Web-Based Health Communities for Self-Help Groups

Åsa Smedberg

Department of Computer and Systems Sciences,
Stockholm University, Sweden
What is a Community and a Web-Based Community?

• A traditional community is a place for people who share the same interests to meet - to cooperate and to satisfy each other’s needs.

• A web-based community uses ICT and the Net to mediate interaction.

• Web-based communities are used in many areas and for different purposes.
Web-Based Health Communities

• The usage of web-based health communities for sharing experiences, information, advice and support has increased.
• For self-help groups with peers having similar conditions and health concerns.
• Empowerment through self-help groups.
• Some examples
Virtual Worlds for Children with Medical Conditions

• The ”Zora virtual world”
• A social network of peers
• A virtual city
  – To ease school transition and medical adherence for post-transplant patients.
• A virtual summer camp
  – For cancer patients and their siblings to stay connected after a physical summer camp.
Support Groups for Survivors of Sexual Violence

• Social support as an important coping strategy.
• Anonymity in online support groups allows a combination of personal information, intimacy and discretion.

• Online Support Behaviors
  – Information support
  – Tangible Assistance
  – Esteem Support
  – Network Support
  – Emotional Support
“The Butler System” for Promoting Wellbeing among Elderly

• “Healthy ageing” and “Active ageing”

• Online e-health platform to promote social networks, communication, entertainment, learning, curiosity and training of positive emotions.

• Different levels of action
  – Assessment Action Level
  – Therapeutic Action Level
  – Playful Action Level
Preventive Health and Web-Based Communities

- Overweight/obesity, smoking, stressful lives, e.g.
- Changing established bad habits can reduce the risk of getting severe illnesses
- How can web-based communities enable people to learn a new behavior?
Learning through Web-Based Communication

- Web-based communication enables continuous social interaction, learning and support.
- To help each other to learn, we need to understand the situations of others and to adjust our support, advice and own stories.
- The use of language in a social context.
- Learning a new behavior includes also questioning the way we act today.
  - Underlying models, values and beliefs
Observations of Web-Based Community Communication

• Stored conversations
• Observed unstructured data
• To understand human activity and social interaction
• To detect problems
• Observations are used formatively or summatively
Categories of Conversations for Learning

- Statements
- Requests on neutral issues - fact queries
- Requests on personal issues:
  - Setbacks
    - Personal experiences of recurrent breakdowns
  - Obstacles
    - Foreseen difficulties to overcome
  - Incentives
    - Motivational factors, induce action or motivate effort
## Ex: Frequency of Issues

<table>
<thead>
<tr>
<th>Type of Issue</th>
<th>Issues on Overweight</th>
<th>Issues on Smoking/alcohol/drugs</th>
<th>Total No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fact query</td>
<td>42</td>
<td>38</td>
<td>80 (40%)</td>
</tr>
<tr>
<td>Incentive</td>
<td>12</td>
<td>10</td>
<td>22 (11%)</td>
</tr>
<tr>
<td>Setback</td>
<td>25</td>
<td>10</td>
<td>35 (18%)</td>
</tr>
<tr>
<td>Obstacle</td>
<td>6</td>
<td>17</td>
<td>23 (11%)</td>
</tr>
<tr>
<td>Statement</td>
<td>15</td>
<td>25</td>
<td>40 (20%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>100</strong></td>
<td><strong>100</strong></td>
<td><strong>200</strong></td>
</tr>
</tbody>
</table>
Web-Based Community Interaction

• We can also learn from the ways the community members interact on issues.
  – With confirmation and empathy, experiences and advice, or with opposing perspectives and questioning of ideas.
<table>
<thead>
<tr>
<th>Online Community</th>
<th>Responses with Opposing Ideas</th>
<th>Responses with Strong Rejections</th>
<th>Responses in Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online community on overweight (the Swedish site)</td>
<td>41</td>
<td>3</td>
<td>200</td>
</tr>
<tr>
<td>Online community on overweight (the UK site)</td>
<td>18</td>
<td>4</td>
<td>102</td>
</tr>
<tr>
<td>Online community on smoking (the Swedish site)</td>
<td>11</td>
<td>0</td>
<td>190</td>
</tr>
<tr>
<td>Online community on smoking, alcohol and drug abuse (the UK site)</td>
<td>26</td>
<td>5</td>
<td>146</td>
</tr>
<tr>
<td>Total</td>
<td>96</td>
<td>12</td>
<td>638</td>
</tr>
</tbody>
</table>
E-Health to Empower Patients and Citizens

- Exchange of health information, as well as learning and support through interaction
- Citizens and patients offering complementary knowledge and experiences
- Empowering people
- New roles for the healthcare and healthcare providers
Holistic Approach to E-Health

• Towards integrating different actors, knowledge, conversations and support to a working whole

• Flexible and dynamic web-based systems for both patients/citizens and health professionals
References


