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FULL TITLE: Support, interventions and outcomes for families/carers of people with Borderline Personality Disorder: A systematic review.

SHORT TITLE: Support for carers of people with BPD

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ABSTRACT: It is clear from existent literature that families and carers of relatives and friends with borderline personality disorder (BPD) experience high levels of burden. Whilst family interventions are considered vital to improving the outcomes of those with a range of mental health difficulties, there has been limited development of direct interventions for carers of people with BPD, despite a high level of need. This systematic review aimed to appraise and synthesise the existing research evidence for interventions for carers of people with BPD. Ten studies were included which were directly related to six interventions for families and carers of people with personality disorder. The findings of these studies, whilst limited, do provide some initial evidence that interventions for carers may lead to significant outcomes for the participants, particularly in improving carer wellbeing and reducing carer burden.

KEYWORDS: Borderline Personality Disorder; Carers; Family Interventions; Psychoeducation; Burden

CLASSIFICATION: Systematic Literature Review

Support, interventions and outcomes for families/carers of people with Borderline Personality Disorder: A systematic review

ABSTRACT

It is clear from existent literature that families and carers of relatives and friends with borderline personality disorder (BPD) experience high levels of burden. Whilst family Interventions are considered vital to improving the outcomes of those with a range of mental health difficulties, there has been limited development of direct interventions for carers of people with BPD, despite a high level of need. This systematic review aimed to appraise and synthesise the existing research evidence for interventions for carers of people with BPD. Ten studies were included which were directly related to six interventions for families and carers of people with personality disorder. The findings of these studies, whilst limited, do provide some initial evidence that interventions for carers may lead to significant outcomes for the participants, particularly in improving carer wellbeing and reducing carer burden.

INTRODUCTION

It is clear that families and carers of people with Borderline Personality Disorder (BPD) have high levels of 'carer burden' [1], including significant psychological, practical and financial impact of caring [2]. A number of studies have explored the needs and experiences of these carers, highlighting difficulties such as financial burden [3]; anxiety, depression, guilt and grief [4]; relationship difficulties [5] and feelings of powerlessness [6]. Carers also report experiencing stigma and discrimination [7], and difficulties in communication with care providers [6]. In addition, carers reported a lack of good quality information and carer support [8], and suggested that generic carer support groups did not meet their needs [9]. A systematic review of carer burden and associated support needs analysed data from 465 carers and reported that scores of carer burden, grief and depression are significantly higher, and that carers' sense of empowerment is significantly lower in carers of people with BPD in comparison to other carer groups, including carers of people with a diagnosis of schizophrenia [7].

A systematic review of over 30 randomised controlled trials [10] suggests that family psychoeducation interventions are the 'treatment of choice' for improving family wellbeing in psychosis and related disorders. They also have demonstrated improved recovery and reduced relapse rates for the 'patient'. The National Institute for Health and Care Excellence (NICE) [11] Guidance for Schizophrenia states that services should "*offer a carer-focused education and support programme, which may be part of a family intervention for psychosis and schizophrenia, as early as possible to all carers*" (p14). However, despite the evidence that carers of people with BPD experience high levels of distress, programmes such as the National Alliance on Mental Illness's "Family-to-Family" program [12] have not been routinely offered or evaluated for carers of people with BPD. It is perhaps surprising that such programmes have not historically been offered. There is a compelling case for involving family members in treatment for people with BPD, given the recognised interpersonal and relational difficulties for individuals with this diagnosis [13, 14] and the possible role of the 'invalidating environment' [15] in the development and/or maintenance of the core difficulties associated with BPD. However, there is a lack of clarity as to what interventions or support would be effective for this group of carers. NICE guidance for BPD [1] refers to emerging evidence that structured family programmes may be helpful, and that families report that information about the diagnosis, care and treatment is important to them. Carers have also suggested that they need diagnosis-specific support [9]. However, there has been insufficient empirical research on family/carer needs and interventions to carry out a systematic literature search and so no clear recommendations are provided by NICE Guidance.

A number of interventions involving family members have been described in the literature. The majority used a Dialectical Behaviour Therapy (DBT) informed approach [14, 16-21] with others describing approaches based upon Cognitive Behaviour Therapy (CBT), such as the Systems Training for Emotional Predictability and Problem Solving *(*STEPPS) programme [22], and Family Therapy approaches [23]. Whilst many of these interventions have demonstrated a positive impact on the difficulties experienced by the individual with BPD [18, 20-23], some have not as yet been evaluated [14, 16, 17, 19]. It is noteworthy that none of these interventions have measured outcomes for carers, nor have they evaluated the impact of the carer involvement within the intervention. Whilst biosocial theory would predict a positive impact of a carer learning DBT skills, for example, on both carer and on the individual with BPD, this has neither been explored nor reliably demonstrated in studies of any of these interventions for carers of people with BPD.

Aims

This systematic review aimed to appraise and synthesise the existing research evidence for interventions for carers of people with BPD.

METHOD

Search Strategy

Review databases (DARE; CDSR) were searched first to ensure no previous relevant reviews had taken place. A systematic review methodology was then chosen. The guidelines from the

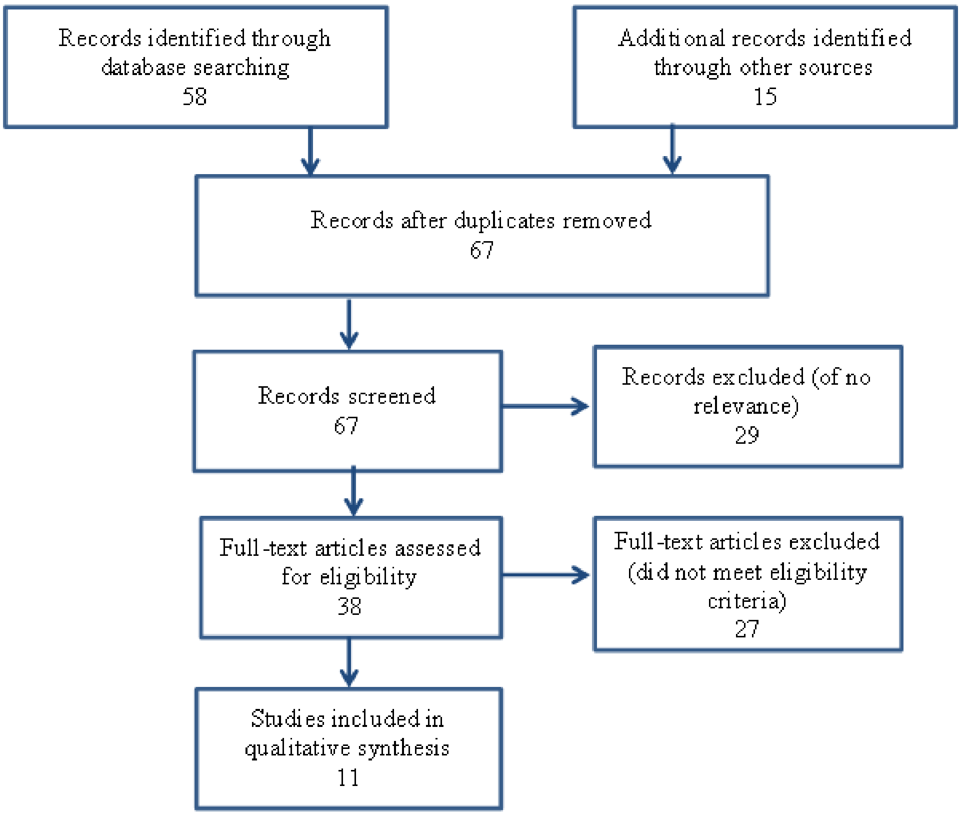
Centre for Reviews and Dissemination for conducting and reporting systematic reviews in health care [24], and the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) statement followed [25]. Databases searched included NHS Evidence (Guidelines), Medline, EMBASE and PsycInfo. Search terms for each database included the following: (family OR families OR carer* OR caregiver* OR caregiver burden) AND (personality disorder OR personality disorders) AND (support OR experience OR intervention). The earliest publication date was set to 2007 to capture studies referenced within and published since the publication of the NICE guidelines in 2009, and the language was limited to English. Reference lists of studies included from the database search were scanned to identify further eligible studies.

Inclusion and exclusion criteria

Studies were screened by RS using the following criteria for inclusion in the review: (1) participants were carers of adults or adolescents with a diagnosis of personality disorder; (2) studies evaluated an intervention or combination of interventions involving carers, including (but not restricted to) psychoeducation, peer support, and skills based interventions; (3) studies that measured clinical outcomes for carers, including (but not restricted to) carer burden, carer wellbeing, mastery, depression; and (4) quantitative studies including Randomised Controlled Trials (RCTs) and quasi controlled trials; however it was anticipated that few studies of these designs will be available and studies using any pre- / post-measurement design were included. Editorials, book reviews, conference abstracts, theoretical or opinion pieces, or descriptive/anecdotal accounts were not included.

Figure 1 details the process of selecting and sorting studies. Fifty-eight studies were identified from the database search (52 with six duplicates removed). Of these, 29 were excluded by RS as the title and abstract clearly indicated that they did not meet the inclusion criteria. The full texts of the remaining 23 studies were retrieved, 18 of which were excluded by the team because they did not relate to interventions for carers, did not measure carer outcomes, or were descriptive/ theoretical papers. This left 5 studies for inclusion for more detailed analysis. Reference lists of studies included from the database search were scanned to identify further eligible studies which included the terms ‘carer’ and ‘personality disorder’ in the title. This identified a further 13 studies which were retrieved for full text, 9 of which were excluded by the team because they did not relate to interventions for carers. This left a further 4 studies for more detailed analysis. Two additional studies were published during the course of the review and were also included for analysis. These searches therefore identified 11 studies as being directly related to interventions for families and carers of people with personality disorder, to be included in the review (See Figure 1 below).

Figure 1: PRISMA Flow Diagram



Data Extraction

RS extracted data from the included studies into a spreadsheet which was checked for accuracy by JB. Data extracted included the source, design, aims, participants, findings, strengths and limitations. Principle findings extracted were reported as differences in means and effect sizes.

RESULTS

Characteristics of the studies

A total of 11 studies [26-36] describing seven interventions for or involving carers of people with Borderline Personality Disorder were retained. Six studies were conducted in the USA [26-28, 30-32], two in Australia [34, 36], one in the Republic of Ireland [29] and two in the UK [33, 35]. **Table 1** provides a brief description of each intervention and identifies the associated studies. **Table 2** summarises each of the included studies in terms of intervention, methodology, participants and outcome measures.

Description of the interventions

Three of the seven interventions are based on Dialectical Behaviour Therapy (DBT) principles [26-32]; with the others based on Cognitive Behavioural Therapy (CBT) & Transactional Analysis (TA) [33], Cognitive Analytic Therapy (CAT) [34], Mentalization Based Therapy [35] and relational models [36]. All interventions were structured as multi-family group sessions, and none described any additional tailoring to meet individual needs of group members. Groups ranged from 3 to 15 weeks/sessions in duration, and four of the interventions were facilitated or co-facilitated by experts-by-experience.

Table 1: Summary of Interventions

Participant Characteristics

The eleven studies had relatively small sizes (ranging from 12 to 80 participants), and together report on a total of 511 carers. Across the studies the gender, age and relationship to the person with BPD of participants was reported differently, including ranges, mean averages or in purely descriptive terms (e.g. 'the majority of participants were parents'), meaning this data cannot be aggregated. However, participants appear to be mostly female, mostly parents of a person with BPD, ranging in age from 18-74 years. Other participants included spouses/partners, siblings and (adult) children of the person with BPD. All but one study [33] reported on dropout rates, which ranged from 1.5% to 57%, with the *Family Skills* program [32] reporting the lowest dropout rate at 1.5%.

Table 2: Summary of included studies

Methodology

The range of methodologies and absence of randomisation or control groups in the majority of the studies mean that there are significant limitations impacting on the reliability and generalizability of the results. Only two studies were RCTs, comparing *Staying Connected* and *MBT-Family and Carer Training and Support* to waiting list control groups. The former study used pre- and post- treatment outcomes plus a 12-month follow up [36], with the latter using pre-, weekly and post-treatment outcomes plus a 12-week follow up [35]. Another study [29] was a non-randomised controlled study, comparing *Family Connections* to 'optimised treatment as usual', using pre- and post-treatment outcomes, plus follow-up outcomes at 3 months and 12 or 19 months, although there were significant discrepancies in duration of the TAU intervention which may limit the value of the control group in this study. The remaining eight studies [26-28, 30-34] were conducted in naturalistic settings, typically within a community mental health service, with no control group. These studies collected a range of pre- and post- treatment outcome measures, the majority of which were self-report questionnaires. Six of these studies had no follow up [28, 30-34] and the remaining two had only a short term follow up at 3 months [26, 27]. None of the studies reported on fidelity to treatment manuals.

Outcomes

The majority of the studies measured carer burden and carer mental health/wellbeing. Additionally, some studies also measured carer grief [26-29], carer mastery/empowerment [26-29, 35, 36], family functioning [28, 35, 36] and/or knowledge of Personality Disorder [28, 33, 34] (see **Table 3** for summary of measures and outcomes). Three studies directly measured outcomes for the person with BPD [30, 31, 35]. The studies included have insufficient commonality in their methodology, outcome measures and reporting of statistics to carry out a feasible meta-analysis. Instead, the main findings are summarised below.

Carer Burden: Nine studies [26-29, 32-36] measured burden using the Burden Assessment Scale (BAS) [37], which measures objective and subjective burden. Objective burden refers to the more practical effects of caring such as financial problems; subjective burden refers to emotional impacts such as guilt or embarrassment. Outcomes were mixed across interventions; all studies of the *Family Connections* [26-29] and *MS-BPD* [34] interventions reported a significant reduction in carer burden post-intervention ($p<0.05$), with three of five studies reporting small ($d=.28$) to moderate ($d=.56$) effect sizes. *Family Connections* also demonstrated a significant treatment effect in comparison to Optimised Treatment as Usual ($p=0.02$) in one study [29]. Whilst the *MBT-FACTS* also demonstrated a significant decrease in burden, there was no significant treatment effect in comparison to waiting list [35]. The *Staying Connected* study reported a significant reduction in carer burden at follow-up only ($p=.042$)

with a moderate effect size (*d*=.45) [36]. Neither the *OFAFE* [33] nor *Family Skills* [32] studies demonstrated any significant change in burden.

Carer Mental Health/Wellbeing: All eleven studies measured carer mental health and/or wellbeing using a wide range of outcome measures, typically measuring symptoms of depression. Outcomes varied significantly between and within interventions. Three *Family Connections* studies [27-29], both *MF-DBT* studies [30, 31], the *Family Skills* [32] and *MBT-FACTS* [35] studies reported significant post-treatment decreases in depression (p<.05) with small (d=.32) to large (d=.72) effect sizes; in addition the *MBT-FACTS* study [35] outcomes demonstrated a significant treatment effect in comparison to waiting list for wellbeing (p=.035), although not for depression. The *Family Skills* study [32] also noted that 20% of participants demonstrated reliable and clinically significant change in their individual scores. The *Staying Connected* study [36] found significant change at 12-month follow up only (moderate effect size d=.52). However, neither the fourth *Family Connections* study [26], nor the *OFAFE* [33] and *MS-BPD* [34] studies found any significant changes, and there was no significant treatment effect in comparison to O-TAU in the controlled trial of Family Connections [29]. The reliability of one *MF-DBT* study [30] is affected by high numbers of sub-clinical scores pre-treatment, which may have created a floor effect, and also suggests that depression may not be the most important target for change.

Grief: Grief was measured in the four *Family Connections* studies [26-29] using the Grief Assessment Scale (GAS) [38]. The GAS assesses feelings of grief associated with the mental health of a family member. All four studies reported a significant decrease in grief (p<.001 to p<.01) with one study [27] reporting a small effect size (d=.28). The RCT [29] also reported a significant treatment effect in comparison to Optimised Treatment as Usual (p=.013).

Carer Mastery/Empowerment: The four *Family Connections* studies [26-29], the *Staying Connected* study [36] and the *MBT-FACTS* study [35] measured carer mastery/empowerment using a range of outcome measures including the Mastery Scale [12], Pearlin Mastery Scale [39] and the Family Empowerment Scale [40]. These scales measure coping, sense of personal control and sense of family and community empowerment. All five studies reported significant increases in mastery/empowerment post-intervention (p<.001 to p<.01) with two studies [27, 36] reporting large effect sizes (*d*= -.95 and *d*=1.4). However, neither of the controlled trials [29, 35] reported any significant treatment effect in comparison to control groups.

Family Functioning: Just three studies [28, 35, 36] measured family functioning using a range of measures, including the McMaster Family Assessment Device (FAD) [41], Dyadic Adjustment Scale (DAS-4) [42] ,The Family Questionnaire (TFQ) [43] and the Score-15 Index of Family Functioning and Change (SCORE-15) [44]. These measure the health of family relationships, distress/problems within family relationships, and the level of expressed emotion within the family environment. The *Staying Connected* [36] (DAS-4 *p*=.008; large effect size *d*=0.78; TFQ Emotional over-involvement *p*=.017; TFQ Criticism *p*=.026) and *MBT-FACTS* [35] (SCORE-15 p<.0003) studies both found a significant improvement in comparison to controls. The *Family Connections* study [28] found no significant change on the FAD scale.

Carer Knowledge of Personality Disorder: Three studies [28, 33, 34] measured carer knowledge of personality disorder using three different measures; the Family-to-Family Outcome Survey (FTF) [12] , a non-validated satisfaction questionnaire, and the Personality Disorder Knowledge, Attitudes and Skills Questionnaire (PD-KASQ) [45] . These are all self-reported measures which aim to measure the carer's knowledge and understanding of personality disorder. A significant improvement in carer knowledge was reported in the *Family Connections* study (*p*<.01) [28] and in the *MS–BPD* study (*p*=.001; large effect size *d*=1.33) [34]. The OFAFE study [33] utilised a non-validated satisfaction questionnaire, responses to which suggested that carers had an improved understanding of their relative, but was not compared to a pre-treatment measure. Additionally, self-report questionnaires may not be the most effective way of assessing knowledge.

Impact on person with Borderline Personality Disorder: Both of the *Multi-family DBT* studies [30, 31] measured outcomes for the 'cared-for' adolescents, using self-reported and parent-reported measures including the CBCL [46], YSR [47] and RADS [48]. Both studies reported significant improvement in the adolescents' symptoms of BPD as rated by some self-report and parent-reported measures (ranging from p<.001 to p=.24). However, as the adolescent was also receiving the treatment jointly with their carers, it is not clear from the methodology whether this change could be attributed to their carers' involvement in the treatment or was simply a result of their own engagement in a DBT skills programme. The *MBT-FACTS* study [35] asked participants to keep a daily diary of 'critical incidents' (e.g. self-harm, aggression, suicidal threats, fights, withdrawal, etc.) for a week prior to the intervention, daily throughout the five week intervention, and for three weeks post-intervention follow-up. Due to difficulties in adherence to the diary, some data may not have been accurate and had to be aggregated for analysis; however the reduction in number of reported incidents was significantly lower in the treatment group during the second phase of the intervention and during follow-up, in comparison to the waiting list control group. This data was reported by carers rather than by the person with a diagnosis of BPD; as such it is unknown whether the person with the diagnosis of BDP would also report a decrease in incidents, or whether this solely reflects a change in how the carers are managing or interpreting such incidents.

Table 3: Outcome measures

DISCUSSION

This study aimed to systematically review the available evidence regarding outcomes of interventions for carers of people with Borderline Personality Disorder. Despite clear evidence that carers of people with BPD experience high levels of burden, there has been limited development of direct interventions for carers, and only seven interventions have been evaluated to date. Eleven studies evaluating these seven interventions for (or including) carers were eligible for inclusion in this review.

Outcomes of Interventions for Carers

The findings of this review suggest that interventions for carers may be important and lead to significant outcomes for the participants. However, these studies have considerable limitations that impact on the reliability and generalizability of the results, particularly the lack of control groups in the majority of studies and their limited follow up. The *Family Connections* intervention appears to have the most evidence for its effectiveness in reducing carer burden, grief and depression, and may be more effective than TAU. One study also suggested that carers of people with more severe difficulties (e.g. multiple hospital admissions) may benefit the most from these interventions. The other six interventions have all reported at least one significant post-treatment outcome, and carer feedback suggests that the interventions are acceptable to participants; however each intervention has only been evaluated by one or two studies. Furthermore, the outcomes vary significantly across studies and the effect sizes (where reported) are typically small.

All the included studies had significant methodological limitations. Only three studies compared treatment to a control group (waiting list or TAU) and most had limited or no follow-up data. The studies were also limited by small sample sizes, high dropout rates and/or incomplete data sets. Three studies noted that many participants had subclinical scores for depression, introducing the possibility of floor effects, which suggests that depression may not be the most meaningful target for change. A range of factors that might impact on the reported changes were not controlled for and hence may impact on the internal validity of the studies. For example, there was no control for family members and/or 'cared-for' person attending other psychological therapies at the same time as the carer intervention, or for the impact of multiple members of the same family attending a group together. Additionally, the methodologies used in these studies have not clarified what the mechanism(s) of change might be for participants. A number of variables could be involved; indeed, all seven interventions include elements of psycho-education, skills development and peer support, or other factors.

Whilst the naturalistic design of the studies may provide some ecological validity for other community services considering providing an intervention for carers, the methodology raises the question of who is intended to benefit from the intervention – the carer, the family member with BPD, or both. Only the *MF-DBT* studies directly measured outcomes for both carer and cared-for person, and this was confounded by a lack of control for whether parental attendance added value to the benefits of the adolescents attending the groups and learning DBT skills themselves. The *MBT-FACTS* study also aimed to measure outcomes for the cared-for person through the daily incidents diary; however, this methodology does not sufficiently clarify whether the person with BPD is experiencing less distress/symptoms, or whether this reflects the carer's capacity to manage such distress; neither does it address whether such change in the carer might directly or indirectly bring about symptom relief for the cared-for person. There is perhaps an assumption that helping the carer will help their family member; however this has not been demonstrated. Three studies attempted to measure outcomes related to family functioning; one *Family Connections* study found no significant change, whereas the *Staying Connected* and *MBT-FACTS studies* found significant changes in functioning post-treatment*;* however, all were based on carer self-report and did not seek the perspective of the cared-for person.

Limitations of the review

A small number of relevant studies were identified through the literature search. The search strategy may have introduced bias as it was carried out by one author and there was no second screening. The search did not incorporate any formal assessments of methodological quality or risk of bias. The studies were highly heterogeneous, evaluating seven very different carer interventions using a wide variety of outcome measures, and significant differences in reporting key data, including demographic information and dropout rates, and only half the studies reported effect sizes. As such, it was impossible to carry out meta-analysis and difficult to compare study characteristics and outcomes.

Clinical Implications and Future Research

This review provides some preliminary evidence that interventions for carers can reduce burden and improve carer wellbeing, and together with the evidence relating to high levels of carer burden, supports the recommendation for more services to provide interventions for carers of people with BPD.

However, further research is required to ensure that interventions offered are acceptable and effective. An RCT with clear control groups would help to establish which elements of intervention are active in bringing about change. For example, the group intervention could be compared with provision of online educational materials, and/or with a peer support group. The measures used in studies to date have typically focussed on reducing negative experiences such as depression and burden, and the outcomes have varied significant within and between interventions. Further clarity is needed about whether these outcomes are important to carers, and a coproduced, qualitative approach may help identify what carers would see as a meaningful outcome. Future research may focus on enabling family members to reflect on and articulate exactly how they believe that their participation in these programs has helped them. Miller and Skerven suggest that participants may experience "*positive, growth-oriented changes*" (p91) which may be elicited through a qualitative methodology or through a different type of outcome measure [32]. In addition, carer outcomes should be included in future evaluations of other interventions which include a family element, such as *Walking the Path* [21] and STEPPS [22].

Further exploration of variance could help improve understanding of which carers are most likely to benefit from the intervention. These studies suggest that there may be differences in benefit from the intervention related to carer gender, whether the carer and 'cared-for' person live together or apart, whether the carer is a parent or a spouse, and on the severity of symptoms experienced by the 'cared-for' person.

We would also suggest the impact of the carer intervention on the family member with BPD should also be measured, perhaps including measures of relationship and/or family functioning, including self-report by the ‘cared-for’ person, in order to enable understanding of how change might occur in families. Longer term follow up is required to identify whether changes are maintained.

CONCLUSION

Interventions for carers of people with a diagnosis of BPD aim to provide psychoeducation, develop skills and improve family relationships. This review provides preliminary support that group interventions for carers may lead to some improvements in carer wellbeing, reductions carer burden and grief, although there is limited follow up data or comparison with control groups. It is unclear what the mechanism for change is, as groups by their nature provide an opportunity for peer support in addition to the planned psycho-educational and/or skills development elements. Further research is required to better understand what carers need from interventions, what they find helpful, and whether change for the carer leads to change for the cared-for person.

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Table 1: Summary of Interventions

Family Connections Hoffman et al, 2005 Hoffman et al, 2007 Neiditch, 2010 Flynn et al, 2017	12-week multifamily group based on DBT principles. Aims to provide psychoeducation, to develop core DBT skills and 'family skills' such as validation, and enable carers to build a support network. Groups are led by trained carers.
Multi-family DBT skills for adolescents Woodberry & Popenoe, 2008 Uliaszek et al, 2014	15-week multi-family manualised group intervention for adolescents and their families, based on DBT for Adolescents (Miller et al, 2007). Aims to teach adolescents and their family members core DBT skills.
Oxford Friends & Family Empowerment service Sanders & Pearce, 2010	8-week group based on CBT and TA principles. Aims to provide psychoeducation and improve communication/ relationships. Includes a presentation from former service users.
Family Skills Miller & Skerven, 2017	9-session multi-family group based on DBT principles Aims to provide psychoeducation and to develop core DBT skills.
Making sense of BPD Pearce et al, 2017	3-session multi-family group for family members of adolescents/young adults (15-25 years) with BPD, based on CAT principles within a developmental context. Aims to provide psychoeducation and improve interpersonal skills, relationship patterns and self-care. Final session co-facilitated by carer.
Staying Connected	10-week multi-family group based on a relational model of

Grenyer et al, 2018	BPD. Aims to provide psychoeducation and opportunities to improve relationships within families.
MBT-Families And Carers Training & Support Bateman & Fonagy, 2019	5-week multi-family group, based on MBT principles. Aims to provide psychoeducation and improve skills to help manage and respond to problems encountered with the person for whom they care. Facilitated by carers.

Table 2: Summary of included studies

Authors (Year) Country	Intervention	Study Design	Participants	Measures
Hoffman et al (2005) USA	Family Connections	Naturalistic. Pre-treatment, post-treatment and 3-month follow up questionnaires	44 family members representing 34 families. 88.6% parents, of which 61.4% were mothers; average age 55.5 yrs.	Carer Burden: BAS, PBS Carer Mental Health/Wellbeing: CES-D Carer Grief: GAS Carer Mastery/ Empowerment: Mastery Scale
Hoffman et al (2007) USA	Family Connections	Naturalistic. Pre- and post- treatment and 3-month follow up questionnaires	55 family members (representing 44 families). 77% parents, of which 56% were mothers. Average age 53.4 years	Carer Burden: BAS Carer Mental Health/Wellbeing: CES-D Carer Grief: GAS Carer Mastery/ Empowerment: Mastery Scale
Woodberry and Popenoe (2008)	Multi-Family DBT (MF-DBT)	Naturalistic. Pre- and post- treatment questionnaires	46 adolescents and parents. Adolescents ranged from 13-18yrs.	Carer Mental Health/Wellbeing: BDI---II Impact on person with BPD: CBCL, RADS

USA				
Neiditch (2010) USA	Family Connections	Naturalistic. Pre- and post- treatment questionnaires	67 participants. 76% female, 70% mothers of person with BPD Age range 29-74yrs.	Carer Burden: BAS, PBS Carer Mental Health/Wellbeing: CES-D; BDI-II Carer Grief: GAS Carer Mastery/ Empowerment: FES Family Functioning: FAD Knowledge of PD: FTF
Sanders & Pearce (2010) UK	Oxford friends and family empowerment (OFAFE)	Naturalistic. Pre- and post- treatment questionnaires	28 family members. 59% parents, 30% spouses/ partners. 52% were between 50-60 years of age.	Carer Burden: BAS Carer Mental Health/Wellbeing: Friendship Scale Knowledge of PD: Satisfaction questionnaire
Uliaszek et al (2014)	Multi-Family DBT (MF-DBT)	Naturalistic. Pre- and post- treatment questionnaires and	12 families: 13 adolescents (11 female, 2 male, mean age 15) with difficulties consistent with BPD;	Carer Mental Health/Wellbeing: SCL90-R Impact on person with BPD: YSR

USA		structured interviews.	16 parents/step-parents (10 female, 6 male, mean age 47)	
Flynn et al (2017) Republic of Ireland	Family Connections Vs Optimised Treatment-As-Usual (OTAU)	Non-randomised controlled study Pre & post –treatment questionnaires, plus follow-up at 3 months and 12/19 months	80 family members representing 53 families. (35 completed FC, 22 completed OTAU). Age range 18-70; majority were parents.	Carer Burden: BAS Carer Mental Health/Wellbeing: CES-D Carer Grief: GAS Carer Mastery/ Empowerment: PMS
Miller and Skerven (2017) USA	Family Skills	Naturalistic. Pre- and post- treatment questionnaires	70 family members. 57.1% female. 67.1% parent of patient, 12.9% partners.	Carer Burden: BAS Carer Mental Health/Wellbeing: BDI-II
Pearce et al (2017) Australia	Making Sense of BPD (MS-BPD)	Naturalistic. Pre- and post- treatment questionnaires	23 family members Average age 49.95, range 23-66. 69.6% female, 26.1% male 82.6% were parents of person with	Carer Burden: BAS Carer Mental Health/Wellbeing: K-10 Knowledge of PD: PD-KASQ

			BPD	
Grenyer et al (2018) Australia	Staying Connected vs Waiting list control group	Randomised Controlled Trial Pre- and post- treatment questionnaires 12 month follow up	33 family members in intervention group (63.6% female); 35 family members in waiting list group (68.6% female) Average age 54	Carer Burden: BAS Carer Mental Health/Wellbeing: MHI-5 Carer Mastery/ Empowerment: FES Family Functioning: TFQ, DAS-4
Bateman & Fonagy (2019) UK	MBT-Families And Carers Training & Support (MBT-FACTS) vs Waiting list control group	Randomised Controlled Trial Pre-, during and post-treatment questionnaires and 'diary of critical events' 3 week follow up and 12 week extended follow up	29 family members in intervention (52% female; average age 49) 27 family members waiting list group (56% female; average age 53) 37 family members were parents (22 mothers, 15 fathers), 16 partners, 2 siblings, 1 unrelated.	Carer Burden: BAS Carer Mental Health/Wellbeing: BDI-II, STAI; WEMWBS Carer Mastery/ Empowerment: FES Family Functioning: SCORE-15 Impact on person with BPD: Daily diary of critical events (e.g. self-harm, aggression, etc)
Notes: BAS, Burden Assessment Scale; BDI-II, Beck Depression Inventory-II; CBCL, Child Behaviour Check List; CES-D, Centre for Epidemiological Studies – Depression Scale; DAS-4, Dyadic Adjustment Scale-4; FAD, General Functioning subscale of the McMaster Family				

Assessment Device; FES, Family Empowerment Scale; FTF, Family-to-Family Outcome Survey; GAS, Grief Assessment Scale; K-10, Kessler Psychological Distress Scale; Mastery Scale; MHI-5, Mental Health Inventory-5; PBS, Perceived Burden Scale; PDKASQ, Personality Disorder – Knowledge, Attitudes and Skills Questionnaire; PMS, Pearlin Mastery Scale; RADS, Reynolds' Adolescent Depression Scale; SCL-90-R, Symptom Checklist 90 Revised; SCORE-15, Score-15 Index of Family Functioning and Change; STAI, Spielberger State-Trait Anxiety Inventory; TFQ, The Family Questionnaire; WEMWBS, Warwick-Edinburgh Mental Well-Being Scale; YSR, Youth Self-Report.

Table 3: Outcome measures

Outcome	**Measures**	**Significant Findings**
Carer Burden	Burden Assessment Scale (BAS) [37] Perceived Burden Scale (PBS) [38]	*Family Connections/Making Sense of BPD:* Significant decreases in burden post-treatment Hoffman et al, 2005: BAS p<.05, small effect size *d*=.28; PBS not significant Hoffman et al, 2007: BAS medium effect size *d=.56* Neiditch, 2010: BAS p<.01; PBS p<.01 Flynn et al, 2017: BAS p<.001 in treatment group; also significant treatment effect in comparison to O-TAU p=0.02 Pearce et al, 2017: BAS p=.03, small-medium effect size *d*=.48

		Staying Connected: Significant decrease at follow up Grenyer et al, 2018: Post treatment - no significant change compared to control; at follow up BAS p=.042; moderate effect size *d*=.45 compared to post-treatment scores *Oxford Friends and Family Empowerment Service / Family Skills:* BAS: No significant change in burden *MBT-Families And Carers Training & Support:* Significant decline in burden in both treatment and waiting list groups at post-treatment Bateman & Fonagy, 2019: BAS p<.001 in both groups, however no significant difference between treatment and waiting list groups. *Multi-family DBT skills for adolescents:* Burden not measured
Carer Mental Health/ Wellbeing	Centre for Epidemiological Studies – Depression Scale (CES-D) [49] Beck Depression Inventory-II (BDI-II) [50] Symptom Checklist 90 Revised	*Family Connections:* Significant decreases in depression post-treatment in 3 of 4 studies. No further changes at follow up: Hoffman et al, 2005: CES-D not significant Hoffman et al, 2007: CES-D small effect size *d*=.32 Neiditch, 2010: CES-D p=.02; BDI-II p<.01; Flynn et al, 2017: In treatment group CES-D p<.001; no significant treatment effect in

	(SCL-90-R) [51] Friendship Scale [52] Kessler Psychological Distress Scale (K-10) [53] Mental Health Inventory-5 (MHI-5) [54] Spielberger State-Trait Anxiety Inventory (STAI) [55] Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) [56]	comparison to O-TAU *Multi-family DBT skills for adolescents:* Moderate-large effect sizes for decreases in depression Woodberry & Popenoe, 2008: BDI-II p=.007, large effect size *d*=.72 (NB many carers subclinical at pre-treatment) Uliaszek et al, 2014: SCL-90-R not significant; however moderate effect size *d*=.54 *Family Skills:* Significant decreases in depression post treatment Miller & Skerven, 2017: BDI-II p<.05; 20% of participants ‘recovered’ (i.e. scores demonstrated both reliable and clinically significant change). *Staying Connected*: Significant changes found at 12-month follow up Grenyer et al, 2018: MHI-5: Not significant compared with controls at post-treatment; at12-month follow up significant improvement since post-treatment - moderate effect size *d*=.52 *Oxford Friends and Family Empowerment Service / Making sense of BPD:* No significant changes in anxiety/depression/wellbeing as measured by Friendship Scale (Sanders & Pearce, 2010) or K-10 (Pearce et al, 2017) *MBT-Families And Carers Training & Support:* More rapid decline in anxiety and depression

		and increase in wellbeing throughout treatment as compared to waiting list Bateman & Fonagy, 2019: BDI-II p<.015; STAI p<.02, however no significant treatment effect in comparison to waiting list group at post-treatment; WEMWBS p<.02; significant difference between groups at post-treatment (p=.046) and at follow-up (p=.035)
Carer Grief	Grief Assessment Scale (GAS) [38]	*Family Connections:* Significant decreases grief post-treatment; no further changes at follow up: Hoffman et al, 2005: GAS p<.01 Hoffman et al, 2007: GAS small effect size *d*=.28 Neiditch, 2010: GAS p<.01; Flynn et al, 2017: In treatment group GAS p<.001; also significant treatment effect in comparison to O-TAU for GAS p=.013 Grief not measured in other 7 studies.
Carer Mastery/ Empowerment	Mastery Scale [12] Pearlin Mastery Scale (PMS) [39] Family Empowerment Scale (FES) [40]	*Family Connections:* Significant increases in Mastery and Empowerment. No further changes at follow up: Hoffman et al, 2005: Mastery Scale p<.01 Hoffman et al, 2007: Mastery Scale large effect size *d*= -.95;

		Neiditch, 2010: FES p<.01 Flynn et al, 2017: In treatment group PMS p<.001; no significant treatment effect in comparison to O-TAU *Staying Connected:* Significant improvement in Empowerment compared to controls: Grenyer et al, 2018: FES p=.003; large effect size *d*=1.4 *MBT-Families And Carers Training & Support:* Significant increase in empowerment throughout treatment Bateman & Fonagy, 2019: FES p<.001, no significant treatment effect in comparison to waiting list group (p=.06) Mastery not measured in other five studies.
Family Functioning	General Functioning subscale of the McMaster Family Assessment Device (FAD) [41] Dyadic Adjustment Scale-4 (DAS-4) [42] The Family Questionnaire	*Staying Connected:* Significant improvement compared to controls Grenyer et al, 2018: DAS-4 p=.008; large effect size *d*=0.78), TFQ-Emotional Over-involvement p=.017; TFQ Criticism p=.026 *Family Connections:* One study found no significant change (FAD; Neiditch, 2010), *MBT-Families And Carers Training & Support:* Family problems declined more rapidly for treatment group and significant difference between groups at follow-up

	(TFQ) [43] Score-15 Index of Family Functioning and Change (SCORE-15) [44]	Bateman & Fonagy, 2019: SCORE-15 p<.0003 significant treatment effect in comparison to waiting list group. Family functioning was not measured in the other eight studies.
Knowledge of PD	Family-to-Family Outcome Survey (FTF) [12] Personality Disorder – Knowledge, Attitudes and Skills Questionnaire (PDKASQ) [45] Satisfaction Questionnaire (non-validated) [33]	*Family Connections:* One study found significant increases in carer knowledge about BPD Neiditch, 2010: FTF p<.01 *Making sense of BPD:* Significant increase in carer knowledge about BPD Pearce et al, 2017: PD-KASQ p=.001; large effect size *d*=1.33 *Oxford Friends and Family Empowerment Service:* Non-validated satisfaction questionnaire suggested that carers have improved understanding of their relative. Knowledge about PD was not measured in the other eight studies
Impact on person with BPD	Child Behaviour Check List (CBCL) [46] Youth Self-report (YSR) ; Achenbach, 1991) [47] Reynolds' Adolescent	*Multi-family DBT skills for adolescents:* Significant improvement in BPD symptoms in 'cared-for' adolescent, as rated by self-report and by parent; no evidence as to whether change is due to carer involvement in treatment. Woodberry & Popenoe, 2008: CBCL p=.24; RADS p<.001 Uliaszek et al, 2014: CBCL items ranging from p=.003 to p-.038; YSR not significant

	Depression Scale (RADS) [48] Daily Diary of Critical Incidents [35]	Impact of treatment on the family member with BPD was not measured in the other eight studies *MBT-Families And Carers Training & Support:* Significant reduction in number of critical incidents (e.g. self-harm, aggression) Bateman & Fonagy, 2019: p<.001 significant treatment effect in comparison to waiting list group.