Author’s response to reviews

Title: User perspectives on a psychosocial blended support program for partners of patients with amyotrophic lateral sclerosis and progressive muscular atrophy: a qualitative study

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BMC Psychology

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Dear Martin Dempster,

Thank you for the opportunity to send in a revised version of our paper: “User perspectives on a psychosocial blended support program for partners of patients with amyotrophic lateral sclerosis and progressive muscular atrophy: a qualitative study” with reference number PSYO-D-19-00008R1.

We have taken carefully notice of the suggestions of the reviewers and incorporated them into our paper. All our changes in the manuscript are visible in track changes. We have listed a point-by-point response to the comments.

We would like to thank the reviewers for their constructive feedback and we hope that we have answered all the questions to your satisfaction. We believe that the applied changes have strengthened our paper.

We look forward to your response.
On behalf of all the authors,

Yours sincerely,

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RESPONSE TO REVIEWER 1 Birgitta Dresp-Langley

This qualitative and purely descriptive study was aimed at assessing the psychological impact of Acceptance and Commitment Therapy (ACT) as a support therapy administered to caregivers (a total number of 23 caregivers was interviewed here) of patients with amyotrophic lateral sclerosis and progressive muscular atrophy. The outcome of these interviews shows that ACT made caregivers more aware of their role and the difficulties associated with that role, and that caregivers generally perceived the therapy as a useful support. It is concluded that ACT has a positive effect as a "product" administered to the caregivers of patients with the pathology stated.

The article is clearly written, but this reviewer here is unsure of whether it is suitable for BMC Psychology. The paper does not deliver any deeper insight into the underlying psychological process that has led to the declared "raised awareness" and "acceptance of problems associated with the role" in the caregivers. The results reported here do therefore not allow the reader to understand why ACT as a specific support tool, with explicit steps and procedures, and with clear targets in limited time, has achieved something that other forms of (online or other) psychological support could not have achieved.

Reply: We thank the reviewer for her positive comment on our paper.

We used the demand and control model as a theoretical base for our intervention. This model implies that the dimensions “demand” and “control” explain the psychological and physical distress perceived by caregivers. Caregivers who experience high caregiving demands and low feeling of control over their caregiving tasks are at risk for psychological and physical distress. Since the demand will increase in the progressive diseases ALS and PMA and we are not able to influence this process, we aimed to increase the feeling of control in caregivers. The aim of our overall study was to assess whether a psychosocial support program could support caregivers in dealing with this demanding situation which is worsening over time by improving their feeling of control over the caregiving situation and in turn decreasing their feelings of distress. In this qualitative study we aimed to gather insight into mechanisms of impact and the experiences with different components of the support program.
The feeling of control over the caregiving situation could be increased and feelings of distress could be decreased by different types of psychological interventions (i.e. Cognitive Behaviour Therapy or Acceptance and Commitment Therapy) since these interventions have proven to be equally effective in other populations (Arch et al., 2012; Forman, Herbert, Moitra, Yeomans, & Geller, 2007; Wetherell et al., 2011). However, we believe that Acceptance and Commitment Therapy is especially suitable for these caregivers. The acceptance component makes this therapy valuable in situations which are unchangeable, such as the incurability of the diseases ALS and PMA. The values component encourages caregivers to identify their values and to take actions to meet these values. Using acceptance strategies and taking actions to live up to personal values may increase feelings of control over their caregiving situations.

To clarify this in the manuscript, we have made the following adjustments:

- To further clarify the psychological background of our study, we have added more information about the demand and control model in our introduction (page 4, line 68-72):

  Caregivers who experience increasing demand but do not feel in control over the caregiving situation are more likely to experience emotional distress according to the demand and control model (Molloy et al., 2005; Orbell & Gillies, 1993).

- To explain why ACT is considered as a valuable therapy for caregivers of patients with ALS/PMA, we have added on page 4, line 77-80:

  ACT encourages individuals to accept unwanted private events which are out of personal control and to identify important values in life in order to pursue these values which might help caregivers of patients with ALS or PMA (Hayes, 1999).

- In this qualitative study, patients reported that the underlying psychological process which led to increased awareness and acceptance of negative emotions and thought was that the program forced them to reflect on the situation which they would not have without the program. Raising awareness is a crucial first step in the process of change. We have described this in the first paragraph of the discussion (page 27, line 509-516):

  Reflecting on their current situation and their role therein does not seem self-evident for caregivers who are in the constant flow of providing care. The program “forced” caregivers to reflect on and become more aware of their situation which was considered as a crucial function of the program by caregivers. Becoming aware of your own situation is one of the first stages that people go through during the process of change that takes place in psychological therapy [19]. In the stages that follow, people modify their behavior, experiences, and environment to overcome difficulties [19]. Becoming more aware of their own situation made caregivers in the current study realize they wanted or needed to do things differently in order to remain healthy.

RESPONSE TO REVIEWER 2 Jo Hart
This is an interesting article, developing the important area of understanding caregivers. As the RCT is published in this journal, it feels like a good fit.

The article is well written, thorough and clear.

Reply: We thank the reviewer for her positive comments on our paper.

Title - I wondered why the authors hadn't included the term caregiver in the title and think it should do so - a recognisable term for identifying articles in this area

Reply: We agree with the reviewer that the term “caregiver” could also be an appropriate term to use in the title. We considered this option but would like to use the term “partner” for three reasons:

• We used the term “partner” in our protocol article: “A blended psychosocial support program for partners of patients with amyotrophic lateral sclerosis and progressive muscular atrophy: protocol of a randomized controlled trial”. This article was also published in BMC Psychology. We would like to formulate the title of the result paper in line with the protocol title in order to increase the findability of these papers for readers.

• In this program we pay explicit attention to the romantic partner relationship. The program in its current form is therefore not suitable for other caregivers (such as parents, siblings, neighbours).

• Family members of people with ALS/PMA stated in the interviews that they do not appreciate the Dutch term for the word “caregivers”. They do not feel addressed when this term is used, therefore, the word partner is more in line with their preferences.

If the editor decides that the word “caregiver” should be involved in the title, we would like to use the words “caregiving partner”.

Theme 1. Product evaluation doesn’t seem like a title that reflects the content (internationally, product is usually associated with something that is sold). Would program evaluation be appropriate instead?

Reply: We thank the reviewer for her valuable suggestion. We have been struggling with this term and do agree with the reviewer that “program evaluation” is more appropriate. We have changed “product evaluation” into “program evaluation” throughout the manuscript.

Conclusions. I think the conclusions in the main text and the abstract would appropriately include some of the mixed feelings about the mindfulness and peer support elements.

Reply: We agree with the reviewer and have added this information in the conclusion in the main text and in the abstract (page 3, line 53-55) and (page 31, line 610-612):
The different components of the program were overall appreciated by caregivers, but the mindfulness and peer support components should be further adapted to the needs of the caregivers.

Partners of patients with ALS and PMA overall appreciated the blended psychosocial support program based on ACT but they expressed mixed feelings about the mindfulness and peer support components.

References


