Working with family carers of people with autism and eating disorders on the PEACE Pathway'

PEACE

Pathway for Eating disorders and Autism developed from Clinical Experience

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My background – professional & lived experience

- Family systemic and psychoanalytic psychotherapist
- Running mental health studies courses and teaching at King's College London
- Parent-carer of young adult son who has autism and other conditions
- Researching family carers' experiences and offering them support and workshops as part of the PEACE Pathway at the South London & Maudsley Hospital.
- My research has been conducted online and the carers come mainly from all over the UK, and some from outside the UK, in countries such as Ireland, the USA and Australia

My personal carer journey

- I’ve written about my shock at becoming a family-carer of my son, who has autism, when I was used to working as a family psychotherapist and helping others in this position (Tchanturia et al 2021)
- It took me a while to realise that through my professional training in family therapy, I had access to ideas which were helpful for my own carer journey, and that these might also be helpful to other carers.
- The combination of being a clinician and having a son with autism and other concurrent conditions gave me a dual perspective of coping strategies which I thought could be further developed, refined and offered to other carers.

My research & aims on the PEACE pathway

- ‘Developing online interventions for families with autism spectrum condition and concurrent eating disorders’
- To examine and explore the needs and experiences of family carers of people with concurrent autism and eating disorders’
- To offer these carers online support support-groups and online psychoeducational workshops
- To evaluate the support groups and workshops and implement the carers’ preferred models of help and support.

Finding out what autism-ED carers want

- When I interviewed carers about their experiences of getting help for themselves and their loved ones (in 2020), autism-ED carers expressed frustration with existing ED services, feeling that they were designed ‘for neurotypicals’.
- They wanted tailored interventions for their loved ones and peer-led support for themselves.
- Adamson et al 2020
- Kinnaird et al 2021
- Oakley et al 2021

What carers said that they wanted – for themselves (Kinnaird et al 2021)

- Mentoring by other carers with lived experience
- More knowledge about the two conditions – autism and eating disorders
- Connections with other carers
- Respite for themselves
- Peer-led support
- Better signposting for help for carers
- A road map of what to expect on their carer journey

Putting feedback into action

- Following this feedback I offered a series of online support groups & workshop sessions between 2020-23 to autism-ED carers.
- These were advertised via the PEACE Pathway Twitter profile so carers from all over the UK (and other countries) were offered help.
- Different group sizes and formats were tried: weekly, monthly, short term, long term, and also workshops followed by support groups.
- Feedback was gathered from carers each time a new group or workshop was offered, until I arrived at a clear idea of the type of help that the carers wanted.
- This was a combination of advice and support: peer-led psychoeducational carers' workshops followed by support groups

Carers preferred psychoeducational workshops followed by support ‘coffee groups’

- The online workshops were given by myself. Four one- hour sessions across four consecutive Friday mornings, each one followed by one-hour support ‘coffee groups’.
- The workshops covered the following topics which were adaptations of key ideas to carer contexts:
- 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 Therapy - what can and can’t be changed. How carers can have achievable goals which reflect their values.
- 4) Autism as a neurological difference throughout the lifecycle – how the experiences and the stress of coping will affect the person and their sense of self. Overlapping features between autism and eating disorders.

The support ‘coffee groups’

- Four consecutive peer-led support groups followed the workshops. Groups had a ‘secure base’ model (Bowlby 2005)
- Each carer was invited to ‘check in’ and say how they were feeling at the beginning of each group.
- Then, the carers spoke spontaneously, with the group leader aiming to ensure that each participant had a chance to talk.
- I always shared that I too was an autism-carer, as part of the ‘joining process’ (Minuchin 2012)
- Carers appreciated the support groups following the workshops as they were able to share their feelings about the workshops with others in the group and also make new social connections.

Feedback from the workshops & support groups

- Carers valued the format and content of the workshops; being online meant greater accessibility
- Sharing experiences with other carers in the support groups gave them hope, more confidence and a sense of optimism; carers felt less isolated.
- Carers felt that the workshops and groups were safe places where they could learn from and build relationships with the other carers.
- Carers valued learning about new ideas and strategies from the workshops, and getting emotional support and reassurance from the groups. Learning from listening to other carers' experiences made carers feel more confident about problem-solving themselves.
- Carers felt that they were 'not alone' and made lasting friendships and connections with each other following the workshops and groups.

Conclusions

- Carers would like to be facilitated to connect with each other and skill up. They learned about the importance of regulating their own emotions and how this can lead to better outcomes for the people they are caring for, and help protect the carers themselves from emotional burnout.
- The online support groups and workshops led to lasting connections with other carers. Here, they could connect with others who’ve had similar experiences, have niche knowledge and who are non-judgemental.
- There was a huge amount of lived experience, resources and expertise within each unique carer group. The online format makes the groups easy to set up, but does rely on peer-carers having the professional knowledge and emotional resilience to lead the workshops and groups.
- The research highlights the importance of lived experience and carers as partners in care with clinicians and service users (Worthington et al 2012)
- Autism can’t be changed but adaptations can be made for loved ones, and carers can change the ways they deal with the autism and concurrent conditions, build better networks with other carers, and improve their own self-care.

References

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