

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



THE UNIVERSITY
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at CHAPEL HILL

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background	method	participants																																														
<p>Patients increasingly look for health information online (Johnson & Case, 2012).</p> <p>Credibility of static resources online has been examined (e.g. Metzger, 2007).</p> <p>Limited understanding of credibility and relevance assessments on the social web (Saracevic, 2007; Savolainen, 2011).</p> <p>How do patients with a chronic illness assess the relevance and credibility of health information in online support groups?</p> <p>Findings from a larger grounded theory study, "Investigating information seeking and disclosure in online support groups for chronic kidney disease" (UNC-CH IRB #13-1952)</p> <p>references</p> <p><small>Johnson, J. D., & Case, D. O. (2012). <i>Health Information Seeking</i>. Peter Lang Publishing.</small></p> <p><small>Metzger, M. J. (2007). Making sense of credibility on the Web: Models for evaluating online information and recommendations for future research. <i>Journal of the American Society for Information Science and Technology</i>, 58(13), 2078-2091.</small></p> <p><small>Saracevic, T. (2007). Relevance: A review of the literature and a framework for thinking on the notion in information science. Part III: Behavior and effects of relevance. <i>Journal of the American Society for Information Science and Technology</i>, 58(13), 2126-2144.</small></p> <p><small>Savolainen, R. (2011). Judging the quality and credibility of information in Internet discussion forums. <i>Journal of the American Society for Information Science and Technology</i>, 62(7), 1243-1256.</small></p>	<p>10* participants diagnosed with chronic kidney disease were recruited from 3 online support groups.</p> <p>*to date; theoretical sampling ongoing</p> <p>Two 90-minute interviews with each participant (33.2 hours audio total).</p> <p>Interviews were recorded, transcribed, and pseudonyms were assigned.</p> <p>1,461 threads containing comments from participants were harvested from each group.</p> <p>Data analyzed using grounded theory methods including inductive analysis, open coding, constant comparison, and analytic memoing.</p> <p>Analysis verified with member checking and peer debriefing.</p>	<table border="1"> <thead> <tr> <th>Pseudonym</th> <th>Current treatment</th> <th>No. years on OSG</th> <th>No. posts on OSG</th> </tr> </thead> <tbody> <tr> <td>Joan</td> <td>Transplant (deceased donor)</td> <td>6.5</td> <td>High (>1000)</td> </tr> <tr> <td>Nina</td> <td>Transplant (living donor)</td> <td>2</td> <td>Low (<100)</td> </tr> <tr> <td>Brent</td> <td>Home hemodialysis</td> <td>2</td> <td>Medium (250-500)</td> </tr> <tr> <td>Amy</td> <td>Fistula placed for in-center dialysis</td> <td>2.5</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><1</td> <td>N/A</td> </tr> <tr> <td>Candice</td> <td>Recently diagnosed</td> <td><1</td> <td>Low</td> </tr> <tr> <td>Jacob</td> <td>In-center dialysis</td> <td>3</td> <td>Medium</td> </tr> </tbody> </table>	Pseudonym	Current treatment	No. years on OSG	No. posts on OSG	Joan	Transplant (deceased donor)	6.5	High (>1000)	Nina	Transplant (living donor)	2	Low (<100)	Brent	Home hemodialysis	2	Medium (250-500)	Amy	Fistula placed for in-center dialysis	2.5	Lurker (0)	Steve	Fistula placed for in-center dialysis	4.5	High	Travis	In-center dialysis	2	Low	Gretchen	Peritoneal dialysis	2	High	Sherri	Recently diagnosed	<1	N/A	Candice	Recently diagnosed	<1	Low	Jacob	In-center dialysis	3	Medium		
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assessing similarity

One of the profiles that I naturally gravitate to are those folks that do reveal that they have polycystic kidney disease. 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. (Brent)

- Etiology
- Illness timeline
- Past illness experiences
- Location
- Age
- Lifestyle

I'm looking for people with similar problems – people that can give me information, or I can give them information. (Travis)

illness vitae

- Comment signatures
- User-generated
- Voluntary
- Contextualizes comments
- Quick relevance assessments
- Similarity heuristic

example

April '91	Stage III CKD found
January '94	Fistula, ESRD
June '94	Starting hemo in-center
April 13, 1998	Cadaver transplant
March '08	Transplant rejection
June '09	In-center hemo again
July '10	Relisted for transplant

Their kidney history is usually a signature at the bottom of [their comment].... Sometimes I will glance down and think, "That's not even worth trying to read in depth." (Amy)

future forecasting

- Experiential information from patients
- Similarities shared – but farther along in illness trajectory
- Prolonging initiation of dialysis

The really big question is: What's it going to be like when it comes down to actually doing [dialysis]? Or what is a transplant really like? These people who post – they are living my future. And that's what brings me back to [the OSG].... It's all about real people struggling with real problems. (Nina)

What I am asking the people who have been through this longer than me is what did you learn too late? What did you wish someone had told you? I am looking for any tidbits of knowledge that may help me make decisions in the future. (Steve)

crosschecking

- Verification activities
- Multiple sources
 - Personal experience
 - Other patients
 - Healthcare providers
 - Static web resources (e.g. WebMD, peer-reviewed medical journals, Mayo Clinic, National Kidney Foundation, government sites)

You hear other people's stories, but that's all they are. They're just other people's stories. And in the end you have to make your own decision and you can get a lot of information online and from your own doctor or your own surgeon, but you have to make the final decision. (Joan)