role that personal experience plays in these assessments.

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REFERENCES


