Co-creation of an online portal for dialysis patients with low eHealth literacy: effect on adoption

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Governments and health care organizations present eHealth as solution for cost reduction and self-management support. The needs, barriers and impact for patients with low eHealth literacy need more attention.

Aims

Explore perspectives of low eHealth literate dialysis patients and their supporting professionals on eHealth
Evaluate the impact of co-designed eHealth prototypes on adoption and usability

Methodology

Explore perspectives of patients and professionals
- eHeals questionnaire to determine literacy level
- Focus group discussions and in-depth interviews among patients with low eHealth literacy (N=7)
- Interviews and brainstorm with professionals (N=6)
- Transcription and analysis with Atlas.ti

Evaluate the impact of co-designed prototypes
- 5-item screener on eHealth literacy and adoption
- Test group with low literacy (N=18)
- Control group with adequate literacy (N=20)
- Usability recordings and thinking-out-loud during tests with three prototypes
- Adoption questionnaire (14 items) after use
- After each test results were used to re-design upcoming prototypes

Participants

Participants with low eHealth literacy more often were low educated. Other characteristics are:

<table>
<thead>
<tr>
<th></th>
<th>Interviews (N=7)</th>
<th>Test group prototype (N=18)</th>
<th>Control group prototype (N=22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (% men)</td>
<td>57,1</td>
<td>38,9</td>
<td>70</td>
</tr>
<tr>
<td>Mean age</td>
<td>70,4</td>
<td>65</td>
<td>49,8</td>
</tr>
<tr>
<td>Mean score on eHeals</td>
<td>18/40</td>
<td>n.a.</td>
<td>n.a.</td>
</tr>
<tr>
<td>Mean score 5-item...</td>
<td>n.a.</td>
<td>21/35</td>
<td>29/35</td>
</tr>
</tbody>
</table>

Results

Barriers for eHealth use are Internet skills and trust. Patients mention they don’t want to ‘take the disease home’. Professionals acknowledge specific needs for patients with low literacy.

1. I fear eHealth will replace the personal contact with my doctor and believe it is better to discuss my health in the hospital.
2. I only use technology if it is absolutely necessary and mostly with help of my social network.
3. Online insight in lab results and medication might be useful, but I lack skills and knowledge to use an eHealth patient portal.
4. eHealth can support self-management. But I believe professionals should guide patients with low literacy. I think patients might see benefits if they could practice with a prototype.

- Co-creation helps to meet the needs of low literate patients and narrows the differences between the test and control group
- After use several patients from the test group were not sure they would use eHealth in the future
- Essential navigation (browsing) was problematic in the test group
- ±50% refused participation. Main reason: low computer use

Discussion and conclusions

- We should temper our expectations of eHealth, since low eHealth literate patients might benefit marginally
- Developers should make time for co-creation of eHealth with the users, since it seems effective to improve usability and content
- Further research is needed to clarify the relation between literacy, eHealth use and health outcomes and to develop and test co-created interventions for patients with low eHealth literacy in different health care settings.