Investigating experiences of the Family Connections Programme for supporters of individuals with a diagnosis of Borderline Personality Disorder

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We interviewed relatives and carers following their participation in a novel Family Connection (FC) programme, designed for supporters of individuals with a diagnosis of Borderline Personality Disorder. A mixed methods approach was utilised to quantitatively measure depression, 'burden', grief and mastery, pre and post-group, whilst qualitative analysis identified four themes: 'Positive Experience', 'Not Alone', 'Management of Emotions and Behaviours' and 'Recommendations'. Quantitative measures suggest that FC could be helpful in alleviating depression and 'burden' and increasing mastery, although it could increase the experience of grief. Implications for future research and the possible impact of FC amongst this group are discussed.

Introduction

BORDERLINE Personality Disorder (BPD) is defined by a persistent instability in emotion-regulation, self-image, impulse control and interpersonal relationships (DSM-5, 2013). Individuals diagnosed with BPD often have difficulties with hypersensitivity, hostility, recognition of others'

feelings, intense and unstable relationships and can experience dissociative states (DSM-5, 2013), often displayed through self-harm and suicide attempts (Flynn et al., 2017).

As distress typically experienced by individuals with a BPD diagnosis often results in high healthcare utilisation (Horz et al.,

2010), there has been substantial research into interventions to support distress management and promote coping. Dialectical Behaviour Therapy (DBT; Linehan, 1987) has the largest evidence base in this population and has been found to improve individuals' safety, stability and emotion regulation, reducing distress and risk-taking/impulsive behaviours (Fruzetti & Payne, in press).

Contrastingly, few studies have explored the impact on those *supporting* the individual with a BPD diagnosis or evaluated the effectiveness of support programmes for supporters (Hoffman et al., 2005, p.218). Hoffman et al. (2005) found that family members/carers experience considerable stress in this context, depleting their capacity to cope and increasing their sense of burden, grief and depression. Scheirs and Bok (2007) demonstrated that carers, related or unrelated, experience greater rates of psychological and somatic disorders. Furthermore, gaps in supporters' understanding of the individual's difficulties increased this burden and risk of depression (Hoffman, Buteau, Hooley, Fruzetti & Bruce, 2003).

Social support significantly affects how individuals manage their emotions and behaviour (Fruzetti & Shenk, 2008). Supporters' ability to create a non-stressful environment and manage unpredictability promotes recovery (Ekdahl, Idvall & Persius, 2014). Family involvement reduces relapse whilst also increasing relatives' wellbeing (Dixon et al., 2001). However, supporting someone whose behaviour can be chaotic, hostile or exhibiting reduced impulse control is challenging. To provide effective support and maintain their own wellbeing supporters must develop constructive coping strategies (Ekdahl et al., 2014).

Programmes based on Linehan's DBT (1987) have been effective for both individuals with a BPD diagnosis and their supporters. Ekdahl et al. (2014) evaluated a DBT-based group intervention for spouses which mirrored standard DBT group sessions, focusing on skills training and psychoeducation. Although the number of participants was limited (*N*=53) and did not include a control condition, a mixed methods analysis found the intervention reduced anxiety and depression.

Family Connections (FC: Fruzetti & Hoffman, 2004) is a 12-week manualised training programme, based on DBT, for families or supporters of individuals with a diagnosis of BPD. FC contains six modules: The first provides information to enhance understanding of the diagnostic criteria and BPD symptomatology. The second examines the aetiology of BPD mechanisms which either maintain, or can be used to treat, symptoms of BPD. The third module focuses on attendees' wellbeing and emotion management. The fourth teaches skills to improve interactions and relationships. Module five covers techniques such as validation and effective communication and module six explores collaborative management and problem-solving.

Data from pilot studies outside the UK, employing pre-post designs, provide limited evidence that FC may be helpful for families of individuals with a BPD diagnosis (Hoffman et al., 2005). Rajalin, Wickholm-Pethrus, Hursti and Jokinen (2009) reported that attendees experienced increases in wellbeing and reductions in discomfort, anxiety, depression and perceived burden. They also reported reductions in criticism from both relative and the individual they support.

Currently, little is known about the qualitative experience of supporters in everyday life, or as they participate in programmes like FC. After interviewing FC participants, Herley's (in preparation) evaluation was broadly positive; analysis of interview transcripts revealed a number of themes including gaining 'clarity' and 'safety', achieving 'self-focus' and a 'new way of living'.

The present study aimed to include all supporters of individuals with a diagnosis of BPD. We interviewed this group and analysed transcripts using thematic analysis (Braun & Clark, 2006). Our research questions were: 'What is the group experience of the FC programme?'

Method

Participants

The sample comprised of seven supporters (three males, four females aged 27–57) who participated in a pilot FC intervention lasting 12 weeks. Three supporters were parents, one was a spouse, two were friends and one was a Pastor. Each participant was referred to the group because they supported someone who had required urgent care services.

Design

We employed a mixed-methods design collecting qualitative and quantitative data. Participants completed self-report measures before and after the FC intervention. Qualitative interviews were conducted three months after the intervention was completed.

Semi-structured interviews were designed to allow participants to report their experiences and the impact on their relationship and personal wellbeing. The epistemological stance incorporates the social constructionist approach and the realist/essentialist paradigms.

Measures

Self-report measures were used to assess *grief*, *burden* (of families with a significantly distressed member), *depression* and the sense of personal *mastery* following the programme, as reported by Hoffman et al., (2007). The present study used the same measures of grief, burden, depression and mastery as Flynn et al. (2017), namely: The *Grief Assessment Scale* (Struening et al., 1995); The *Burden Assessment Scale* (Reinhard, Gubman, Horwitz & Minsky, 1994); The *Revised Centre for Epidemiologic Studies of Depression Scale* (Radloff, 1977); and The *Personal Mastery Scale* (Pearlin, Menaghan, Lieberman & Mullan, 1981).

Procedure

The seven attendees completed the pre and post-intervention measures as part of a service evaluation. After completion of the group, participants were invited to join a further evaluation/future research on the programme. Those who consented were contacted three months post-intervention to participate in an individual telephone or face-to-face interview, lasting approximately 30 minutes. Qualitative data were obtained from five attendees.

Data analysis

Recordings of the interviews were transcribed and analysed using Thematic Analysis (Braun & Clarke, 2006). Thematic Analysis is 'compatible with both essentialist and constructionist paradigms' (Braun & Clarke, 2006, p.78), enabling in-depth interpretations of qualitative data. It is suitable for a variety of research questions, can be used with small sample sizes (Braun & Clarke, 2013), and is often used in mixed methods designs. Analysis was completed by one researcher independently using the semantic approach (Braun & Clark, 2006). Initial codes were generated and, from these, themes were reviewed and defined in discussion with the research supervisor.

We included quantitative measures to provide additional context for our qualitative analysis, and to pilot these measures for future evaluations of FC. Given the small sample size these data were unlikely to permit statistical inferences of effectiveness, but we nonetheless report descriptive statistics and summaries to guide future sample size calculations. Data were analysed in R and we used the rstanarm package to provide i) Bayesian credible intervals for changes before and after the intervention, ii) graphical summaries of the available information on the probable range of the intervention effect, and iii) probabilities that the intervention effect fell outside a region of practical equivalence (ROPE; Kruschke & Liddell, 2018) which we defined as a standardised mean difference ± 0.2.

Ethical considerations

The study was approved as an evaluation of service by the researcher's university and the Research and Development department at the healthcare provider.

Results

Attendance at sessions ranged between 7 and 11 sessions (with an average attendance of 9.29).

Figure 1: Posterior density distributions for the pre-post effect size (D) for each outcome. Points are means and intervals are the 95% HPDI.
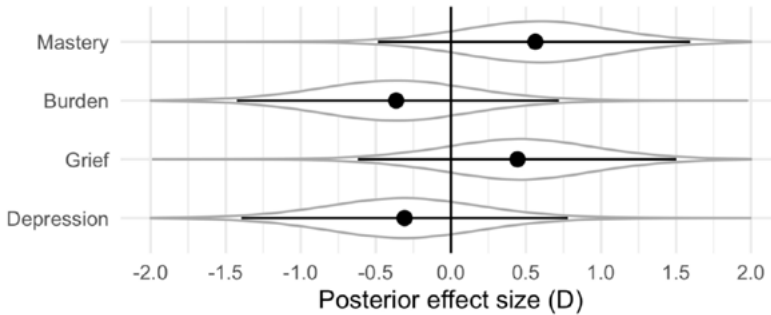
Descriptive statistics for quantitative scores are provided in our data supplement (doi:10.5281/zenodo.4302141). Comparisons of pre- and post-intervention scores suggest that FC has potential to produce modest effect sizes for depression (D = -0.32, 95% HPDI = -1.45 to 0.75), burden (D = -0.37, 95% HPDI = -1.44 to 0.70), and mastery (D = 0.57, 95% HPDI = -0.48 to 1.62). Contrary to expectations participants reported more grief after the intervention (D = 0.46, 95% HPDI = -0.62 to 1.56). Figure 1 provides a visual representation of the plausible range of effects that FC might exert. Bayesian hypothesis tests, defining a region of practical equivalence as ± D= 0.2 (Krushke, 2018) were inconclusive, as expected. However, for depression, burden and mastery the evidence ratio (Bayes Factor) in favour of a net benefit of FC was 4.8, 6.5 and 3.4 respectively. The evidence ratio for a worsening of grief was 2.1.

Thematic Analysis (Braun & Clarke, 2006) identified four themes: 'Positive Experience', 'Not Alone', 'Management of Emotions and Behaviours' and 'Recommendations'.

Positive experience

This theme included skills/techniques, helpful taught information, a sense of progression and improving supporters' coping skills. Increased knowledge of BPD enabled participants to understand the individual they support better and enhanced their own coping/management:

'*Learning more about BPD made it a bit easier to cope with. To understand why the person … maybe acts that way and ways to communicate better with them.*' (P3)

'*The principle behind it of informing and educating and encouraging family members is very good… That has been very helpful to see that and then to adapt accordingly*' (P5)

Learning specific skills/techniques was helpful for improving interactions. Some spoke of general skills they had learnt, such as '*just to be a bit more aware of what you say and how they might interpret it and clarifying what you mean*' (P3). Others recalled specific techniques, particularly the 'DEAR MAN' communication exercise:

'*I think it was just good mentally to go through it and to learn from the paperwork we were given how to better control the situation we were daily in. […] I think my reactions improved.*' (P4)

Participants recognised group progression and improvements in their own wellbeing:

'*I think it was good that we met regularly week after week… we could see changes in all of us, in our attitudes in our self-esteem ourselves really by putting things into practice.*' (P4)

'*I still remember some of the things that was shared and actually one of the encouraging*

things from the course for me was to see how other members of the course seemed to improve and their own emotional stress was eased over the course.' (P5).

Not alone

This theme encompasses a sense of support and shared experience. Supporters frequently referred to advice given from facilitators and other group members.

'They listened to the situation you were in and made you feel they were going to help you … I think it was good to meet other people in similar situations. Just to know that sort of you're not on your own…and the support from the professionals, being able to know that there are trained people you can talk to and just a deeper understanding' (P3)

'It was important to be there just for support for them sometimes. I spoke with some of them outside the group, just sharing different stuff and advice and that.' (P2)

Participants described group experiences and practices together whilst also having shared, normalising interactions:

'It was good to know that you are not the only person living with somebody who is difficult as somebody with borderline personality disorder… it was a positive experience I would say quite painful at times but positive.' (P1)

'it is hard to express really but it does all revolve around just not being the only person on the face of the planet who has had to go through this and how other people deal with' (P1)

Management of emotions and behaviours

This theme focused on skills/techniques around managing the individual they support and improving their own wellbeing. Participants described managing challenging situations, reflecting, reducing reactivity, and providing validating statements to show empathy and understanding:

'Looking forward to see things that have the potential to go wrong, spotting them before they get to the point of crisis…now I am more aware how delicate she can be so I will be a bit more, try to see life from her side a bit more' (P1)

'I think not getting as worked up or as stressed with the situation. Trying to take a step back and think about it a bit more.' (P3)

'We definitely are less confrontational and, I can't think of the proper word, but saying that we understand how she feels and can understand why she feels like that…rather than saying "no you're wrong, that's not what so and so did or said".' (P4)

Participants talked about the ability to manage their own emotions and behaviours although some participants reported that they still struggled with the behaviour of those they support:

'I feel scarred by her and her behaviour, whatever you want to call it, so I'm quite anxious about it but I do have more knowledge that I had before' (P1)

'It was all getting me down. It still is getting me down… My mental health was just suffering too much and as a friend I am still there for her but not to the extent I was … I have learnt from it but in another way, I have learnt to protect myself from it as well.' (P4)

Recommendations for future groups

Participants suggested recommendations around the support offered to those with a BPD diagnosis, mainly around therapeutic interventions, but also about the programme.

Participant 2 explained that it was helpful that the individual had received DBT previously as:

'X is getting more on DBT and skills set so if there is any situation it opens up for more personal assessment and objective, critical, analytical assessment of oneself. That then leads to better communication … I think more what X has done has made a bigger improvement.' (P2)

Participant 4 explained frustrations that the individual they supported had not received DBT and felt this was unhelpful:

'My understanding of her illness is better… but she's not gone on the course yet, which is very frustrating. … we would dearly love for her to do the borderline personality course herself. To start putting those things into practice so both of us are coming from the same level' (P4)

Participants also talked to specific changes to improve the programme. While some felt the group did not need improvement, *'I think it was very good. Yeah, I don't think I would change anything really.'* (P3), others made suggestions regarding the structure, measures and ability to remain in contact for continued support:

'…it did build up session by session, so I think it's not a dip in dip out session. You needed to turn up to all sessions to make it as valuable as possible.' (P1)

'Some of the questions were really, for example one of them said 'do you feel you can cope with things in life' obviously we can think that this is to the specification of managing within our interrelations … but depending on what is happening in that person's life that could then cross the bridge to so many potential options.' (P2)

'I think perhaps at the end a way of keeping in touch would have been good… You know perhaps, I don't know whether to say, arrange a venue for coffee in a month's time to say you will come along for a cup of coffee and a chat […] that could have perhaps helped everyone.' (P5)

Discussion

In this small study, participants' experience of the FC intervention was generally positive. In interviews participants reported that they had learned about BPD alongside new skills to manage relationships. Some participants reported progress among others in the group and that this sense of solidarity was helpful.

Participants identified feeling supported by the facilitators and attendees and that this support, accompanied by shared experience, created a sense they were not alone.

All participants identified that implementing new skills/techniques from FC enabled them to improve interactions/communication with those they support; however, discussing improvements in their own wellbeing, some mentioned managing their mental health better whilst others continued to struggle. Those who struggled to manage/cope identified, in the 'Recommendations' theme, that the person they supported had not yet received DBT interventions. Several participants reported that it was helpful that the individual they supported had previously accessed DBT, and it would be worthwhile to explore the potential for synergies in treatment of those with a BPD diagnosis and their supporters.

This study was too small to make precise estimates of the effectiveness of FC and did not include a control group. Nonetheless, the numerical summaries presented here suggest that these participants experienced a modest reduction in depression and burden, and increasing sense of mastery, across the period of intervention. These data may be useful to researchers designing future evaluations. However, as our participants noted at interview, these numerical measures did not always feel relevant to their experiences. A twin strategy of adopting both broader measures (for example, indexing quality-of-life) and more condition-specific instruments may be advisable.

Our quantitative findings are broadly consistent with previous studies (Hoffman et al., 2005; Hoffman, Fruzetti & Buteau, 2007). However, in contrast to Hoffman et al.'s (2005) findings in this small sample levels of grief *increased* following the programme. Whilst wary of overinterpretation, it is possible that increases in grief were associated with increased awareness and acknowledgement of the personal costs of supporting someone in distress, or a deeper emotional connection made with that person. Connecting, or recon-

necting, with distressing experiences of the individual might well represent a 'healthy' or normal processing of grief (Worden, 2018).

Strengths and limitations

The study was the first to include all supporters in this context. It is, currently, the only study using mixed methods to assess FC. Furthermore, the primary researcher was external to the programme and, although she attended one session to observe the content, was able to remain independent, enabling participants to give honest and open views regarding the group.

This study provides useful pilot data for future research seeking to evaluate the effectiveness of FC. Quantitative measures were obtained data from all seven attendees before and after treatment although, as noted above, future studies might benefit from selecting alternative or additional measures.

Interview data was gathered from five of the attendees. Records show that groups were well-attended and that the intervention itself is welcomed by supporters who engaged with this often-challenging content.

Nevertheless, this is a small sample, recruiting from one group following a 12-week programme and the follow-up period was only three months. Although we have presented summary statistics to inform future research, clear inferences from these data are impossible and our qualitative findings are not comprehensive. Future studies will require recruiting larger samples and collecting data over longer periods. Of particular interest would be the degree to which the use of skills taught in FC persists.

Implications for clinical practice and recommendations for service

This study demonstrates that the FC programme may be beneficial and provides supporters with skills, techniques and coping strategies to alleviate the impact of the challenges they face. Participants' comments suggest that the programme may be enhanced when paired with DBT treatment for the individual they support. This may enable greater improvements in interactions and communication, as in Fruzetti, Gunderson and Hoffman (2014), and gives supporters more time to develop constructive coping strategies (Ekdahl et al., 2014). Although attendance was relatively high, in the 'Recommendations' theme, participants identified that it would be helpful to know in advance that the programme is cumulative and that full attendance is important.

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