“It’s like having a friend in your pocket”: Refining CBT-informed digital support for people with autoimmune conditions

Background

Mood disorders are common among patients with autoimmune conditions such as Rheumatoid Arthritis and Crohn’s Disease. Low mood in this population is associated with poor medication adherence and limitations to physical, social, and role functioning. (Cognitive Behavioural Therapy (CBT) has been shown to reduce depressive symptoms, but is costly and time consuming to roll out. Using electronic delivery of CBT (eCBT) for sub-clinical low mood may be an effective way to promote adaptive coping for physical and emotional aspects of autoimmune disease management.

The principles of CBT are well established (e.g. cognitive restructuring, behavioural activation), but they must be delivered in a way that tackles the issues faced by autoimmune patients. Further, they must feel relevant to the user to maintain engagement.

Aims

A Health Psychology Specialist-led Multidisciplinary Team (MDT) at Atlantis Healthcare set out to co-create a series of modules with patients, based on the principles of CBT. Specifically to:

- Assess whether the modules are perceived to be acceptable, usable, motivating, informative and effective
- Assess whether the aims of the modules are understood
- Assess if the modules are perceived to provide autonomy, confidence and to be relatable.
- Create recommendations that can be used to adapt both current and future modules

Sample & Methods

Sample

Initial module prototypes were created as mobile-responsive web modules. Prototypes were then tested in one to one Skype interviews with 9 autoimmune patients in the UK and 6 in Germany. A combination of observation by screen-share, survey questions, and in-depth discussion were used to elicit patient feedback.

Modules

Modules were created in Articulate, an online service designed for creating e-Learning modules. Four modules were selected for the initial piloting process, based on topics selected for importance to autoimmune conditions, identified by the literature. Working titles for modules were:

- Identifying Unhelpful Thoughts
- Challenging Unhelpful Thoughts
- Relaxation and Mindfulness
- Social & Communication

Procedure

Interviews were conducted by a Health Psychology Specialist. Interviews were conducted via Skype with screen share. Patients completed one module while the facilitator followed by a 5-question, 5-point Likert scale survey to assess immediate attitudes. This was followed by a semi-structured discussion. The process was repeated for a second module.

In the UK, feedback was then discussed by the design team, changes agreed, and then implemented prior to a second round of testing.

Take home messages:

- Academia/researchers: Ensuring online digital interventions are appropriately tailored to the needs of a target population is vital. There is great value in taking the time to validate and ensure applicability of techniques for people with the target long-term condition(s), even when based on commonly used techniques such as cognitive restructuring or relaxed breathing

- Industry/practitioners: Brief, CBT informed psychosocial support for people with autoimmune conditions was very positively received by patients, and the web was identified as an appropriate method of delivering support

Results

Q1. The module was easy to navigate
Q2. The language was tricky to understand
Q3. It was difficult to understand what was expected of me
Q4. As part of a broader support programme, this module would help me live with my condition
Q5. As part of a broader support programme, I would use something like this in my day to day life

Table 1: Summary scores for each question, by module

<table>
<thead>
<tr>
<th>Module</th>
<th>Q1 Easy navigation</th>
<th>Q2 Clear language</th>
<th>Q3 Clear expectations</th>
<th>Q4 Would help live with condition</th>
<th>Q5 Would use in own life</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - Identifying unhelpful thoughts</td>
<td>5</td>
<td>2.3</td>
<td>1.6</td>
<td>4</td>
<td>4.2</td>
</tr>
<tr>
<td>2 - Challenging unhelpful thoughts</td>
<td>5</td>
<td>1.5</td>
<td>1.5</td>
<td>4.5</td>
<td>4.5</td>
</tr>
<tr>
<td>3 - Relaxation &amp; mindfulness</td>
<td>4.75</td>
<td>1.75</td>
<td>2.5</td>
<td>4.25</td>
<td>4.5</td>
</tr>
<tr>
<td>4 - Social &amp; communication</td>
<td>4.4</td>
<td>1.8</td>
<td>1.6</td>
<td>4.2</td>
<td>4.2</td>
</tr>
</tbody>
</table>

Scale range = 1 to 5

*These questions were phrased negatively to avoid inattentive-style response bias – so lower scores are better for these questions

Qualitative findings were broken in 4 categories:

<table>
<thead>
<tr>
<th>Category</th>
<th>Example comment</th>
<th>Example remedying strategy</th>
<th>Feedback on new module (round 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improving relevance</td>
<td>“So sometimes booking up to see a friend and making it very, very structured and then you’re ill, you have a flare-up, it’s very difficult.”</td>
<td>Text added around setting realistic expectations with friends, and to show self-compasation when goals are not met.</td>
<td>Positive feedback around self-compassion</td>
</tr>
<tr>
<td>Clarifying techniques</td>
<td>“Maybe something could be added about, “Don’t worry if you drop off to sleep.”</td>
<td>Test added about the potential benefits of relaxation exercises for sleep, and to make people aware that the exercises may make them sleepy</td>
<td>“I especially like the you might feel sleepy doing this, [...] I’d been sleeping so badly it’s ridiculous.”</td>
</tr>
<tr>
<td>Clarifying language</td>
<td>“I felt there was quite a lot of information in there, and for someone who is not very well it was quite a lot to follow.” [...] “We’re talking about people with brain fog, you know, put a cup of coffee in the fridge...”</td>
<td>Language simplified in specific areas identified as problematic</td>
<td>“Everything you’ve put down there is very well explained, I think it’s probably just about right”</td>
</tr>
<tr>
<td>Improving design</td>
<td>“I didn’t realise that there was additional content behind the boxes.”</td>
<td>Introduction flaps the presence of interactive content throughout the module more clearly, interactive boxes highlighted more prominently</td>
<td>Participants observed to click and use interactive elements more frequently</td>
</tr>
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</table>

Overall impressions:

Overall participants appeared to be highly supportive of the content and delivery of the modules (for summary scores, see Table 1):

- “I honestly think there is so much value and so wholeheartedly... there’s not been anything like this for people with Crohns. One of the things that’s been very badly neglected is the mental health aspect. This is brilliant. This is pure gold.”
- “It’s like having a friend in your pocket”

Conclusion

Digital modules based on the principles of CBT can be applied to the specific challenges of autoimmune patients. Any such intervention will benefit from collaborative development with the patients it seeks to help.

Table 2: Examples of qualitative feedback, improvements, and outcomes

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