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

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background

Patients increasingly look for health information online (Johnson & Case, 2012). Credibility of static resources online has been examined (e.g. Metzger, 2007).

Limited understanding of credibility and relevance assessments on the social web (Saracevic, 2007; Savolainen, 2011).

How do patients with a chronic illness assess the relevance and credibility of health information in online support groups?

Findings from a larger grounded theory study, "Investigating information seeking and disclosure in online support groups for chronic kidney disease" (UNC-CH IRB 813-1952)

method

10* participants diagnosed with chronic kidney disease were recruited from 3 online support groups.

*to date; theoretical sampling ongoing

Two 90-minute interviews with each participant (33.2 hours audio total).

Interviews were recorded, transcribed, and pseudonyms were assigned.

1,461 threads containing comments from participants were harvested from each group.

Analysis verified with member checking and peer debriefing.

participants

<table>
<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 (&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>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>&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>

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

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 think, “Well, I can look at this and think, ‘This person’s story is maybe worth looking into,’” but it’s not worth trying to read in depth.

Joan

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