Update to: self-help cognitive behavioural therapy for anxiety in pulmonary hypertension

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To the Editor:

We were pleased when our pilot randomised controlled trial (RCT) testing the acceptability, feasibility and preliminary effectiveness of a 4-week unguided self-help programme, based on cognitive behavioural therapy (CBT) and targeting anxiety in pulmonary hypertension (PH), was published in *ERJ Open Research* [1]. Conception of the trial was motivated by high rates of anxiety (28–46%) and depression (20–36%) [2], and challenges accessing evidence-based psychological interventions reported by this group [3, 4].

The trial involved 77 adults. Drop out was low (15.6%) and all participants agreed they would recommend the programme to someone with PH. Individuals who participated in the programme reported a significant reduction in anxiety and depression; at 1-month follow-up 71.4% and 39.3% reported a reliable change, respectively.

Here we provide an update on the self-help programme tested during the trial. In November 2022, the programme was made available to all adults with PH in the UK free of charge *via* the Pulmonary Hypertension Association UK (PHA UK) [5]. As of August 2024, 223 people have contacted the charity requesting the programme. This would represent 2–3% of the total population in the UK diagnosed with PH (approximately 7000–8000 people). When we asked PHA UK about the impact of the programme they explained:

> *"This intervention has been of huge value to the UK's PH community. It's enabled us, as a patient organisation, to make a tangible difference to people living with the huge challenges of PH. Our own research in 2019 showed that 92% of people with PH feel the condition has affected their mental wellbeing, showing a clear need for support in this area. The intervention has empowered people living with this disease to manage their mental health, and with the underpinning evidence base provided by the RCT, it has given them confidence in the resource."*

To further evaluate the programme, in April 2024 we invited individuals who received the resource to provide feedback. To access the programme, service users must complete an electronic order form, which requests an email address so the charity can send confirmation of the order. We contacted individuals *via* this email address. After 2 weeks, we sent individuals a reminder to request that they complete the feedback questionnaire. The questionnaire was completed anonymously and so we were unable to follow-up with individual participants.

18 people replied. Based on the median score, individuals felt "comfortable" using the programme. It was judged as "acceptable" and required "little effort". The resource was rated with a score 7.5 out of 10. Responders "disagreed" that the programme interfered with other priorities and were "likely" to recommend it. Reasons against recommending the programme largely reflected a preference for a different type of support. One person stated they would like to speak to "a real person" about their experiences, while others felt the content was less tangible due to the self-help nature.

Shareable abstract (@ERSpublications)
Since being published in 2021 in *ERJ Open Research*, a self-help resource has been made widely available to adults with PH in the UK *via* PHA UK. This is an update on the continued impact of the intervention hearing from services users and PHA UK. https://bit.ly/3YLHIHm

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In the UK, self-help interventions are a recommended form of treatment for anxiety and depression; however, current interventions do not cover the nuances of anxiety associated with PH. Self-help can be therapeutically and cost-effective, reduce waiting times, and remove barriers sometimes caused by the stigma of seeking help. Self-help methods are not intended to replace other means of delivering therapy, such as face-to-face or in a group, if those approaches would be more suitable. While our programme is unguided, some self-help interventions can be guided with the support of a professional. This appears to be closer to what participants described here and there may be scope to offer a guided version in the future. For now, we recognise the programme is not suitable for everyone and we recommend people wanting another form of support to talk to their healthcare provider about what is available where they live.

When asked whether the programme was helpful, the modal response was indifferent (endorsing "no opinion"). It is difficult to make any strong conclusions as only seven people reported completing the programme. This, and as most did not respond to our invitation, may speak to the need to embed strategies to help people stay engaged. Attrition is a complex and common problem with treatment – and perhaps more so for self-help. Numerous ideas have been proposed to help improve adherence; recognising processes such as attrition and fidelity are crucial for the effectiveness of interventions. The COM-B framework [6] has been influential in helping to change factors related to people's behaviours in healthcare settings. This proposes that for someone to perform a behaviour, they need to have the Capability, Opportunity and Motivation. Changing behaviour will require focusing on one or more of these factors. The model could be applied here by recognising barriers to engagement and embedding helpful strategies within the programme, such as reminders, feedback, rewards and self-monitoring.

Our trial remains the largest examining the use of psychological therapy in PH [7]. This can be contrasted with other long-term lung disorders, where the evidence base for psychological support is comparatively much larger [8]. We have since conducted a secondary analysis of the dataset, revealing cognitions and behaviours as targets in the treatment for anxiety and depression [9], further supporting the use of CBT. Findings have helped develop a similar unguided self-help programme targeting depression in PH. An RCT testing this intervention ended in April 2024 and following publication, the programme will be made available *via* the PHA UK [10].

While research has helped us to understand the symptoms and impact of PH, a crucial next step is to continue designing and evaluating new interventions addressing PH-specific challenges. Alongside continuing to test the usefulness of self-help interventions, we also plan to build on this literature to develop and evaluate other formats of psychological interventions, particularly within clinical settings, to help individuals better manage the psychological distress associated with PH. Working alongside Pulmonary Hypertension Associations will be important in achieving this goal as they can be highly effective at all stages of intervention design and implementation.

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