

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

Authors: Dr Jonathon Reston,
Lucy Ashworth, Dr Sumaira Malik.

Affiliation: Atlantis Healthcare

Contact: jonathan.reston@atlantishealthcare.com

► 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, useable, 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. This will give an understanding of whether participants feel confident to use these modules on their own, and think the topics covered are applicable to them
- Create recommendations that can be used to adapt both current and future modules

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/practice:**
 - 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

► Sample & Methods

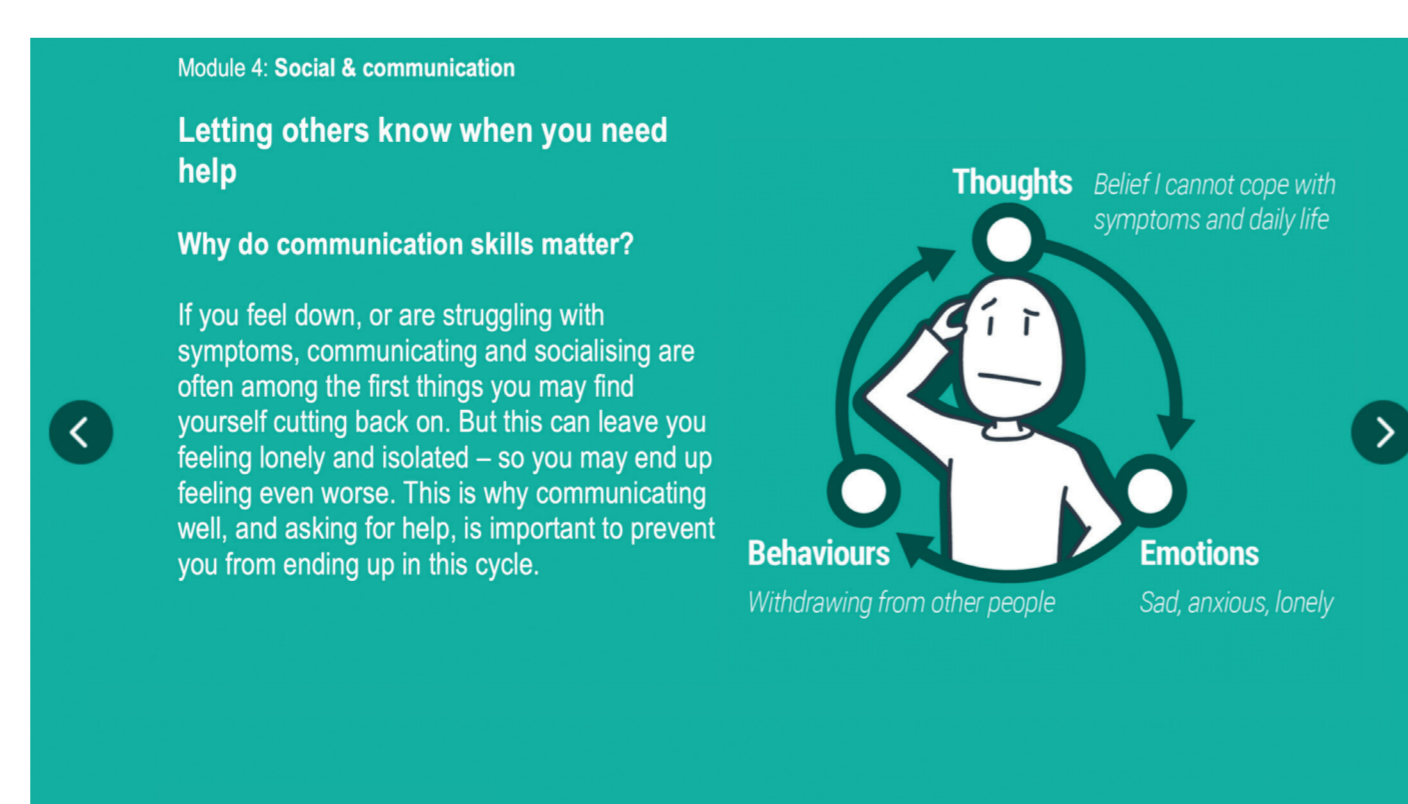
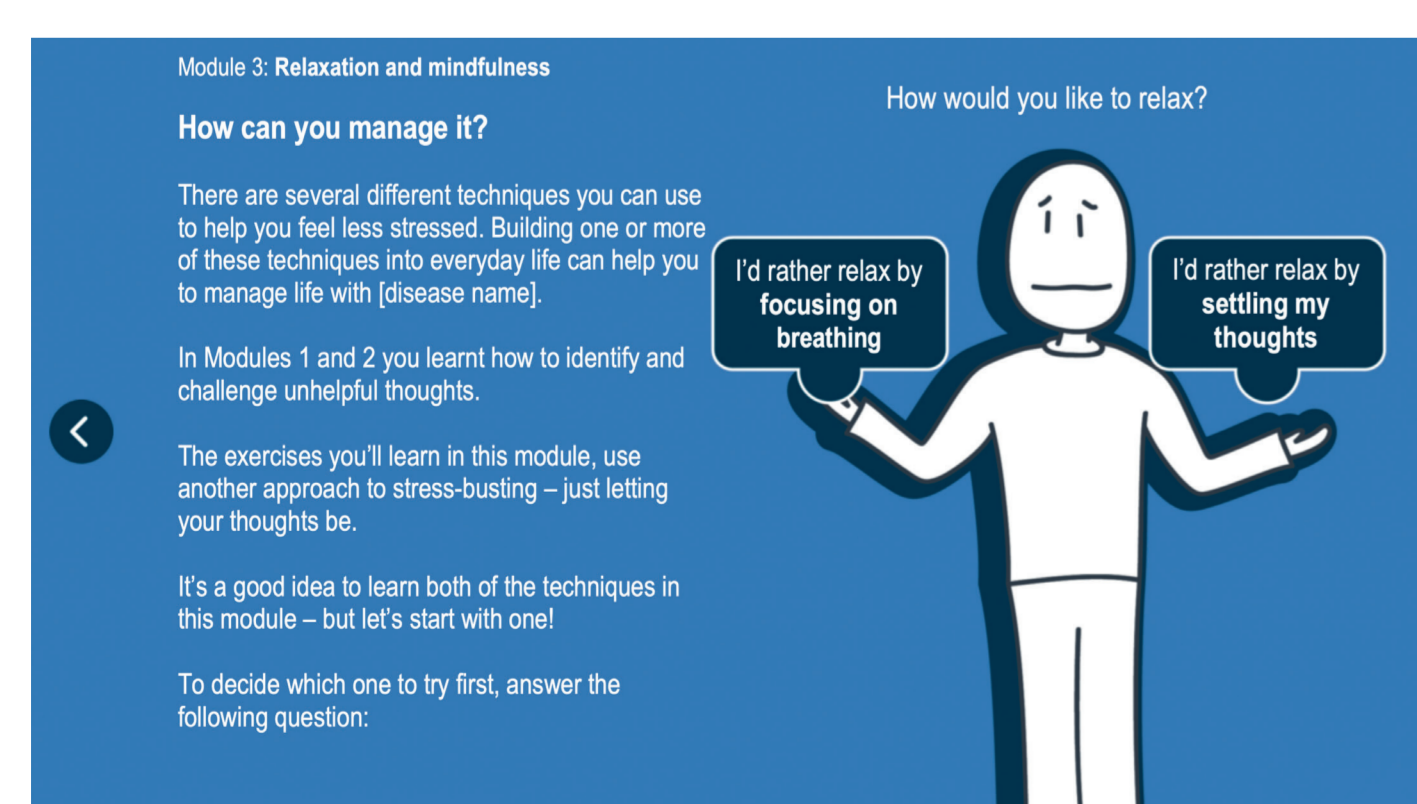
Sample

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
 - First two modules based on the principles of cognitive restructuring – identifying unhelpful thoughts, their triggers, and more helpful ways of approaching them
- Relaxation and Mindfulness
 - Relaxed breathing and simple mindfulness exercises to be used at any time
- Social & Communication
 - The first half of the module focused on initiating social activities
 - The second half focused on tips around patient-HCP 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.

Each interview lasted between 45 and 60 minutes.

► 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

Module	Q1 Easy navigation	Q2 Clear language*	Q3 Clear expectations*	Q4 Would help live with condition	Q5 Would use in own life
1 - Identifying unhelpful thoughts	5	2.3	1.6	4	4.2
2 - Challenging unhelpful thoughts	5	1.5	1.5	4.5	4.5
3 - Relaxation & mindfulness	4.75	1.75	2.5	4.25	4.5
4 - Social & communication	4.4	1.8	1.6	4.2	4.2

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 2: Examples of qualitative feedback, improvements, and outcomes

Category	Example comment	Example remedying action	Feedback on new module (round 2)
Improving relevance	“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.”	Text added around setting realistic expectations with friends, and to show self-compassion when goals are not met.	Positive feedback around self-compassion
Clarifying techniques	“Maybe something could be added about, “Don’t worry if you drop off to sleep.”	Text added about the potential benefits of relaxation exercises for sleep, and to make people aware that the exercises may make them feel sleepy	“I especially like the ‘you might feel sleepy doing this. [...] I’d been sleeping so badly it’s ridiculous.”
Clarifying language	“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...”	Language simplified in specific areas identified as problematic	“Everything you’ve put down there is very well explained. I think it’s probably just about right”
Improving design	“I didn’t realise that there was additional content behind the boxes.”	Introduction flags the presence of interactive content throughout the module more clearly, interactive boxes highlighted more prominently	Participants observed to click and use interactive elements more frequently

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 I so wholeheartedly... there’s not been anything like this for people with Crohn’s. One of the things that’s been very badly neglected is the mental health aspect. This is brilliant. This is pure solid 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.