

Supporting the Wellbeing Needs of Caregivers of Individuals with Autism Spectrum Disorders (ASD) and Learning Difficulties: A Mixed Methods Study

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Background



Caring for individuals with ASD and Learning Difficulties (LD) can be overwhelming, with parents experiencing high levels of stress, depression, and anxiety, indicating a need for interventions to promote their well-being.¹

It is unclear what type of interventions might be helpful to the caregivers considering their diverse context and needs.²

Interventions like CBT and ACT show promise for parental well-being, but research on supporting caregivers of adults with ASD and learning difficulties is limited.³

Methods



Phase 1

Systematic literature review with meta-analyses (Global)

1. Explore the effectiveness of the interventions available for the parental well-being across various neurodevelopmental conditions
2. Map the ways in which the interventions are offered and evaluate the quality of available studies



Phase 2

Survey (Global) and Semi-structured Interviews (UK)

1. Understand the wellbeing needs of ASD/LD caregivers, using Family Quality of Life Survey and interviews.
2. Explore the support needs, factors that influence the choices of parents when selecting wellbeing support, the facilitators and barriers to access support across age groups



Phase 3

Intervention Evaluation in Peru

1. Evaluate the feasibility, acceptability, impact and adherence of an online group ACT-informed intervention in comparison with online peer support group and control group for ASD/LD caregivers through a mixed-methods, multiple-baseline experimental design

Reference List

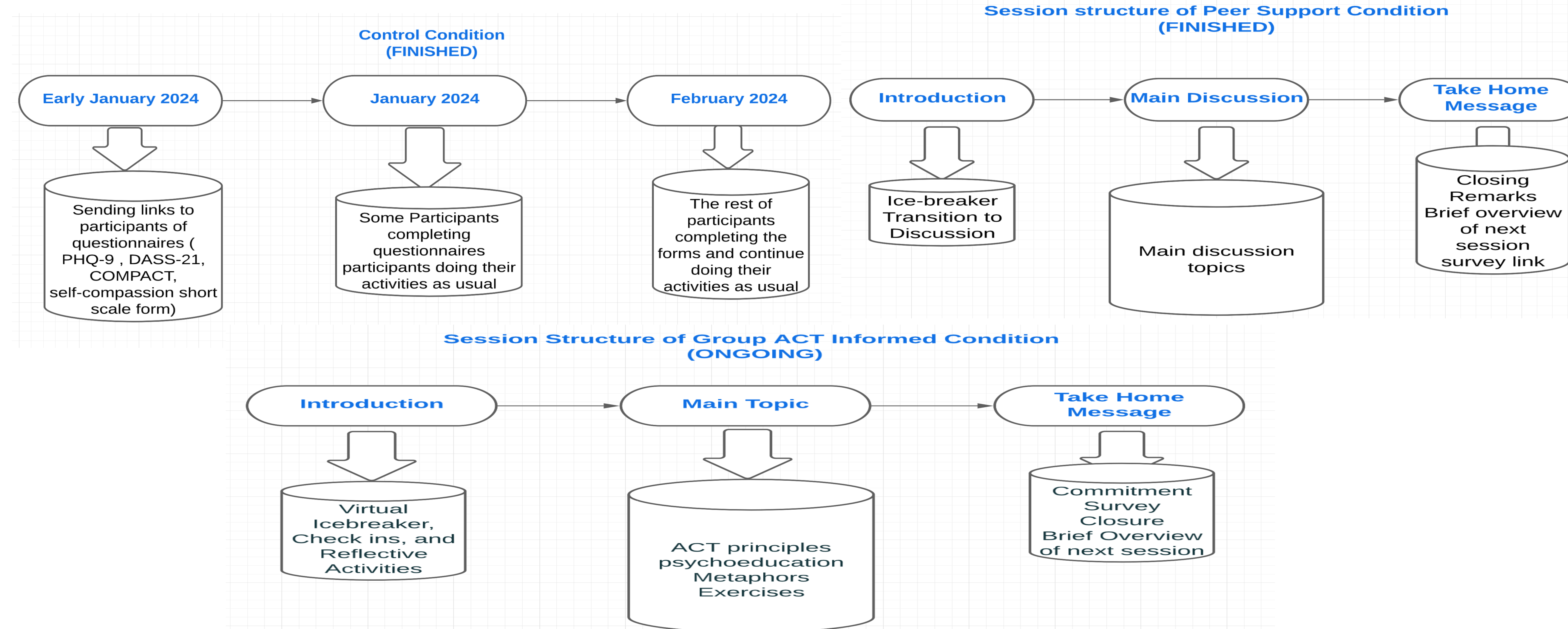
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² Lerman, D.C., O'Brien, M.J., Neely, L., Call, N.A., Tsami, L., Schieltz, K.M., Berg, W.K., Graber, J., Huang, P., Kopelman, T. and Cooper-Brown, L.J. (2020) 'Remote coaching of caregivers via telehealth: Challenges and potential solutions', Journal of Behavioral Education, 29(2), pp.195–221.

³Schlebusch, L., Chambers, N., Rosenstein, D., Erasmus, P. and de Vries, P.J. (2022) 'Supporting caregivers of children with developmental disabilities: Findings from a brief caregiver well-being programme in South Africa', Autism, 0(0).

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Phase 3 (ongoing) Online group peer support and ACT informed intervention



Preliminary Results (Phase 3) (statistical analysis and RTA yet to be done)

Improved self-care, coping strategies, and tolerance:

- "I have learned to be tolerant, to appreciate more myself and what I do."
- "I felt more relieved and I didn't feel alone because I have seen that other moms can also help you at least with supportive words and have a conversation."
- "I felt supported and understood. I also didn't feel judged when I shared my experience with the other participants in the program."

Impact of peer support program

- "I found a relaxation, peace and calmness... I was depressed before... I found that calmness and relaxation that I needed."
- "It has helped me a lot... you learn and take things that can help you."
- "I noticed [my child] got closer to me... I am much more relaxed... we enjoyed [activities] we have not done [for a long time]."

Preliminary Results (Phase 2) (statistical analysis and RTA yet to be done)

Need for tailored support and understanding

- "Professionals don't seem to have a good enough understanding of autism, disability or what a caring role entails."
- "A lot of parents don't bother... it's difficult to access [support] anyway. If you can afford to pay privately, you could get more support."

Impact of parenting a child/adult with ASD and LD on Wellbeing

- "It has impacted my mental health... I am hyper vigilant to possible things happening that are bad."
- "Lots of pains on my body... because I've been under a lot of stress for so long."

Preliminary Results

Phase 2

- Participants described the immense impact of parenting a child or adult with autism and learning difficulties. They grappled with constant worry, anxiety, stress, feeling overwhelmed, physical exhaustion, and even health issues from the intense caregiving demands.
- There was a strong need expressed by participants for tailored support from professionals who truly understand the unique circumstances of raising individuals with autism and learning difficulties.

Phase 3

- Participants reported improved self-care, coping, and tolerance. They mentioned to have learned to prioritize personal wellbeing while caregiving. Also, they mentioned the program increased their self-appreciation.
- Participants reported the most impactful for them was sharing experiences with other parents, providing relief, support, and reduced isolation. Some noticed increased closeness with their autistic children.
- While these are initial findings, they highlight the potential for tailored interventions to significantly improve the wellbeing of this underserved population of caregivers.

Implications

- Identify evidence-base for interventions to enhance caregivers' wellbeing.
- Insights on caregivers' specific wellbeing needs to inform for the development of tailored support programmes.
- Inform future large-scale studies which aim to generalise the findings to influence in policies for the benefit of this population.
- If the online group format is found helpful to this caregiving population, the use of technology developed out of necessity due to COVID 19 quarantines might enhance accessibility and sustainability of wellbeing support.²