PEACE

Working with families with neurodivergence and eating disorders

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Aims of research: to explore needs of autism-eating disorders carers & offer support

Findings about the needs of autism-ED carers (Adamson et al 2020) & Kinnaird et al 2021) in PEACE Pathway research suggested that carers would benefit from:

- Accessing peer-led support and skills-based learning where they would get more knowledge about neurodivergence-ED, from learning strategies for caregiving

- Connecting with other carers

- Getting better support and recognition from services for their neurodivergent family members and themselves.

- Clinicians having a better understanding of neurodivergence & ED

My lived experience as an autism-carer is presented in (Tchanturia ed 2021). I describe:

- How lowering emotional overinvolvement (EE) helps carers step back; this reduces their 'burden of care' & helps care recipients

My PhD research offered carers workshops in:

- How Non-violent Resistance (NVR) helps de-intensify conflict in caregiving relationships

- How lowering EE & using NVR ideas can both help carers regulate their own emotions

- How Acceptance & Commitment Therapy (ACT) can help carers to better recognise and meet their own needs; ACT also provides a model for accepting what can and can't be changed in caregiving relationships

Autism-ED carers were offered peer-led online support ‘coffee groups’ & workshops (2020-23), based on ideas I had found useful & what carers asked for

- The ‘coffee groups’ are presented (Oakley et al 2021)
- ‘Coffee’ support groups had a ‘secure base’ model (Bowlby 2005). I always shared that I was a peer-carer.
- Each carer was invited to ‘check in’ and say how they were feeling at the beginning of each group.
- Then, carers speak spontaneously, with the group leader aiming to ensure that each participant has a chance to talk.
- Each carers is invited to ‘check in’ again and say how they are feeling before the end of each group.
- Carers were able to share their feelings in a supportive, therapeutic, peer-led space and also make new social connections with other carers.

The psychoeducational workshops covered:

- 1) The value of low Expressed Emotion – how to ‘step back’ - emotional overinvolvement has serious consequences for carers
- 2) NVR – non-violent resistance – strategies for de-escalating conflicts with loved ones; the importance of support networks and self-care for carers
- 3) ACT – Acceptance & Commitment of what can and can’t be changed. How carers can put their values into action and improve their own quality of life
- 4) How autism & concurrent conditions may play out throughout the lifecycle - the experiences and the stresses of coping will affect the person and their sense of self. Overlapping features between autism and other conditions were mentioned.
- In the workshops carers learnt new ideas and strategies to support them in their caregiving roles.

Carers valued the ‘coffee groups’ & workshops…which are straightforward to replicate

- Sharing experiences with others in the ‘coffee groups’ and getting support gave carers hope, more confidence and a sense of optimism making them feel less isolated. Listening to other carers’ experiences also made carers feel more confident about problem-solving themselves.
- Carers valued learning about new caregiving strategies adapted from ideas about EE, NVR & ACT in the workshops; being online meant greater accessibility for them. Carers felt that the workshops and the coffee groups were safe places where they could learn from and build relationships with the other carers.
- The coffee groups & workshops made carers feel that they were ‘not alone’ and they made lasting friendships and connections with each other following the workshops and groups
- The coffee groups and workshops can be delivered together or separately. The online delivery makes the interventions portable and low-cost. They are best delivered by a clinician with some lived experience of caregiving.
- A manual with protocols for the ‘coffee groups’ and workshops was developed in the PhD.

Where to from here?

- The PEACE Plus Pathway is developing further resources to support neurodivergent patients and their families. PEACE has expanded from autism-ED to helping ADHD-ED patients and their families
- PEACE recommends a wider use of Communication Passports for neurodivergent-ED patients
- Carers would benefit from online peer-led support coffee groups and skills-based workshops, and a better recognition of carers' essential roles by services, workplaces & benefits systems
- Training for clinicians to work more in partnership with carers would benefit patients, clinicians & carers in strengthening the 'Triangle of Care' (Worthington et al 2013) relationship.

References

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