BPD Community Relational Support

Final project report

October 2022

Acknowledgements

Acknowledgement of Country

The University of Melbourne and *BPD Community* acknowledge and pay our respects to the Traditional Owners – the Wurundjeri and Boon Wurrung people of the Kulin Nation – of the land on which this work took place. This land was never ceded, and always was, always will be, Aboriginal land.

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Abbreviations and acronyms

BD	bipolar disorder
BPD	borderline personality disorder
EE	expressed emotion
F&F	Friends & Family Group
DBT	dialectal behaviour therapy
DSM	Diagnostic and Statistical Manual of Mental Disorders
MDD	Major depressive disorder
PD	personality disorder
UoM	University of Melbourne

Glossary

borderline personality disorder	A complex mental illness affecting a person's ability to regulate their emotions and impulses, their sense of self, and impacting relationships with others. BPD is easy to understand in terms of five domains of dysregulation: emotional, behavioural, relational, cognitive and identity, with relational dysregulation considered a core domain. Individuals may receive a diagnosis of BPD using set criteria, with those who do not meet diagnostic criteria considered to have BPD traits.
community members	Refers to members of *BPD Community*, both those with a diagnosis of BPD and those who love and care for them as family, friends and carers, mental health professionals and clinicians.
lived experience of BPD	Applies to anyone with a diagnosis or who lives with features of BPD, as well as any family member, relative, carer, friend or professional who has a relationship, connection, or who works with BPD and the *BPD community*.
relational support	An area of learning and intervention, focused on social, relational, and interpersonal domains of people's lives, with the aim of improving connections and building networks that support recovery and wellbeing.
BPD-informed relational support	Involves the teaching of the techniques and skills that a person can use to actively improve their relationships with loved ones. It recognises that people with lived experience of BPD, including family members and friends, can be challenged and damaged in their relationships, but that working towards more positive relationships is possible and valuable. *BPD Community* focuses on addressing 'relational dysregulation' as a core domain of BPD and the ways in which this domain affects all others in a person's life.

Executive summary

Background

Borderline personality disorder (BPD) is a complex mental illness affecting a person's ability to regulate their emotions and impulses, to have a healthy sense of self, and to form and maintain stable relationships with others. It affects approximately 1.8% of global populations (Winsper et al., 2020), though some studies in countries comparable to Australia place prevalence estimates closer to 6% (Grant et al., 2008).

In 2020, SANE Australia released a landmark report on stigma and discrimination and living with complex mental health issues (Groot et al., 2020). Out of 14 different life domains explored in terms of experienced and anticipated stigma and withdrawal from opportunities, participants endorsed and were most concerned about relationships. While results for participants with BPD are not disaggregated, the results of this study highlight the concerns around stigma and discrimination, particularly in the domain of relationships, that people living with complex mental health issues such as BPD experience, anticipate, and are impacted by.

For people living with BPD, and to an extent for their loved ones and carers, conversations and available supports are now moving more towards a focus on living well and building healthy relationships, rather than on pathology, discrete symptom reduction, and deficit-based models of treatment (Ng et al., 2016), though significant ongoing work is needed to improve experiences and supports towards recovery. In the context of the particular challenges and domains of life affected by BPD, relational approaches to treatment and recovery are noteworthy in creating and fostering personal relationships as environments that support healing, empowerment and wellbeing for all involved.

> 'A 'relational approach' is a way of interacting or communicating with others that embodies core values such as respect, inclusiveness, honesty, compassion, cooperation and humility.' (Brookes, 2022).

Relational approaches include mechanisms to build and rebuild relationships through interpersonal skills (see Section 1.2 for further details), and relational support involves the learning and teaching of those techniques and skills that a person can use to actively improve their relationship with their loved ones. BPD-informed relational support recognises that a core domain of BPD is relational dysregulation, which can lead to familial trauma for the person with BPD as well as for their family members. It recognises that people with lived experience of BPD can be challenged and damaged in their relationships, but that working towards recovery and more positive relationships is a valid and valuable undertaking.

Relational support approaches and models of care for people with BPD as well as their family, friends, carers, and professional workers, are an emerging area of focus for research. Fitzpatrick, Liebman and Monson (2021) point to a significant lack of attention in the research literature to the interpersonal elements of how BPD pathology is maintained in adulthood, particularly in the context of informing BPD interventions and treatment targets.

Exploring BPD Community relational support

This project aimed to explore relational support as an area of learning and intervention contributing to more positive relationships, recovery, and wellbeing for people with lived experience of BPD. This study focused on family, friends and carers of someone with BPD as a priority group in the BPD community, and an identified gap in research and literature. This project aimed to contribute to the emerging discourse surrounding the role of relationships and social connection in recovery from BPD and support for family, friends, and carers, and provide an initial evidence base for further inquiry in this under-researched and complex area.

As a collaborative project between *BPD Community* and the University of Melbourne, this project also aimed to generate research evidence to inform *BPD Community's* program of work and future grant-

seeking and funding activities, particularly as they relate to further research collaborations and exploration of relational support as an effective model contributing to recovery and quality of life for people with lived experience of BPD.

Key findings

What does the research literature say about 'relational support' approaches to wellbeing and recovery, support for family, friends, and carers of people with borderline personality disorder?

Despite the high prevalence of personality disorder (PDs), carers and loved ones of people with PDs have been stigmatised and not given as much attention in the research literature as people with the diagnosis (Bailey, 2013).

Emerging evidence indicates that family and friends, the community and the wider social context are all important for recovery, though the research around this has so far been limited (Williams, 2012). Our literature review revealed seven family and friends-based interventions which contained a relational component:

- Project Air (Grenyer et al., 2019)
- MBT-FACTS (Bateman & Fonagy, 2019)
- Kindred (Gleeson et al., 2021)
- DBT-FST (Ekdahl, 2014)
- Family Connections (Hoffman et al., 2007; 2005)
- GOER (Mannion et al., 2022)
- ATraPA-FAL (Mayoral et al., 2020)

These family programs had similar overall aims. They comprised elements of psychoeducation, and aimed at providing/building support, and developing relationship skills between family and friends and the loved one with BPD. Where programs differed was mostly in the mode of delivery (online and face-face), duration (from a couple of weeks to months), intensity and theoretical orientation (e.g., based on DBT, mentalisation or relational).

Two programs that articulated a directly **relational** approach were Kindred (Gleeson et al., 2021) and Project Air (Grenyer et al., 2019). Both these programs were evaluated using RCTs, with promising results, though sample sizes of participants were small. The remaining five programs we reviewed mostly delivered their interventions using a DBT approach to skills training, which has a relational component. One of them used a mentalisation approach. Only one of these programs (ATraPA; Mayoral et al., 2020) has not been evaluated. Results from these evaluations indicated that all of these approaches may improve outcomes for family functioning and reduce burden (Bateman & Fonagy, 2009).

- Family programs that were delivered in a group format all reported participant appreciation of peer support from and connection with members (Bateman & Fonagy, 2019; Ekdahl et al., 2014; Grenyer et al., 2019; Mannion et al., 2022; Penney et al., 2008).
- Improvement in relationship with loved one/reduction in adverse family events (Bateman & Fonagy, 2019; Grenyer et al., 2019)
- Reduction in expressed emotion (Gleeson et al., 2021; Grenyer et al., 2019)
- Improvement in carer depression/anxiety or burden (Bateman & Fonagy, 2019; Gleeson et al., 2021; Penney et al., 2008)
- Improved empowerment, knowledge, and attitude (Bateman & Fonagy, 2019; Ekdahl et al., 2014; Gleeson et al., 2021; Mannion et al., 2022)
- Only ATraPA-FAL directly addressed emotional dysregulation of parents, but this was not evaluated (Mayoral et al, 2020).

What has *BPD Community* members' experience of relational support been, and what are their thoughts about a relational support approach in terms of recovery from BPD and supporting people with BPD as a friend, family member, or carer?

- Community members found mental health systems challenging to navigate and that no other services provided support for carers of loved ones with BPD. Mental health practitioners and medical systems often did not understand BPD or the experience of being a carer, family member or friend of someone with BPD. They reported being told by health services that their loved one was either too ill or not ill enough for their services, leaving family and friends taking on the care of their loved one without support.
- Community members articulated that they experienced unique relational challenges being a family member or friend of someone with BPD. The relational support provided by *BPD Community*, and the skills developed through *BPD Community* Family and Friends Group provided participants with lifelines and anchors. They reported being greatly helped by the skills they learned in relating to their loved one with BPD.
- Community members reported feeling grounded by their involvement in the Family and Friends Group and they described valuing the sense of community and unconditional support immensely, as this was not always present in their external support networks. Participants articulated the importance of belonging to a community that understood them and their experiences.
- Involvement in *BPD Community* helped participants to increase their understanding of what BPD is, how it can manifest for different people, and the evidence-based strategies that can support recovery and wellbeing for people with lived experience. Participants described particularly their relief at being given practical strategies that they could apply in their everyday lives and relationships, underpinned by accessible and values-based theory.
- Participants described evolutionary learning, and the opportunities they had to practice and develop their skills within the Family & Friends Group. Practice and learning over time increased a sense of peace and pride in their achievements and approach, and had positive impacts on their loved ones.
- Overall, community members reported consistent, in-depth learning and support they received through *BPD Community* and the Family & Friends Group. They were extremely grateful to have found this community.

What do *BPD Community* members see as the most important aspects of a relational support approach in terms of recovery from BPD and supporting people with BPD as a friend, family member or carer?

- Relational support helped participants cultivate a sense of self-acceptance, and they learned to understand this as a foundation to any relational interaction. Participants described the Family & Friends Group as a place where they learnt theory behind self-acceptance, and strategies to help them recognise what they could control and what they could not, and accept their situations with a sense of peace. Although some participants spoke about this as a foundation applicable to any relational interaction, they emphasised that the particular dynamics of BPD made this absolutely essential to being able to move towards recovery, ongoing wellbeing and positive relationships with their loved one, as well as a positive relationship with themselves.
- Relational support from *BPD Community* provided participants with a sense of validation and empowerment of self as well as their loved one with BPD. The relational approach helped them to achieve a sense of validation of their past as well as current efforts. The Family & Friends Group provided a safe space for community members to come together to practice their learnings, build a

sense of hope for the future, as well as acknowledging the difficulties. The opportunity to practice was reflective of everyday nature of relationships, and the changes that people go through; and an anchor they returned to and wanted to give back to help others.

- Closely connected to self-acceptance, validation of the participant's own individual emotional struggles and needs was a focus for participants in interviews. Learning about validation as a powerful tool and strategy in being able to support a loved one was positively spoken about, but always in conjunction with the impact these strategies had when used to address the participant's own emotions as well. Participants spoke about being able to better recognise and manage their own past traumas, feelings of co-dependence or other issues that were often uniquely connected to BPD illness experienced by their loved one. This process mirrored the experiences that they saw their loved one with BPD needing to go through on their journey towards healing and self-acceptance. In embarking on their own journey of self-healing and acceptance, they felt more able to meet their loved ones in the middle.

Comments and recommendations

Both the literature review and interviews indicated that family and friends of people with BPD receive little support from most mental health professionals, and often receive conflicting advice. They reported feeling overwhelmed and confused before becoming involved with interventions that addressed their specific concerns of how to manage the relationship with their loved ones. Where support was offered via an intervention or *BPD Community,* participants reported improvements in burden of care and gratitude in improving their understanding of their loved one with BPD.

BPD Community members especially articulated that they received much support in the form of peer relationships as well as manuals and psychoeducation from *BPD Community*. They reported a sense of isolation prior to becoming involved in the Family and Friends Group. Trying to uphold relationships and care when BPD is characterised by instability in this domain often felt isolating as they navigated their love and commitment, frustration, grief, and hope from day to day. Research on family and friends in the literature also revealed the isolation faced, and how family and carers valued meeting other people who shared similar experiences, to the extent that they sometimes continued to meet after the interventions had concluded. The continuing nature of *BPD Community* makes this a unique strength compared to other interventions, most of which were of a finite duration.

Participants were acutely mindful of the limited resources, time, and funding that *BPD Community* operates with. In speaking about the future for the organisation and how they would like to see relational support taken forward, participants referenced the need for consistent, increased funding to be able to build on current activities and access to support for more individuals and families with lived experience of BPD.

Recommendation #1: continue to invest in dedicated website and evidence-based materials.

Literature indicates poor understanding of BPD in family and friends prior to engaging in psychoeducation or skills-based BPD interventions (Carter et al., 2015). The presence of a dedicated website with available resources has been important for participants as they sought support and information, and they emphasised the recognition this warranted in reaching more people with lived experience of BPD. This is especially important for family and friends struggling to navigate health systems focused predominantly on medical treatment of the person diagnosed with BPD. Being able to find something focused on carer needs and wellbeing was described as a lifeline with significant positive impact.

Recommendation #2: Increase accessibility of psychoeducation materials

Materials and their accessibility were a key focus for participants, who all emphasised that the opportunity to reach more people seeking support would be enabled by increasing the availability of materials. Participants provided suggestions for how the materials and resources around relational support and for

family and friends of people with BPD could be enhanced or taken forward. These suggestions most often involved translation of existing materials into different formats and use of different platforms to increase accessibility (e.g., social media, podcasts, YouTube), and echoed those found in the literature (Ekdahl et al, 2014).

Recommendation #3: Build on peer support activities

Participants acknowledged that community sharing, support and meeting people who had similar experiences helped them no longer feel isolated and overwhelmed. They valued meeting other community members and wished to expand on the opportunities to interact with other members. They suggested:

- Provision of face-to-face and online formats to meet, when possible;
- Increase the number of groups available, including:
    - Groups held at different/more frequent times, running concurrently, to support those with limited availability;
    - Localised and expanded groups (such as regional areas, interstate).
- Develop a mentorship or 'buddy' program for people with BPD, who they can contact for one-on-one support.

Literature on formal peer support programs suggests these options would be beneficial (Barr et al, 2020).

Recommendation #4: Raise awareness of BPD via communications that target existing campaigns

To raise awareness of and engagement with BPD, collaborating with high profile advocates or personalities to shine a light on materials and support available has been suggested. These might also be recorded conversations or appearances on podcasts, distributed through mainstream channels (e.g., Spotify). Targeting specific existing campaigns (e.g., R U OK day) to bring a BPD-informed lens and increase public awareness of the nuanced, often unique challenges that face those with lived experience of BPD, and what to do when the answer is 'no' to the question of 'are you okay?', also presents opportunities to increase constructive conversations.

Recommendation #5: Tailor materials to healthcare services to support referrals to BPD Community

Creating information tailored to healthcare referral contexts to maximise the likelihood of people receiving timely information following a crisis or upon discharge from psychiatric care is recommended based on interview participants insights and findings from the literature. This could include summary information about BPD, an overview of *BPD Community's* work, and contact details for further information and support. Creating learning modules, tip sheets, and video series that could be available via the *BPD Community* website to support people who may need immediate support or information, or who may not be ready to be part of a group, would also complement this work.

Recommendation #6: Enlist the help of trained mental health professionals who understand BPD

Have paid, trained professional facilitators to support groups and links to services for participants. Participants expressed a desire to be connected with trained professionals, especially given their difficulty accessing such help directly through traditional mental health services.

Recommendation #7: Make BPD Community sustainable by securing funding and volunteer capacity

Participants emphasised the importance of the following, in order to make the most of the potential of *BPD Community's* programs and work:

- Government recognition and funding contributions
- Consistent funding and collaboration with other community sector and not-for-profit organisations
- The need for more volunteers, and increased support to make the most of volunteer time and expertise

1. 1. Introduction and background

1.1. Borderline personality disorder

Borderline personality disorder (BPD) is a complex mental illness affecting a person's ability to regulate their emotions and impulses, to have a healthy sense of self, and to form and maintain stable relationships with others. It affects approximately 1.8% of global populations (Winsper et al., 2020), though some studies in countries comparable to Australia place prevalence estimates closer to 6% (Grant et al., 2008). BPD is a relative newcomer to recognised personality disorders, first appearing in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) in 1980. While BPD has been the subject of significant research since then, there is ongoing debate about how it is best conceptualised, diagnosed and treated, particularly in relation to categorical or dimensional methods of diagnosis and conceptualisation (Irwin & Malhi, 2019). Stigma, misunderstanding, and distress continue to be major themes in the experiences of people with BPD and their families, friends and carers trying to support them in accessing healthcare systems and support (Carrotte, Hartnup, & Blanhcard, 2019).

In 2020, SANE Australia released a landmark report on stigma and discrimination and living with complex mental health issues (Groot et al., 2020). Out of 14 different life domains explored in terms of experienced and anticipated stigma and withdrawal from opportunities, participants endorsed and were most concerned about relationships. Rejection, estrangement, and unfair treatment were reported as core concerns, with heightened concern relating to unfair treatment (p.87). Seventy-seven percent of participants who took part in the study reported living with two or more complex mental issues, and BPD accounted for 25.5% of participants with a formal diagnosis of complex mental illness (p.53). While results for participants with BPD are not disaggregated, the results of this study highlight the concerns around stigma and discrimination, particularly in the domain of relationships, that people living with complex mental health issues such as BPD experience, anticipate, and are impacted by. Two out of three key recommendations for action, based on this report by SANE, concern carers and expanding support available to them (SANE Australia, 2020).

1.2. Recovery and relational approaches

In recent decades, progress in understanding, conceptualisation and effective treatments have shifted discussions of BPD into more recovery-oriented territory, formalised in Australia by mechanisms such as the National Framework for Recovery-oriented Mental Health Services (Australian Health Ministers' Advisory Council, 2013a; 2013b). Differing constructs, definitions, and descriptions of recovery exist. In the national framework, recovery is conceptualised as 'being able to create and live a meaningful and contributing life in a community of choice with or without the presence of mental health issues' (2013a, p.11), and common characteristics of recovery are listed as the following:

- a unique and personal journey
- a normal human process
- an ongoing experience and not the same as an end point or cure
- a journey rarely taken alone
- nonlinear—frequently interspersed with both achievement and setbacks.

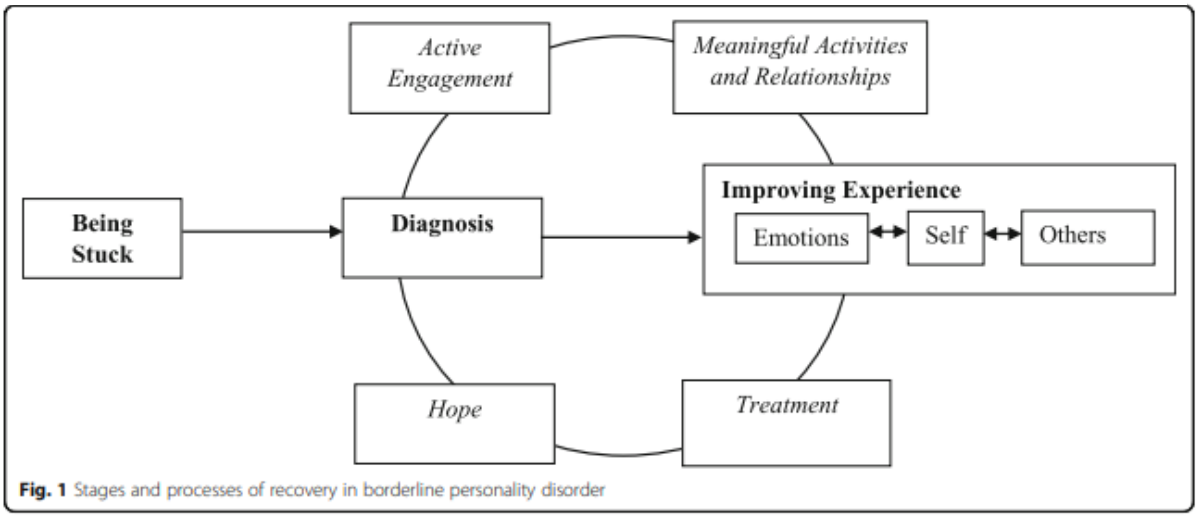
For people living with BPD, and to an extent for their loved ones and carers, conversations and available supports are now moving more towards a focus on living well and building healthy relationships, than on pathology, discrete symptom reduction, and deficit-based models of treatment (Ng et al., 2016), though significant ongoing work is needed to improve experiences and supports towards recovery. In exploring the key elements for trajectories of recovery and improvement across life domains, Grenyer et al. (2022) highlight the 'centrality of achieving the capacity to 'love and work' in fostering a sense of personal recovery' (p.138), including the importance of meaningful relationships with others. Exemplified in the

quote by Deegan below, the concept of recovery as it applies particularly for people with BPD and their loved ones cannot be separated from relationships and relational domains of life.

> 'The recovery process is more accurately described as a series of small beginnings and very small steps […] Recovery cannot be forced or willed. However, environments can be created in which the recovery process can be nurtured like a tender and precious seedling.' (Deegan, 1988, p.11, cited in Australian Health Ministers' Advisory Council, 2013b, p.22).

Ng et al. (2019) describe recovery as an interaction between stages and processes (see Figure 1), and delineate clinical recovery and personal recovery. They highlight that 'whilst clinical aspects are targets of specialist interventions, greater emphasis on fostering individual motivation, hope, engagement in relationships, activities, and treatment, may be required within clinical practice for a holistic recovery approach' (p.1).

Figure 1: Stages and processes of recovery in borderline personality disorder (Ng et al, 2019, p.4)

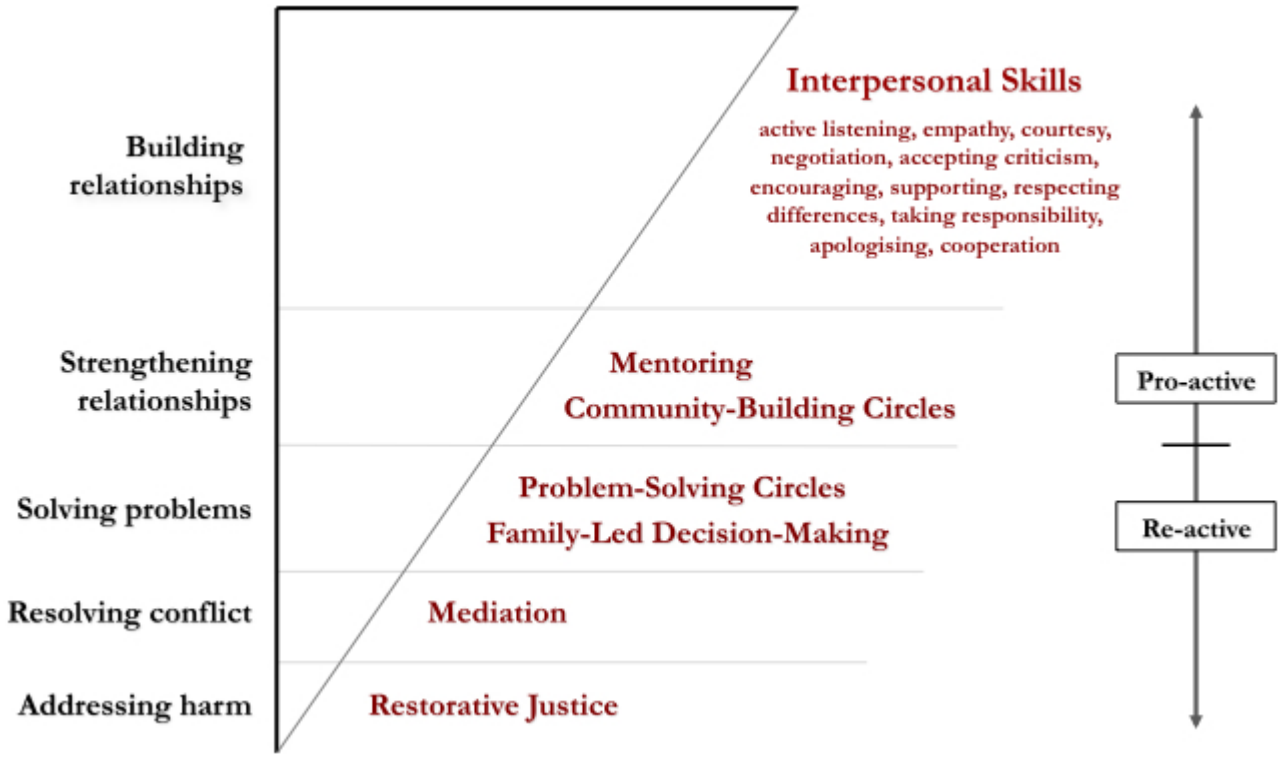


In the context of the above conceptualisations of recovery, and the particular challenges and domains of life affected by BPD, relational approaches to treatment and recovery become increasingly applicable and noteworthy in creating and fostering personal relationships as those environments that support healing, empowerment and wellbeing for all involved.

> 'A 'relational approach' is a way of interacting or communicating with others that embodies core values such as respect, inclusiveness, honesty, compassion, cooperation and humility.' (Brookes, 2022).

Relational approaches include mechanisms to build and rebuild relationships through interpersonal skills, and as conceptualised by Brookes and illustrated in Figure 2 below, can sit along a continuum of reactive or proactivity in those who seek to apply them.

Figure 2: Relational approaches



Relational support involves the teaching of the techniques and skills that a person can use to actively improve their relationship with their loved ones, such as the interpersonal skills listed in Figure 2. Initially the skills and techniques are designed to focus on the other person in the relationship, to understand more their situation but ultimately can leads to deeper self-knowledge and the personal use of skills and techniques to improve the relationship with the self. BPD-informed relational support recognises that a core domain of BPD is relational dysregulation which can lead to familial trauma for the person with BPD as well as for their family members. It recognises that people with lived experience of BPD can be challenged and damaged in their relationships, but that working towards recovery and more positive relationships is a valid and valuable undertaking.

Theoretical perspectives on relational support emphasise the potential for positive, long-term impact across multiple domains of wellbeing, with specific interpersonal processes underlying these effects (Feeney & Collins, 2015). Relational support approaches and models of care, for people with BPD as well as their family, friends, carers, and professional workers, are an emerging area of focus for research. Fitzpatrick, Liebman and Monson (2021) point to a significant lack of attention in the research literature to the interpersonal elements of how BPD pathology is maintained in adulthood, particularly in the context of informing BPD interventions and treatment targets. Proposing the borderline interpersonal-affective system (BIAS) model, they suggest that attending to interpersonal contexts and relationships can optimise BPD treatment and simultaneously improve the mental health and wellbeing of significant others such as family and friends of people with BPD (Fitzpatrick, Liebman & Monson, 2021). The connection between intrapersonal and interpersonal functioning is emphasised and recommended as an area for promising, positive support and intervention, though this model is targeted at consumers with BPD, and not their family and friends.

1.3. Relational support for family, friends, and with lived experience of borderline personality disorder

Family, friends, carers, and professionals working with people with BPD experience a high burden of care, and often face challenges associated with their lived experience of BPD across physical, social, emotional, and financial domains. In 2012, these groups were identified as priorities for future research and support

(NHMRC, 2012, p.134). In 2013, the National Health and Medical Research Group (NH&MRC) released practice guidance for working with the BPD community, including family, friends, and carers (NH&MRC, 2013). This included identification of priority research and practice development areas, such as alternative modes for delivering BPD psychoeducation and therapy; support, psychoeducation and supervision of staff who manage people with BPD; stigma; the role of families in recovery; and effective programs to support carers, including young carers, of people with BPD (p.133-134).

A recent systematic review by Sutherland, Baker and Prince (2020) identified promising but limited research evidence that interventions for carers contribute to better outcomes for people with BPD, concurrently improving carer wellbeing and reducing carer burden. Increased knowledge, education and understanding about BPD as a diagnosis and its treatment have been explored as empowering to family members of people with a BPD diagnosis (Kay, Poggenpoel, Myburgh & Downing, 2018), though views and contributions of family and carers are still often absent from the research literature (Ng, Bourke, & Grenyer, 2016). A recent exploration of how peer workers can support treatment for BPD identified significant value, hope and connectedness for both consumers and carers accessing peer workers with lived experience of BPD (Barr, Townsend & Grenyer, 2020). For carers being supported by a carer peer support worker, the sense of shared understanding of unique relational experiences and hope for recovery was described as a comfort and source of strength in their work, and the non-judgemental relationship highly valued in supporting wellbeing.

While there has been some evidence of improved general awareness and understanding of BPD from consumers and professionals following the release of the NHMRC guidelines (Proctor, Lawn & McMahon, 2021), pervasive, ongoing issues within the Australian mental health system have also been identified in recent literature (Carrotte, Hartnup, & Blankchard, 2019). This includes practice that does not align with a recovery model of mental health, blames carers for a person's difficulties with BPD, and that perpetuates stigma and misunderstanding as well as a complex system of care associated with significant financial burden for consumers (Carrotte, Hartnup, & Blanhcard, 2019). Compared to control groups, people with BPD have been reported to have smaller social networks, with relationships involving more conflict and criticism, and less social support (Lazarus & Cheavens, 2017). Family, friends and carers of people with BPD face uniquely challenging aspects of relationships, given BPD's impact on social and emotion functioning, and when trying to support a loved one with a diagnosis of BPD, often face exclusion and discrimination by the health sector (Lawn & McMahon, 2015).

1.4. BPD Community: Exploring relational support

BPD Community is a peer-led, not-for-profit organisation based in Victoria that works to support recovery, and reduce stigma and discrimination, associated with BPD. *BPD Community* provides education, advocacy, and support services to people with BPD, their families, friends, carers and people working with BPD. *BPD Community's* approach is based on values of collaboration, acceptance, respect and empathy, and their primary goals are (BPD Community, 2017):

- to educate, support and advocate for people living with borderline personality disorders (BPD) in Victoria;
- to provide education and support services to carers and, or family members of people with BPD; and
- to provide education for clinicians and people working with people with BPD and their families.

BPD Community have recently expressed their position on both the prevalence of BPD in the Australian community (Pierce & Mullen, 2020), with a review and explanation for their rationale both grounded in the organisation's lived experience of BPD and supporting the BPD community, as well as in research evidence.

BPD Community also explicitly attend to and address the concerns of carers of people with BPD. In 2015, consultation with carers in *BPD Community* resulted in an endorsed articulation of the needs and desires of

carers in relation to their loved ones with BPD, themselves, and for the BPD community, summarised in Table 1 (BPD Community, 2017).

Table 1: BPD Community carer concerns and wants

For loved ones with BPD	For carers themselves	For the BPD community
• An early and accurate diagnosis; • Emergency Department response based on knowledge about BPD and commitment to the addressing needs of people with BPD; • Treatment readily available in the adequately resourced public system; • A mental health system (private and public) that responds appropriately; • To be a part of the treatment process.	• Training in the techniques to help us support our loved ones; • Support for ourselves in our roles as carers; • Access to treatment in the public health system for our own mental health needs; • Access to the latest research and information on BPD.	• Research on all aspects of BPD, in particular the prevalence of BPD in Australia and in special communities such as prisons or communities which have experienced trauma; • A funded strategy to address the stigmatising and discrimination that affects the BPD community, and therefore the wider community, one that targets the clinical and helping professions; • A public and private mental health system that is responsive to the needs of the BPD community.

BPD Community have run a Family & Friends (F&F) Group since 2015 as part of their work to support family, friends and carers of people with BPD. The group runs monthly, and during the COVID-19 pandemic, was convened virtually. The group is ongoing, and provides both support and education to members. Education materials and resources, and we all as the techniques and strategies used to run the group, are informed by current best-practice and research, as well as lived experience. Members are welcome to attend the group for as long as it is useful to them, and encouraged to support each other as a community.

More information can be found at: https://www.bpdcommunity.com.au/family-friends/family-and-friends-group

2. Research aims, questions and methodology

2.1. Project aims and research questions

This project aimed to explore relational support as an area of learning and intervention contributing to more positive relationships, recovery, and wellbeing for people with lived experience of BPD. Aiming to address gaps in research for identified priority groups in the BPD community, this project focused on the experience of relational support for family members, friends, and carers of someone with BPD. This project aimed to contribute to the emerging discourse surrounding the role of relationships and social connection in recovery from BPD and support for family, friends, and carers, and provide an initial evidence base for further inquiry in this under-researched and complex area.

As a collaborative project between *BPD Community* and the University of Melbourne, this project also aimed to generate research evidence to inform *BPD Community's* program of work and future grant-seeking and funding activities, particularly as they relate to further research collaborations and exploration of relational support as an effective model contributing to recovery and quality of life for people with lived experience of BPD.

This project addressed the following research questions:

1. What does the research literature say about 'relational support' approaches to wellbeing and recovery, support for family, friends, and carers of people with borderline personality disorder?
2. What has *BPD Community* members' experience of relational support been, and what are their thoughts about a relational support approach in terms of recovery from BPD and supporting people with BPD as a friend, family member, or carer?
3. What do *BPD Community* members see as the most important aspects of a relational support approach in terms of recovery from BPD and supporting people with BPD as a friend, family member or carer?

2.2. Project design and methodology

In order to address the research questions, this project included a literature review component, complemented by qualitative semi-structured interviews with members of partner organisation *BPD Community*.

University of Melbourne researchers conducted a literature review to address the research questions and begin building a picture of what evidence exists in the literature around relational support in the context of BPD. The literature review drew on scoping review and rapid review methodologies, using an initial structured search strategy across five databases. This was complemented by additional source reference checking, shortlisting of articles for inclusion, and collaborative analysis and discussion of findings.

The interview component of this project was conducted in partnership with *BPD Community*, and received ethical clearance through the University of Melbourne Human Ethics Research Committee (ethics ID: 23982). BPD Community assisted the University of Melbourne team with recruitment of community members with lived experience of BPD, focusing on friends, family members and carers. This component was critical in bringing forward the perspectives of people with lived experience of BPD, providing insight into priorities and concerns around relational support.

2.3. Limitations

This project was concerned with relational support in the context of BPD, family, friends and carers. The literature search strategy was accordingly limited to published, peer-reviewed research articles that focused on these areas. This meant that grey literature, reports, theses and protocols were not captured in this review, and should be the focus of further research in order to integrate insights and best practices from these sources.

Given the small scale of this project, the number of interviews conducted with members of BPD Community was limited (n=5). All interviewees contributed insightfully and generously, however the research team acknowledge that the findings from this sample are illustrative rather than generalisable.

3. Literature review: Exploring relational support in the context of BPD

3.1. Methods

The literature review component of this project was conducted drawing on systematic scoping review searching (Arksey & O'Malley, 2005) and critical interpretive synthesis methods (Dixon-Woods et al, 2006). This incorporated a structured search strategy of five online databases, using the search terms provided in Table 2. The five databases were APA PsycINFO, CINAHL Complete, Embase + Embase Classic, MEDLINE and SocINDEX. Search terms were developed by the researchers, including a consultation with library experts at the University of Melbourne. They were then tested and refined to maximise relevance of results, prior to a final search of the five databases conducted on May 4, 2022.

Table 2: Database search terms

Search	Search terms	Notes
1	BPD or borderline personality or borderline personality disorder	Focusing search on borderline rather than other personality disorders – a lot of articles concerned with narcissistic/anxiety/bipolar came up in testing
2	(relational support or ((social or support) adj2 network*) or ((relational or relation* or social or interpersonal or recover*) adj2 (support or approach* or model* or framework* or coaching or therap* or practice* or train* or perspective* or skill* or educat* or function*)))	Relational support and variations on how this might be described/applied
3	famil* or friend* or partner* or carer* or peer* or practitioner* or clinician* or worker*	Groups we are interested in who might be participating in relational support
4	1 and 2	Combines focus on BPD, relational support
5	3 and 4	Limits to groups of interest

The final search returned a total of 703 references across the five databases as presented in Table 3. Search results were imported Covidence[1], an online systematic literature review management platform. Duplicates were removed using Covidence's automated function (313), resulting in 390 final references to be screened. Two additional duplicates were identified and removed manually during screening, resulting in 388 final references.

Table 3: Database search results and final references

Databases searched	Results returned
APA PsycINFO	215
CINAHL Complete	95
Embase + Embase Classis	128
MEDLINE	217
SocINDEX	48
TOTAL initial results	**703**
Duplicates removed in Covidence	**315 (313 automated + 2 manual)**
TOTAL final references for screening	**388**

[1] https://www.covidence.org/

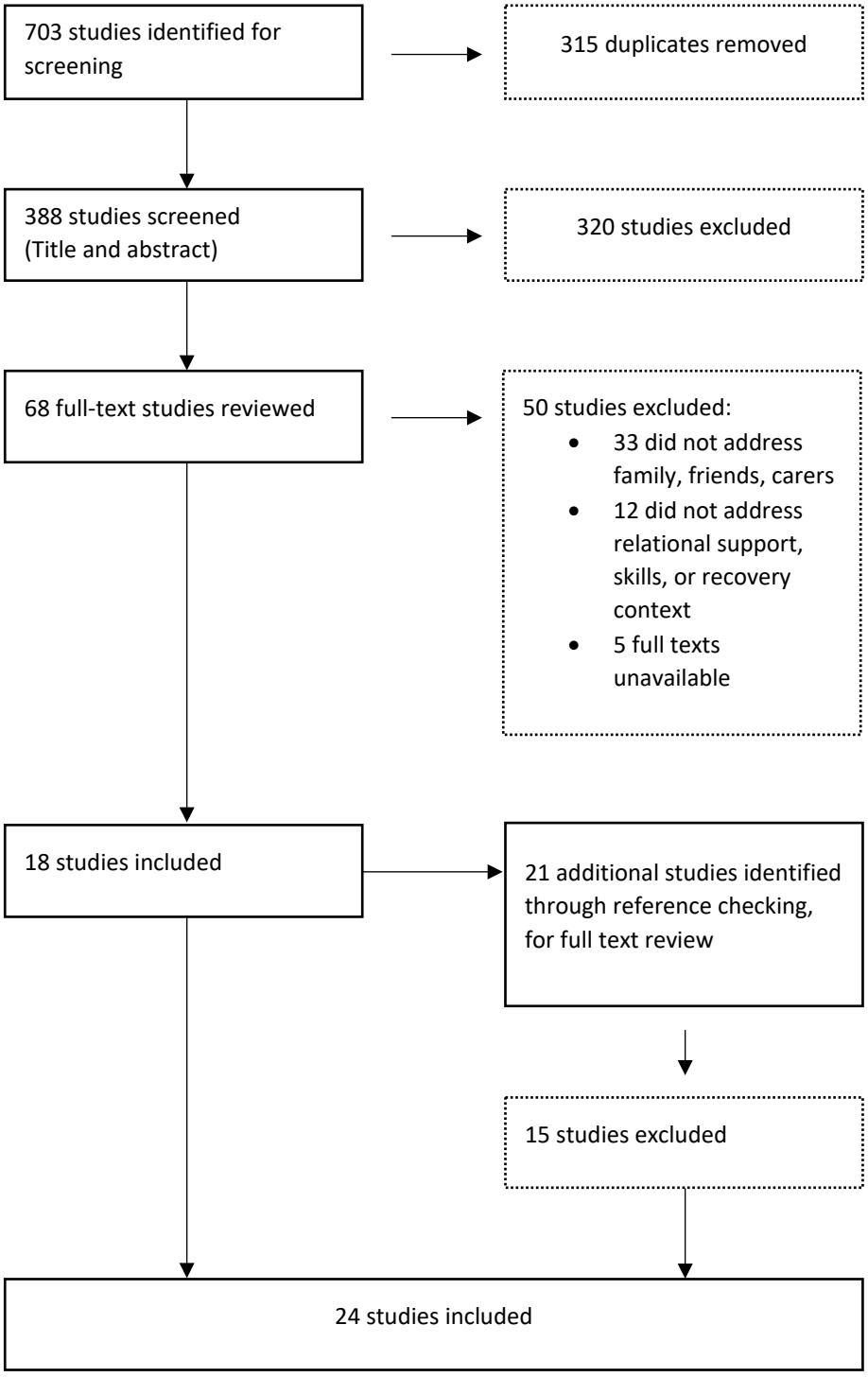
Using Covidence, all 388 titles and abstracts were screened by one researcher using broad inclusion and exclusion criteria, provided in Table 4. This initial screening involved a 'yes', 'maybe', and 'no' vote on each article. Articles deemed irrelevant to the current project were voted 'no'. The researchers held regular check-ins and discussions to ensure these decisions were consistent.

Table 4: Initial screening inclusion and exclusion criteria

Broad inclusion criteria for initial screening	Broader exclusion criteria for initial screening
• addresses relational/social support in the context of borderline personality disorder or a closely related personality disorder (e.g., bipolar) • addresses relational or social support for mental disorders like anxiety or depression relevant for borderline personality disorder • includes reference to insights/evidence from programs, studies, trials, case studies, feedback or projects that contribute to understanding relational support in the context of personality disorders • addresses relational support for people with lived experience of borderline personality disorder (or a closely related personality disorder), including people with a diagnosis, family members, friends, carers, workers or professionals • address relational or social support in the context of recovery or living with a personality disorder • refereed journal article • English language	• non-English language • does not address relational/social support • does not address personality disorder context • protocol papers, books, book reviews, poster presentations • addresses relational or social support in the context of BPD development only • nothing pre-DSM-III (1990)

All 'yes' and 'maybe' votes were reviewed by both researchers and 68 articles agreed to progress to full text review. Full text review was conducted collaboratively by both researchers, and a final list of 24 articles agreed on for inclusion. This process is illustrated in Figure 3.

Figure 3: Article screening and selection process



The 24 included studies are summarised in Table 5. These included a range of qualitative, mixed methods, outcome and randomised controlled trials, as well as descriptive and reflective pieces.

Table 5: Final articles included in review

Author(s) & year	Title	Study design	Country	Key findings
Barr, Townsend & Grenyer (2020)	Using peer workers with lived experience to support the treatment of borderline personality disorder: a qualitative study of consumer, carer and clinician perspectives	Qualitative research	Australia	All groups emphasised the hope, connection and validation that peer workers provided. Two models of peer support work emerged with differences regarding the level of integration or complementarity to mental health teams.
Bateman & Fonagy (2019)	A Randomized Controlled Trial of a Mentalization-Based Intervention (MBT-FACTS) for Families of People With Borderline Personality Disorder	Randomised controlled trial	UK	Both groups showed improvement on measures of depression, total anxiety and burden; immediate-intervention group experienced more empowerment and sense of well-being than delayed intervention group. MBT-FACTS reduced reported adverse incidents for families.
Bernardon & Pernice-Duca (2012)	Integrating Recovery and the Narrative Attachment Systems Perspective to Working Through Borderline Personality Disorder	Literature review/summary	United States	Attachment theory, narrative therapy and reflective functioning provide a useful framework to explore and explain changes in relationships and personal identity and functioning in relation to BPD and family.
Carter, Sired & Gordon (2015)	Evaluation of borderline personality disorder awareness workshops for service users and carers	Outcome study	UK	Workshops provided validating and safe learning environments, and opportunity to meet others in similar situations. Workshops acted a catalyst for a learning journey regarding BPD, self-discovery and future planning for change.
Ekdahl, Idvall & Perseius (2014)	Family Skills Training in Dialectical Behaviour Therapy: The Experience of the Significant Others	Descriptive mixed methods	Other: Sweden	Life before DBT-FST was a struggle, with DBT-FST providing hope for the future, strategies helpful in daily life. Anxiety and depressive symptoms significantly decreased for those with high initial levels.
Fitzpatrick, Wagner & Monson (2019)	Optimizing Borderline Personality Disorder Treatment by Incorporating Significant Others: A Review and Synthesis	Systematic review	Canada	Interventions that incorporate SOs may be able to more directly and effectively target BPD and the interpersonal context, expediting and optimising individual interventions. Disorder-specific or SO-assisted formats may provide improved outcomes for all involved.
Flynn et al (2011)	Family Connections versus optimised treatment-as-usual for family members of individuals with borderline personality disorder: non-randomised controlled study	Randomised controlled trial	Ireland	FC participants showed significant improvement on all measures, while OTAU participants showed some but not significant change in the same direction.
Gleeson et al (2020)	A pilot trial of moderated online social therapy for family and friends of young people with borderline personality disorder features	Pilot outcomes study	Australia	Carer burden, stress, expressed emotion, family communication, quality of life, functioning, coping and perceived knowledge of BPD improved at follow-up. Kindred was shown to be acceptable, usable and safe.
Greer & Cohen (2018)	Partners of Individuals with Borderline Personality Disorder: A Systematic Review of the Literature Examining Their Experiences and the Supports Available to Them	Systematic review	Canada	Themes of partner experiences: emotional challenges, dual roles, and lack of control. Interventions addressed only a small portion of sub-themes identified in partners' experiences. Development and evaluation of more partner-oriented programming should focus on psychoeducation, peer support, individual- and relationships-based skills development.

Author(s) & year	Title	Study design	Country	Key findings
Grenyer et al (2019)	A Randomized Controlled Trial of Group Psychoeducation for Carers of Persons With Borderline Personality Disorder	Randomised controlled trial	Australia	Intervention participants reported sustained improvements in dyadic adjustment with relatives, increased empowerment and reduced expressed emotion. Perceptions of increased ability to play active roles were also reported. Structured programs for carers extend interventions and address high burden.
Gunderson et al (1997)	Families of borderline patients: A psychoeducational approach	Literature review and program description	United States	Families report increased communication by 6 months after starting psychoeducation, and feeling less burdened. Psychoeducational multiple family group (PE/MFG) approach appears appropriate to early phases of long-term treatment.
Hoffman & Fruzzetti (2007)	Advances in Interventions for Families with a Relative with a Personality Disorder Diagnosis	Literature review/summary	United States	Most often associated with DBT, family psychoeducation programs and family education programs are becoming more available to relatives of someone with BPD. Early studies suggest these programs benefit family members and may be beneficial to their relatives with BPD as well. More research and funding is needed to develop, evaluate and improve more programs.
Hoffman et al (2005)	Family Connections: A Program for Relatives of Persons With Borderline Personality Disorder	Outcomes study	United States	Levels of burden and grief decreased, and mastery increased from pre- to post-Family Connections. No changes in depression observed.
Hoffman, Fruzzetti & Buteau (2007)	Understanding and engaging families: An Education, Skills and Support Program for relatives impacted by Borderline Personality Disorder	Outcomes study	United States	Participants showed improvements on all measures. At program completion, male and female outcomes were comparable except for grief, with women remaining higher than men.
Hoffman, Fruzzetti & Swenson (1999)	Dialectical Behavior Therapy - Family Skills Training	Program description	United States	DBT-FST aims to: 1) provide all family members an understanding of borderline behavioral patterns in a clear, nonjudgmental way; 2) enhance the contributions of all family members to a mutually validating environment; and 3) address all family members' emotion regulation and interpersonal skills deficits
Krawitz et al (2016)	Family Connection in New Zealand and Australia: an Evidence-Based Intervention for Family Members of People with Borderline Personality Disorder	Descriptive	New Zealand	Family Connections has been shown to be effective in addressing distress and morbidity for family members of people with BPD. Family Connections has been delivered at time of writing in the United States for nearly 15 years, New Zealand for seven years, and in Australia for one year with 650 people on the waiting list.
Mannion et al (2022)	Pilot project for a recovery-oriented, DBT-informed skill-building education course for families of adults with borderline personality, bipolar or major depressive disorders	Quasi-experimental	United States	The intervention was effective in reducing caregiver burden, and attitudes, knowledge and skills showed improvement in the intervention group. Particularly where inaccurate diagnoses and ineffective treatment of a loved one with emotion regulation disorder is occurring, this intervention filled an important gap in resources for families. Adaptation to virtual learning is highlighted for future development.
Marschke (1997)	An alternative support model for family members of the mentally ill: modifying dialectical cognitive-behavioural skill building (DBT)	Literature review and pilot study	United States	Dialectical cognitive-behavioural Skill Building (DBT), with minor modifications, resonates and is applicable to family members of patients with emotional disorders. The model appeals to health rather than pathology, provides skills to address problems rather than diagnoses, and holds a dialectical or relationship-

Author(s) & year	Title	Study design	Country	Key findings
				based view of reality and mental illness rather than adhering to a linear framework. Family members receive support, learn specific and applicable relationship-based skills, and have the opportunity to develop self-awareness and interpersonal effectiveness.
Mayoral et al (2020)	Development of an early intervention program for adolescents with emotion dysregulation and their families: Actions for the treatment of adolescent personality (ATraPA)	Descriptive study	Other: Spain	Presents ATraPA program, including ATraPA-TAI (intensive outpatient treatment), ATraPA-FAL (Families on the border) and group of alternatives.ATraPA-FAL is specific to parents of adolescents not taking part in ATraPA-TAI.
Miller & Skerven (2017)	Family Skills: A Naturalistic Pilot Study of a Family-Oriented Dialectical Behavior Therapy Program	Outcomes study	Unites States	Depression, hopelessness and interpersonal sensitivity decreased significantly from pre- to post-intervention, with clinically significant change observed.
Pearce et al (2017)	Evaluation of a psychoeducational group intervention for family and friends of youth with borderline personality disorder	Outcomes study	Australia	Participants reported significantly decreased levels of subjective burden and increased knowledge of BPD, however, objective burden and distress did not change. A brief group-based psychoeducation program benefits family and friends of young people with BPD in areas of subjective burden and knowledge, and findings are supportive of proceeding with further studies including RCT.
Penney (2008)	Family Connections An Education and Skills Training Program for Family Member Well Being: A Leader's Perspective	Descriptive and reflective	United States	Key insights provided include: early intervention and treatment need to focus more on youth; while knowledge is gained, most importantly family members will learn skills for themselves and their own well-being; leaders must recognise the last 2 weeks as a transition period for the group, allow time for discussion and help prepare for life after FC; time period of the program is limiting, and ideally would be available to family members as long as needed.
Ratnaweera, Hunt & Camp (2021)	A Qualitative Evaluation of Young People's, Parents' and Carers' Experiences of a National and Specialist CAMHS Dialectical Behaviour Therapy Outpatient Service	Qualitative research	Switzerland	Identified themes for young people included a new way of living, better understanding of self, new skills, person-centred approach, and relationships with others. They reported improvements in BPD symptoms following DBT. Identified themes for carers included f improved relationships, feeling supported, improved quality of life, and time/timing.
Smith (2008)	BPD and the Need for Community: A Social Worker's Perspective	Descriptive and reflective	United States	Emphasises need for community for family/friends as well as patients and those treating BPD, with modelling of individual/family/community level relationships. The organisational model presented includes a holding environment incorporating combined treatment approaches for patients and families (e.g., DBT, DBT-FST, FC, Multiple Family Group). Families supported for as long as needed in group work, and provided ongoing monthly workshops with experts.

3.2. Findings from the literature review

Despite the high prevalence of personality disorder (PDs), carers and loved ones of people with PDs have been stigmatised and not given as much attention in the research literature as people with the diagnosis (Bailey & Grenyer, 2013). In particular, early research regarding families of people with BPD was dominated by findings of family trauma, abuse, neglect, and psychopathology (Bailey & Grenyer, 2013). This implicit suggestion that families are to blame contributed to stigma and shame and further isolated carers, family and friends from seeking help (Buteau et al., 2008; Mannion et al., 2022).

The ongoing trend of care moving towards being community-based care rather than hospital-based care has resulted in families and carers taking on more and more responsibility for the care of those with mental illness, including PDs (Bailey & Grenyer, 2013). The behaviours that accompany BPD, such as suicide attempts, self-harming, and intense anger are reported to be overwhelming for family and friends of people with BPD (Hoffman et al., 2005) and carers of people with BPD experience the greatest severity of burden relative to other family psychiatric populations (Bailey & Grenyer, 2013). Carers of people with BPD also reported difficulty navigating the mental health system and conflicting advice from mental health professionals (Bailey & Grenyer, 2014).

More recently, research is viewing the aetiology of PDs not as the direct result of parental style, trauma, abuse, or neglect, but rather an interaction of many factors that define a biopsychosocial model of BPD development (Bailey & Grenyer, 2013). Within this new framework, carers, family and friends are seen as integral in the journey to **recovery** of their loved ones with BPD (Bailey & Grenyer, 2013). Within the Australian context, recovery is defined as involving "the development of new meaning and purpose and a satisfying, hopeful and contributing life as the person grows beyond the effects of psychiatric disability." (Commonwealth of Australia, 2010, p.31).

Emerging evidence indicates that family and friends, the community and the wider social context are all important for recovery, though the research around this has so far been limited (Williams et al., 2012). Qualitative interviews conducted with clinicians suggested that recovery from BPD needs to be supported within a trusting relationship with another person who could be a clinician, family member, partner or friend (Donald et al., 2017). Family interventions have recently gained interest as an important focus in the treatment and recovery of people with BPD, as well as recovery for their caregivers (Mannion et al., 2022). A review of family programs involved in treatment of BPD (Hoffman & Fruzetti, 2007) found that there is consistent evidence of good outcomes for burden, grief and depression for family members in family programs for mental state disorders but that despite this, development of such programs for personality disorders has been lacking. Early studies on family involvement for PDs, especially BPD has been promising, however.

Initially, family interventions were delivered as psychoeducation only, with the goal of informing family members about their loved one's disorder, in order to reduce 'expressed emotion[2]' and environmental stressors in the family (Mannion et al., 2022). Within a psychoeducational approach, families are taught that neither the family members nor the patient are to blame and that that families can learn to manage (Fristad, 2006). Through this approach, families are offered validation and recognition of their own experiences and difficulties in living with a family member who has mental illness. Evidence to date suggests psychoeducation is an effective adjunctive treatment (Fristad, 2006).

A community-based single session psychoeducation in-person workshop for service users (people with BPD), carers, family members and friends achieved positive results of increased understanding and management of BPD (Carter et al., 2015). The session delivered information on BPD diagnosis; aetiology;

[2] High Emotional Expression (EE, high in critical comments, hostility, and emotional over involvement) show high relapse rates in adults with schizophrenia (Fristad, 2006).

relationships and attachment theory/principles; and treatment and support options. An additional session was held for carers only, as they felt unable to express themselves in front of the family members with BPD, highlighting the need for separate services for carers/family and friends.

Carers spoke of their need for practical tools and support. Evaluation measures for both carers, friends and service users demonstrated not only increased understanding of BPD but more empathic attitudes, and confidence to manage BPD. One participant stated *"There is a huge need to provide training/workshops for family members and carers of BPD to provide practical tools and ways of helping people with BPD. This in turn could aid recovery and provide greater support for patients*" (Carter et al., 2015, p 29). One of the study's measures revealed that there was poor awareness of BPD in 87% of participants prior to the workshop. While promising, the long-term effects of this workshop were not assessed, and only self-report measures were used.

Another psychoeducation program that received an evaluation was *Making Sense of BPD* (MS-BPD), a psychoeducation group intervention designed specifically for family members of young people with BPD. The program integrated psychologically informed clinical case management with Cognitive Analytic Therapy and general psychiatric care and was run during 3 sessions over 15 days. An evaluation of this program was conducted with 23 family or friends, the majority of whom attended all three sessions (74%) (Pearce et al., 2017). This is one of the few studies which reported the portion of family members who completed all sessions. The study found significant improvement on measures of personality disorder knowledge, overall burden and subjective burden[3] but no change on objective burden[4] and level of distress.

Over time, approaches have expanded into relationship skills-based training as well as psychoeducation. The family programs we reviewed had similar overall aims. They comprised components of psychoeducation, aimed at providing/building support, and relationship skill development. Programs differed in the mode of delivery, from online to face-face, duration, from a couple of weeks to months, intensity and theoretical orientation (e.g., based on DBT, mentalisation or relational). Two programs articulated a directly **relational** approach, Kindred (Gleeson et al., 2021) and Project Air (Grenyer et al., 2019). Both these programs were evaluated using RCTs, with promising results, though sample sizes of participants were small. The remaining five programs we reviewed mostly delivered their interventions using a DBT approach to skills training, though one of these used a mentalisation approach, and all addressed skills to improve relationships with loved ones with BPD. Only one of these programs (ATraPA; Mayoral et al., 2020) had not been evaluated. Results from these evaluations indicated that all of these approaches may improve outcomes for family functioning and reduce burden (Bateman & Fonagy, 2009). These studies, their approaches and results are presented below. Further technical details about the studies discussed below are available in Appendix 9.1.

3.2.1. Project Air

Project Air (AIR) is a program based on the understanding that BPD is a **relational disorder**, whereby relationships have an impact on affect and identity (Bailey & Grenyer, 2014; Grenyer et al., 2019; Project Air Strategy for Personality Disorders, 2015). The program was delivered in a group therapy format, with 6-8 participants in the group and two facilitators, and 16 hours of face-to-face content delivery over 10 weeks, and an initial one-day introductory session. AIR combines psychoeducation with practical skills building sessions, aiming to improve relationship skills and reduce carer/family burden. The program has a flexible structure so that it can be tailored to the group members.

[3] Subjective burden refers to feelings, attitudes and emotions expressed about caregiving. For example, shame and stigma (Reinhard et al., 1994).

[4] Observable behavioural effects of caregiving, including financial problems, limits on personal activities (Reinhard et al., 1994)

An intervention comparing this program to family and friends on a waitlist for the program found that participating in the intervention resulted in reported in improvements in the relationship with the loved one with BD, improvement in the carer/family member's confidence in being able to play an active role in interacting with BPD service providers and a sense of empowerment, as well as reduced EE. Follow-up 12 months later showed that these gains had been maintained. A further benefit reported by participants was the sense of peer support they felt from going through the program with people who had similar experiences to them.

3.2.2. Mentalisation-based Intervention (MBT-FACTS) for families of people with Borderline Personality Disorder

This RCT compared immediate versus delayed-treatment of a mentalisation based program for family and friends (Bateman & Fonagy, 2019). Mentalisation in this context refers to a person's concerns and emotional states being accurately reflected by another person whom they see as experiencing similar problems. The aim is that family members may continue to mentalise despite stressful circumstances. This was program was developed because family members wanted less emphasis on psychoeducation and more on skill development for managing interactions with their loved one.

Therefore, the program was skills based and hosted over five 1.5-2 hour sessions, by trained family members. The primary outcome was adverse incidents reported by family member in relation to the loved one with BPD, secondary outcomes of self-reported well-being, empowerment, burden, improved anxiety and depression. Outcomes from the immediate intervention were the most promising, with significant reductions in adverse incidents, compared to those who received a delayed intervention. Family functioning was also reported to have improved more in the immediate intervention. There were no differences between the interventions on scores in depression, anxiety, and burden, but both groups showed improvement on these measures.

3.2.3. Kindred

This trial differed to some of the others discussed in that it was delivered purely online, via an interactive social media platform and designed for carers of young people who were in the early stages of BPD (Gleeson et al, 2021). Kindred was informed by a **relational view** of BPD, and based on the HYPE[5] model of care (Chanen, McCutcheon, & Kerr, 2014). Components of Kindred included psychoeducation as well as therapy and was available to consumers for 3 months. The therapy component focused on building communication skills between families and their loved one, self-care, mindfulness and well-being of carers.

The trial explored whether Kindred use was associated with clinical improvements for caregivers on measures of burden or caregiving, stress, expressed emotion, family communication, disability, coping and knowledge of BPD. They also assessed severity of BPD symptoms and functional impairment for the loved one with BPD. Being a pilot study, the sample was small, involving n=17 adult carers, 8 young people aged 15-25 with BPD (carers were relatives, legal guardians or friends of current HYPE client). Measures were taken at baseline with follow ups at 3 months. Follow-up revealed improvement on scores of carer burden, stress, expressed emotion, family communication, quality of life, functioning, coping and perceived knowledge of BPD. Sixty-six percent of the young people with BPD reported that their family members demonstrated increased understanding of BPD.

Carers mostly access content around relationship and communication styles to interact with their loved one. They engaged less with content that was designed to improve carer wellbeing. Gleeson et al. (2021) reported that carers engaged less with content that was designed to improve carer well-being in preference to content that would improve their understanding and relationship with the young person. Gleeson et al. (2021) stated that in further iterations of the Kindred, more overt links could be made between self-care and the benefits for the young person. For example, that parents who invest in self-care

[5] Helping Young People Early (HYPE) program at Orygen Youth Health, for people aged 15-25 years

such as mindfulness are more likely to respond with greater psychological flexibility which has been shown to be beneficial to their children (Leeming & Hayes, 2016).

3.2.4. DBT-FST Dialectical Behaviour Therapy Family Skills Training

This program was delivered using a dialectical behavioural therapy (DBT) approach (Lineham, 1993), which is a common and effective approach to treatment of people with BPD (Ekdahl et al, 2014). Focus was given to training family members in five DBT skills: 1) interpersonal effectiveness, 2) mindfulness skills, 3) emotion regulation, 4) distress tolerance, and 5) validation (Hoffman et al, 1999). Using these skills, the program aimed for family members to achieve the following goals: become educated different aspects of BPD, learn communication styles that create and maintain a mutually validating environment. Further, an overarching goal was to understand the underpinnings of DBT i.e., there is neither "one truth" nor any "absolute" truth, and engage in a safe forum where patients and family members can discuss issues like self-destructive behaviour, feelings of rejection, anger, sadness, and suicide thoughts.

Prior to the intervention, family members described that they had lived with stress, anxiety and struggled to get help for themselves. Engagement in the DBT-FST program provided them with a sense of hope for the future and empowerment in being able to engage with their children. They also felt a sense of recognition and connection to other family members in addition to learning useful strategies to engage with their loved one.

3.2.5. Family Connections

The Family Connections program was one of the earliest programs targeted at family members of people with BPD that moved beyond psychoeducation (Hoffman et al., 2005; Hoffman & Fruzzetti, 2007; Penney, 2008). The program is also based on DBT, delivered by trained family members of people with BPD, in a 12-week, two-hour, interactive, manualised, education/skills training course. Leaders undergo training and selection and must have a family member with BPD (lived experience). There are six modules taught in Family Connections – Introduction, Family Education, Relationship Mindfulness Skills, Family Environment Skills, Validation Skills, and Problem Management Skills.

The program aims to help family members manage both the family dynamics and the negative emotion that comes with BPD, and to help build a supporting and validating environment for the whole family. Pilot research demonstrated significant improvements in mastery of skills as well as significant reductions in measures of grief and burden from baseline to post-group assessment and a 6 month follow up (Penney, 2008). Though connectedness with other families had not been a specific research aim, the authors of the intervention paper noted that some family groups continued to meet monthly with each other even after the program had been completed.

3.2.6. Getting off the Emotional Roller Coaster Skill-Building Family Education Course (GOER)

The GOER course was DBT-informed and aimed at family and friends (adults) of people with either BPD, bipolar disorder (BD), or major depressive disorder (MDD) (Mannion et al., 2022). It was delivered over 10 weekly two-hour classes by three co-facilitators comprising a peer facilitator, clinician/family member facilitator and family peer facilitator. The course included family recovery tasks, such as developing hope and optimism about their own futures; connecting to people with lived experience similar to themselves and their loved ones; redefining their identity as being less burdened by their caregiving role, working on emotions such as unresolved grief and guilt; and empowering them to have control over their own lives.

Evaluation of this course revealed a reduction in caregiver burden, improved attitude, knowledge and skills about BPD over the control group. The course was followed by a monthly meetup for graduates of the course ("Grad Group") so that they could retain ongoing peer support from similar graduates, but this part of the course has not been evaluated.

3.2.7. Actions for the Treatment of Adolescent Personality (ATraPA-FAL[6])

ATraPA-FAL is a 12-session psychoeducational group for parents of adolescents with emotional dysregulation (Mayoral et al., 2020). This intervention provides parents with a summary of the DBT that was originally designed for adolescents suffering from BPD symptoms, but adapted to the parents (e.g., distress tolerance, emotional regulation). The purpose was to support families to provide a validating environment to aid and engage their adolescent by helping parents to be aware of their own emotions and expression, understand emotional dysregulation better, improve both communication and crisis management skills. The authors notes that emotional dysregulation of parents is not usually addressed by other family-based interventions. A randomised trial is being conducted to assess the FAL component.

[6] ATraPA is the Spanish acronym for Actions for the Treatment of Adolescent Personality

4. Research interviews: Relational support through BPD Community

4.1. Methods

This aspect of this project aimed to address questions 2 and 3 through semi-structured, qualitative interviews with members of *BPD Community*.

2. What has *BPD Community* members' experience of relational support been, and what are their thoughts about a relational support approach in terms of recovery from BPD and supporting people with BPD as a friend, family member, or carer?
3. What do *BPD Community* members see as the most important aspects of a relational support approach in terms of recovery from BPD and supporting people with BPD as a friend, family member or carer?

The interview aspect of the project was granted ethical approval by the University of Melbourne Human Research Ethics Committee (ethics ID: 23982) on July 5, 2022.

4.1.1. Participants

People with lived experience of BPD and a relational support approach, are uniquely positioned to provide insight, experiential description and recommendations for how this approach can best be used to contribute to wellbeing and recovery, and inform ongoing development of programs and resources for people with lived experience of BPD.

Participants in this component of the project were family members, friends, or carers of people with BPD, who were members of *BPD Community*. All participants were either attendees of the Family & Friends program or members of the Carer's Committee run by BPD Community.

The project aimed to speak to between 5 and 10 family or friends of people with BPD and experience of relational support through *BPD Community*. Anyone who was over the age of 18, and a member of *BPD Community* was eligible to participate. The project did not target people diagnosed with BPD themselves.

Five interviews were conducted with four women and one man, including a range of relationships to people with BPD. Given the small sample size, demographics are not reported in detail to protect participants' privacy and confidentiality.

4.1.2. Participant recruitment

Participants were recruited with the help of *BPD Community* staff, who were provided with all relevant ethics documentation and recruitment materials. A project information sheet and consent form were circulated via the Family & Friends network and Carer's Committee run by *BPD Community*, requesting any members interested in participating to contact the research team directly. Only those members who had attended three or more sessions in a year were contacted (n=10). Table 6 sets out the recruitment process and timeline.

Table 6: Recruitment process and timeline

Interview process outline	Timeline
Ethics approval granted to undertake interviews	July 5, 2022
Invitation to participate sent out through *BPD Community* to members of Family & Friends group who had attended >3 sessions in a year (n=10)	July 7, July 14, 2022
Seven members contacted researchers expressing interest in participating	July 14 to August 1, 2022

Five[7] interviews set up and conducted between researchers and participants	July 26 to August 23, 2022
Two of five interviewees provided additional thoughts via email following interview	

4.1.3. Data collection

Interviews were conducted via Zoom videoconferencing software. All participants gave their informed consent to record the conversation. Recordings were saved to the University of Melbourne's secure OneDrive platform. Interviews lasted between half an hour to just over an hour (with an average of 37 minutes).

The semi-structured interviews were guided by a set of questions developed in collaboration with *BPD Community* (see Appendix 9.2). Following interviews, the interviewer wrote up summary notes and referred to recordings to source quotes included in the following section to present the emerging themes in participants' own words. Two interviewees provided additional thoughts via email following their interview. These thoughts were added to the notes taken by the researcher and included in analysis with permission from the participants.

All interviewees were provided with support services information via email following the interview, including contact details of an experienced social worker available to them to debrief with if they wished. All interviewees were thanked for their participation, and provided with a $50.00 eGift Card in acknowledgement of their time and expertise.

4.1.4. Analysis

Summary notes and quotes were analysed using thematic analysis (Braun, Clarke & Rance, 2014), with high level thematic areas generated, grouped, and refined utilising NVivo qualitative analysis software (QSR International, 2020).

4.2. Themes from research interviews

4.2.1. Experiences of relational support

Interview participants generously shared their experiences of relational support, both before and as part of their engagement with *BPD Community* and the F&F group. Three main areas of discussion and experience stood out: relational support (or lack thereof) through the mental health and medical systems; the lifeline and anchor of *BPD Community*; and the unique challenges of being a family member, friend or carer who loves someone with BPD.

Support (or lack thereof) through mental health and medical systems

When relating their experiences of the mental health and medical care systems, participants spoke of feeling overwhelmed with the constellation of issues they were often trying to help their loved one manage, and entirely underwhelmed with how carers, family members and friends were considered within these systems. This applied both to integration into their loved ones' care and how they were able to help them, and to their own wellbeing, sense of agency and empowerment as individuals beyond their caring roles. One participant spoke about the need to better connect professional training, academic research, and government initiatives (e.g., Project Air in NSW), to ensure the systems purporting to support people with BPD and family and friends are adequately equipped to actually do so.

Participants emphasised the lack of knowledge, understanding and expertise around BPD by staff/professionals in these healthcare systems, and the unique challenges that family and friends face in caring for someone with this diagnosis while also maintaining their own wellbeing. Isolation and lack of

[7] Two *BPD Community* members initially expressed interest and did not proceed to interview due to life circumstances and change in their availability.

support defined many of the participants' experiences of trying to help their loved one with their diagnoses and symptoms, and a high level of dismissive, often stigmatising interactions with healthcare staff impacted any sense of optimism they held for effective treatment towards recovery and wellbeing (for their loved one with BPD and themselves). This included interactions where, as soon as BPD was raised, mental health professionals shut down the conversation or denied treatment for the diagnosis. When participants did receive advice from professionals on how to approach supporting their loved one, it was often only surface level or non-specific to BPD. This was in contrast to the consistent, in-depth learning and support they received through *BPD Community* and the F&F group.

> '*It is really hard, because depending on what the person is exhibiting and what they're going through, even your doctor doesn't get it. And It's hard to find someone in the medical field.'* (Int2)

> '*Agreeing on a communication plan with my son's consent for the psych to contact me when he severely escalates, was the best professional support I got outside of the BPD group*.' (Int5)

One participant described the siloed approach to intersecting or co-occurring issues their loved one faced that they saw as interconnected, but that medical or mental health professionals often seemed unwilling to address or assist with except in isolation. Only single presenting issues were attended to within a very diagnostic model, e.g., depression, anxiety, harmful behaviours, resulting in a lack of holistic attention to the person as an individual, let alone how they interacted with their network and personal relationships. This applied both to carers witnessing their loved ones' experiences, and family and friends' experiences of seeking help for multiple issues of their own.

> '*You might go along to a psychologist and get some medication, but that's only treating one thing, it's not teaching them how to cope with life and how to cope with relationships. That's one of the bigger things. […] it's the relationships, and the relationships are the things that cause them the most pain.*' (Int2)

Participants spoke of the complete lack of support offered to them through managing crises and highly complex situations with their loved ones, while also being made to feel responsible and at fault for inadequate care and support. Conversations with medical and mental health professionals were often characterised by feelings of blame, guilt, and inadequacy, while at the same time putting the onus on participants as friends or family members to 'fix' the situation. One participant spoke about conversations with a psychiatrist treating their loved one as being very blaming and at odds with the message that they were essential, as their loved one's only support. Another participant related their extensive experiences and interactions with health, medical, justice and protective services as a young person trying to support their loved one with BPD, including emergency services and police. At no time did they receive any offer of support.

> *'I had so much interaction with emergency services, like I had so much interaction with going to hospital, and calling ambulances, and having police at my house, and this was me as a young person at the time, by myself going through all of this, and I was not offered support once by anyone. I just thought that was so lacking: like yes, my [loved one] was the one who was suicidal, but I was just then sent home by myself, without any support. […] I just remember being on the phone to triage, and them saying we don't want [loved one] to come to hospital, you just have to stay awake with [them] all night and make sure [loved one] doesn't do anything. […] I had to get to the point of being suicidal myself to be offered any support.'* (Int1)

More than one interviewee spoke of responses they received from the mental health care system that had deemed their loved one either too ill to be supported through local services or not ill enough to be admitted to hospital or psychiatric care – resulting in responsibility and safety of their loved one being left entirely up to them.

BPD Community and the relational support approach it takes was described as a lifeline in these circumstances, and a guiding presence for participants as they navigated the mental health and medical systems, their loved ones' care, and their own wellbeing.

> *'I felt my [loved one] fell through the cracks of the mental health system, i.e., most of the time [they were] either "too suicidal" for local support services to deal with or "not suicidal enough" for hospital admission; BPD Community helps guide you through this process.*' (Int5)

Unique relational challenges of being a family member or friend of someone with BPD

Relationships as a life domain were discussed by participants as having, by their very nature, ongoing and changing characteristics that were often not considered by medical or mental health services or support networks. This was described as a unique challenge for family and friends of someone with BPD. Trying to uphold relationships and care when BPD is characterised by instability in this domain often felt isolating as they navigated their love and commitment, frustration, grief, and hope from day to day.

> *'It's distinctly different to support somebody through relationship as opposed to diagnosis.'* (Int4)

> *'[You're] the person who rings every week because otherwise you don't hear anything. You're the person who will drive two hours for a visit, just because you need to, and need them to know that you're there, and that you love them, and so it can be quite exhausting*.' (Int2)

Participants described the ongoing complexity of these day-to-day interactions and the active responsiveness this often required as some of the most challenging aspects of their relationships, particularly when they or their loved one was struggling with multiple issues. People in participants' support networks often did not understand this experience, being unaware of the relational challenges that an illness like BPD poses to individuals and those around them.

> '*It is really isolating, because you're coping with… it's not just, it can be lots of things, it's not just depression, it's not just anxiety, not just anger, not just feeling worthless, or dangerous behaviour, it's not just self-harming. It's a whole lot of stuff, a whole lot of stuff so you're not just dealing with one thing.*' (Int2)

> '*It's isolating for the person with BPD, but it's also isolating for the carer as well.*' (Int2)

Participants described how having an increased understanding of BPD, and its particular challenges, was often an isolating experience (outside of *BPD Community*). One participant described this as the deeper their understanding grew, the more their insight into what drives behaviour expanded. They often felt defensive when others who did not have this understanding or insight criticised their loved one with BPD, and protective of them in the face of accusations or dismissive interactions. Participants described engaging with people who were not willing to learn about BPD as an 'uphill battle' to create context and understanding. This often also fed into feeling that they could not discuss the ups and downs of loving someone with BPD, for fear of misunderstanding, blame and stigma being levelled at themselves or their loved one.

Talking about unique challenges, participants described the guilt and conflict they had often felt when what they wanted for themselves and their loved one, and the reality of their circumstances, did not match. Being able to recognise when this might be case, and not slip into feelings of guilt was something participants emphasised as a difficult skill to develop.

> *'It's normal human behaviour to want it to not be that way. So, I would have a picture in my head of how I wanted my life to be, but in reality, it's quite different to that. And the difference between those two set points, of what I want and what is reality, is suffering.'* (Int4)

This was discussed in relation to how interactions grounded in authenticity and mutual presence, even when this might include wishes for things to be different, were essential to being able to shift relationships towards being more positive. The characteristics of BPD that present particular challenges for relationships, such as fear of abandonment, were described by participants as necessitating a level of awareness within oneself and in interactions with loved ones if positive patterns and changes were to be possible. When carers reflected on their hopes for how they could achieve this, it often revolved around being able to freely acknowledge their own needs and boundaries, as well as being present, supportive and loving towards their family member or friend with BPD. One participant gave an example of an experience of seeing two people join the F&F group to better understand their friend with BPD. The participant described this as such a hopeful experience, because many others would simply give up, cut off ties when things became difficult, or blame the person. These friends were willing to do the work, learn about themselves and what they could do, to support someone with BPD.

Lifelines and anchors: *BPD Community* and relational support

All interview participants spoke about extended periods of having no support and feeling intensely isolated before finding *BPD Community* and the F&F group. They described finding the group as a 'lifeline' in a time of need, and something that they now experience as an anchor in their journey towards wellbeing and more positive relationships.

All participants spoke about how the common, shared experience of loving someone with BPD, and trying to navigate this experience, was integral to a sense of safety, feeling heard, understood, and validated. Though F&F groups consisted of members from all walks of life, this shared experience helped them build trust, acting as the foundation for challenging but impactful learning. Hearing their own story so similarly reflected in other members of the group made participants realise they were not alone or isolated in their experience. This realisation also helped participants to reframe feelings of suffering or struggle as a product of circumstance rather than individual fault.

Shared experience was also critical to being able to learn from each other and 'hear' hard truths and advice. While other people, medical professionals, or loved ones might have given similar advice, when it came from people who shared the experience of loving someone with BPD, it resonated and rang true for participants.

> *'It's hard to put into words…I was in a place myself where I was really hopeless and powerless, and for me it changed everything. I needed some hard truths, and the people that could really deliver that in a way that I could hear it, were other people going through the same thing. […] It's just so unique. When I was really struggling with my situation, you have your psychologist, your helplines, but there's something just so different about it being with peers who are going through the same thing as you. You might even hear the same advice, but when it comes from someone who totally gets it, there's something different about it and it's so much more powerful.'* (Int1)

Participants spoke about the value that the group's firm, respectful boundaries had to them, as examples of positive and mutual investment in supportive relationships. The feeling of being grounded by the group was shared by all participants, and they described valuing the sense of community and unconditional support immensely, as this was not always present in their support networks.

Increased knowledge and understanding of what BPD is, how it can manifest for different people, and the evidence-based strategies that can support recovery and wellbeing for people with lived experience were all spoken about as critical learning for participants to be able to move forward more positively in their lives and in loving someone with BPD. Participants described particularly their relief at being given practical strategies that they could apply in their everyday lives and relationships, underpinned by accessible and values-based theory.

'If I come home and [loved one] is dysregulated, I've learnt not to say, 'what's wrong?', I've learnt to say, 'what happened?' So that the 'wrongness' is not in the person, it's something that's going on. It might be difficult to pin down what happened, but I'm here with you, I'm not going anywhere, I can see that you're upset, and yeah, it's making me upset too, but what happened, maybe we can figure something out. And then they might give you a glimpse.' (Int4)

Participants spoke about the value they found in the group, relating to a grounding point as they navigated 'grey areas' and tensions surrounding BPD and their loved ones. Examples of this included the shared understanding and respect for being able to hold simultaneous understanding that *acceptance* of BPD behaviour does not mean *approval* of this behaviour. Another example related to gaining more knowledge and learning about the dynamics that often characterise relational support and lived experience of BPD involved coming to terms with past attitudes and behaviours that may have impacted negatively on a loved one with BPD. Through the F&F group, participants are able to explore how attitudes might be shifted and how this has a positive impact for their loved ones as well as their own experience of themselves.

One participant described reflecting on how much had changed since becoming involved with *BPD Community* and taking part in the current research project. While they acknowledged that difficulties still existed in their relationships and circumstances, they felt they were coping increasingly well. They gave the example of taking part in the interview, without becoming distressed at all, as something they would not have been able to do previously.

4.2.2. Critical aspects of relational support

Grounded in their experiences of relational support, participants shared their perspectives about what the critical aspects of the approach were that contribute to recovery, wellbeing and positive relationships. These included the opportunity and centrality of cultivating self-acceptance as a foundation to any relational interaction, validation and empowerment of self as well as a loved one with BPD, and having access to community and ongoing practice of relational support.

Cultivating self-acceptance

All participants in this project spoke about the critical need to cultivate self-acceptance, and how their engagement with *BPD Community* F&F group had allowed them to start navigating this journey.

'BPD Community has been a lifesaver for me. I started my journey of learning to help my [loved one] and quickly found out that change starts from within.' (Int3)

Participants described the F&F group as a place where they learnt theory behind self-acceptance, strategies to tap into peace of mind and recognition of what they could control and what they could not. Although some participants spoke about this as a foundation applicable to any relational interaction, they emphasised that the particular dynamics of BPD made this absolutely essential to being able to move towards recovery, ongoing wellbeing and positive relationships with their loved one, but importantly, with themselves.

'By being more aware yourself, how to approach, react, or not to react, can be a big difference between a big blow up and something that can sort of slowly diffuse. […] It's learning I think to make the changes within yourself, that are then going to reflect out into your relationship with your loved one.' (Int2)

Starting from within to be able to understand how to help others was a recurring theme. By building a foundational sense of self that they accepted and found strength in, participants described a turning point in their own wellbeing, as well as better understanding and capacity to have a positive relationship with their loved one with BPD. Practicing and developing self-acceptance was described as a process for participants in their own right as individuals, but also as an important action they felt they could undertake to support and respect their loved one as well.

'The way I look at it now, [name] if you really truly believe that you are acceptable, are you able to pause and find a bit of space to cultivate that self-acceptance, so that it's really, actually, bloody real. So that it's real enough for you to stand on top of, or cling to like a rock face, or believe is so that your eyes shine, or rest on like a rope net, like a safety net. Are you actually doing that, or are you tricking your loved one into getting well so that they will do it for you?' (Int4)

'I can revisit that and top myself up, through mindfulness and self-acceptance. So, that original question of 'are you okay?', is no longer as loaded, as it used to be. So, are you okay, because I'm okay, and I'd like for you to be okay, but if you can't be okay then I'll be patient, and I'll just be with you, and I'll be present. I can now more often be present.' (Int4)

Self-acceptance and inner peace were also described as essential to being able to engage with authenticity and presence with their loved ones who were particularly sensitive to inter- and intrapersonal tension or unease. The skills, strategies, and space to practice these things in the F&F group was lifechanging for participants. They spoke at length of how they all could not imagine not having this experience and being able to be where they are now in their relationships with themselves, and their loved ones. This was often the key take away for participants, and something they all expressed commitment to taking forward into the future.

'When you say relationship, we're doing it through relationship from that perspective. And the first one is relationship with myself. So, if [loved one] can detect that I'm not attuned to myself, she'll call bullshit, and she'll go 'you're not there, you're not there for yourself, so there's no way you're going be there for me, so it's over, this interaction is over […] BPD Community through mindfulness and radical acceptance, there are the tools there to accept yourself.' (Int4)

Validation and empowerment of self as well as loved one with BPD

Closely connected to self-acceptance, validation of individual struggles and needs was a focus for participants in interviews. Learning about validation as a powerful tool and strategy in being able to support a loved one was positively spoken about, but always in conjunction with the impact these strategies had when used within participants' self as well. Participants spoke about being able to better manage their own past traumas, feelings of co-dependence or other issues that were often uniquely connected to BPD illness experienced by their loved one, when they were able to recognise and validate their efforts.

'The relational support BPD Community provides me is invaluable. The training techniques (DBT) I'm learning and practicing each month, is teaching me to be self-compassionate and that I am enough. I'm learning to accept what I can control (myself), validating my own feelings, thoughts and experiences, being more mindful and fully in the present moment, developing a grateful approach to life, becoming less self-critical and judgmental and more compassionate, setting boundaries based on my values (not as punitive), learning and applying nonviolent communication and more!' (Int3)

Acquiring these skills and learning to consistently apply relational support approaches were experienced as incredibly empowering to participants. Participants described the shift in their perspective and outlook on life as a result of finding BPD Community and feeling empowered to take action for themselves, as well as their loved ones. This was often discussed in the context of the lack of support and tools available through the medical and mental health services they had encountered, and had a significant positive effect on feelings of despair and hopelessness in participants.

'The whole approach is so empowering. It wasn't that there was anything wrong with me or my [loved one], but there were things we could both do. […] It was so empowering for me, because I got back this power of wow, there's all this stuff I can do, it's not all on my [loved one] to change, that's

so out of my control. What can I do, what can I change in myself, what do I have control over and what can I work on myself right now. I went from this place of utter despair, of feeling nothing was ever going to improve, to having something to work on, trying stuff out every month, and honestly seeing huge improvement.' (Int1)

Being able to focus on their own behaviour, developing their own skills and responsiveness was a profoundly impactful and ongoing experience for participants. Engaging in the F&F group allowed participants to shift their understanding of the things and actions that were under their control and that they could change, and the aspects of their relationships or circumstances that required validation and radical acceptance but that were situated outside of their control. Participants spoke about feeling empowered in themselves and their actions even when a loved one may not be ready to take on changes in their behaviour, or when other family members, professionals or surrounding people were unwilling to engage with a diagnosis and presentations of BPD. The development of being able to validate and accept what could not be changed, while applying the skills and strategies they learnt to the things that could be improved, was described as a constant process of learning and practice by participants, and something they were wholeheartedly committed to.

Community and ongoing practice

Interview participants spoke about the iterative, ongoing nature of the F&F as invaluable in supporting their development, practice and confidence in relational skills learning. Having the opportunity to each month talk through previous content, how they had attempted or succeeded in applying principles, values and strategies in the intervening period, and their reflections on these processes, was highly valued by all participants. Described as 'not just a switch', participants gave examples of shifting their perceptions, approaches, and behaviours in their relationships, through a dynamic and ongoing process that responded to their loved one and where they found themselves emotionally on a day-to-day basis. Participants described experiencing evolutionary learning, increased sense of peace and pride in their achievements and approach, and positive impacts on their loved ones.

'The whole thing is like, can be a real epiphany, as to there are things I can do to, something that I can put into practice. But it is, it's practice, practice, practice, it's not just like bang, it's not a switch. Because you're a human being too, and you have those emotions, and you have your good days and your bad days too. I just think, it's such a valuable thing for people to have that, it's like a bit of an anchor in a storm.' (Int2)

'I feel more at peace & proud of what I've achieved so far and it's having a positive impact with my loved one with BPD. My learning is evolving!' (Int3)

'I've been going probably for 18 months now, but you're still learning, for me I'm sure I'll never learn it all. I still struggle, using these tools at times, because my emotions get the better of me. But then, without that support and those tools and that knowledge of no, approach it this way, don't say that, it's all going on in your head, it definitely has improved my relationships with [loved ones with BPD], definitely. Doesn't mean to say I don't worry about them 24/7, but it brings you back to earth really that you're not alone, and there are things you can do, in approaching different situations.' (Int2)

This ongoing access and sharing of experience also helped participants with their felt sense of isolation as they navigated the changing and continuing challenges and successes of their relationships with loved ones, and themselves. Participants described having a sense of community from the group that felt unconditional, non-judgemental, and stable in a way that other friendships or support networks did not. This was a unique dynamic, where they felt validated, but also challenged in positive ways that were not part of how they were able to interact with other support networks. This allowed participants to feel open

to learning, practicing and reflecting on behaviour and strategies to manage it (their own and their loved ones'), in a way that they had not had access to before.

> *I need that – that constant reminding […] it's very, very important. I felt alone for years, and even my family haven't understood it.'* (Int2)

> *'When you're kind of by yourself and going through something like that, someone who doesn't get it, doesn't have it, a loved one with BPD, telling you oh maybe you should change – no way, I wouldn't have been able to hear that! No way! But when you're in this beautiful support group, where people are hearing you, validating you, understanding how hard it is, but ALSO saying, maybe you could have communicated differently… I think that's really specific to relationship and the kind of learning. People can hear and take on some hard truths around their own behaviour that I don't think happens very often in other situations or types of support.'* (Int1)

Participants also spoke about the drive they feel to give back to the BPD community, with over half of participants volunteering their time to support the F&F group and *BPD Community*. They described being motivated by the difference the group had made to them and their loved ones, knowing that the isolation and lack of support for family and friends is dire. They also emphasised that giving their time was an invaluable way they could continue to be part of a community and continue their practice of developing understanding, skills, and support networks.

> *'The support I've been afforded, made me want to give back to the group and I've been a volunteer member of the Family & Friends Carers Group for the past year.'* (Int3)

4.2.3. Focusing on future relational support through BPD Community

Participants were keenly aware of the limited resources, time, and funding that BPD Community operates with. In speaking about the future for the organisation and how they would like to see relational support taken forward, participants referenced the need for consistent, increased funding to be able to build on current activities and access to support for more individuals and families with lived experience of BPD. These concerns were a consistent background as participants provided thoughts and suggestions around materials and resources, ways to build on activities and community, as well as their wishes for the future.

Materials and resources

> *'All of the materials are really well thought out. It's like it's been filtered to be the stuff that will actually save your life.*' (Int4)

When speaking about access to information, materials and resources related to BPD and relational support, participants spoke highly of the *BPD Community* website and F&F group materials. The presence of a dedicated website with available resources had been an important touch point for participants as they sought support and information, and they emphasised the recognition this warranted in reaching more people with lived experience of BPD. Particularly for family and friends struggling to find their way through systems focused predominantly on diagnoses and medical/treatment aspects of BPD, being able to find something focused on carer needs and wellbeing was described as a lifeline with significant positive impact.

> '*It's not good when you're, as a carer, really hurting and suffering, and feeling yourself like you just can't cope. I mean it impacts your whole life, it impacts your relationships with your friends, it impacts your work. So, it's important, really important, to have resources that are easily accessible. There's nothing worse than knowing that you need help and coming up against a brick wall. And you're trying to help others, to help your loved ones, but in doing that you're crashing yourself, because you just feel like you have nowhere to go*.' (Int2)

'The website for BPD Community is very informative for people are sort of reaching out for something, for some help, some support, you know, just something, some recognition of what they're going through. So, it would be good to have more of that, but it's all about money isn't it.' (Int2)

Interview participants made reference to the well thought out, thorough but accessible nature of the group materials, and expressed enthusiasm for further materials to be developed and shared more widely. Participants spoke about the learning and strategies around relational support being applicable in multiple contexts of their lives, and useful beyond their relationships with their loved one suffering from BPD.

One participant, who has given back to the F&F group by volunteering their time on the Carer's Committee at BPD Community, emphasised the care and dedication that underpins the preparation of accessible and accurate materials for each month's meeting.

'Being on the committee, you see the work that goes into it, you do some of it, you really do see the effort. And it's done with love, with such love and such compassion, that you think it should be available to everyone. You want to reach people everywhere because they're so in need. We know people with BPD are, but the carers are so important too.' (Int2)

Materials and their accessibility were a key focus for participants, who all emphasised that the opportunity to reach more people seeking support would be enabled by increasing the availability of materials. Participants provided suggestions for how the materials and resources around relational support and for family and friends of people with BPD could be enhanced or taken forward. These suggestions most often involved translation of existing materials into different formats and use of different platforms to increase accessibility (e.g., social media, podcasts, YouTube). The learning component of the F&F groups was discussed as the most appropriate content to be shared and highlighted, with participants acknowledging that the community sharing, support and personal reflection component of group needed to be respected as confidential and not be shared publicly.

Some specific suggestions for taking materials and information forward included:

- Creating a podcast series following the content schedule of the F&F group. This might include summaries, outlines or reflections on each month's topic.
- Collaborating with high profile advocates or personalities to raise awareness of materials and support available. These might also be recorded conversations or appearances on podcasts, distributed through mainstream channels (e.g., Spotify).
- Targeting specific existing campaigns (e.g., R U OK day) to bring a BPD-informed lens and increase public awareness of the nuanced, often unique challenges that face those with lived experience of BPD, and what to do when the answer is 'no' to the question of 'are you okay?'.
- Creating information tailored to healthcare referral contexts to maximise the likelihood of people receiving timely information following a crisis or upon discharge from psychiatric care. This could include summary information about BPD, an overview of BPD Community's work, and contact details for further information and support.
- Creating learning modules, tip sheets, and video series that could be available via the *BPD Community* website to support people who may need immediate support or information, or who may not be ready to be part of a group.

Building on activities to provide relational support and access to community

Interview participants also expressed significant enthusiasm and need for *BPD Community's* current activities to be built on and expanded. Participants all touched on the need for additional marketing, communications, or media presence to support increased access and discoverability of *BPD Community's* work. Participants also spoke of the need to raise awareness of the F&F group with professional mental

health providers, such as psychologists and counsellors, who would provide referral or information about the organisation to their patients. This might involve creating or accessing mental health provider networks, community providers or other services to raise awareness of the group within these contexts, thereby increasing the potential for more family and friends to be linked into *BPD Community* without having to search for it themselves.

> '*I think that's super important, that psychologists and counsellors have an understanding of peer led support groups, because my counselling sessions on their own were great, but it was the combined that really helped me.*' (Int1)

Participants emphasised that while they appreciated the limited funding, resources and volunteers available to the organisation, when asked what they would like to see going forward with a relational support approach they clearly articulated the following suggestions:

- Increase the number of groups available, including:
    - Face-to-face and online formats when possible;
    - Groups held at different/more frequent times, running concurrently, to support those with limited availability;
    - Localised and expanded groups (such as regional areas, interstate).
- Have paid, trained professional facilitators to support groups and links to services for participants.
- Develop a mentorship or 'buddy' program for people with BPD, who they can contact for one-on-one support.

5. Discussion

Given BPD's impact on social and emotional functioning, families and friends are often faced with unique challenges in their relationships with loved ones with BPD. Despite needing support, they were shown to face exclusion and discrimination by the health sector, as indicated in both the academic literature and our interviews with consumers (Lawn & McMahon, 2015). Our findings indicated a lack of services to provide support for carers, family and friends of loved ones with BPD. Where services were set up, they were mostly targeted at direct family members and carers, with support especially lacking for partners and friends of people with BPD.

Members of BPD Community described their day-to-day experience of life with their loved one as 'walking on eggshells' prior to their involvement in the BPD community. The relational skills they learned helped them to more effectively respond to challenges in their relationships. They appreciated not just the presentation of skills and information via the manuals and BPD website, but the opportunities to practice and further develop these skills through the ongoing opportunities to interact with other members.

Being able to focus on their own behaviour, developing their own skills and responsiveness was a profoundly impactful and ongoing experience for participants. Engaging in the F&F group allowed participants to shift their understanding of the things and actions that were under their control and that they could change, and the aspects of their relationships or circumstances that required validation and radical acceptance but that were situated outside of their control. Participants spoke about feeling empowered in themselves and their actions even when a loved one may not be ready to take on changes in their behaviour, or when other family members, professionals or surrounding people were unwilling to engage with a diagnosis and presentations of BPD. The development of being able to validate and accept what could not be changed, while applying the skills and strategies they learnt to the things that could be improved, was described as a constant process of learning and practice by participants, and something they were wholeheartedly committed to.

Insights from leaders of Family Connections groups (Penney, 2008) include the importance of family members learning skills *for themselves*, as well as gaining knowledge and strategies to support their loved one with BPD. This aspect of learning and development towards wellbeing was echoed in the findings from interviews, where F&F members highlighted the opportunity and centrality of cultivating self-acceptance as a foundation to any relational interaction, validation and empowerment of self as well as a loved one with BPD, as critical aspects of their experiences of relational support.

Carter et al. (2015) described workshops for families of BPD as a catalyst for families developing their understanding of BPD, and this also highlighted the way that learning about BPD as a carer was also a journey of self-discovery. This finding was reflected by interviews with BPD Community members who articulated that learning about a how a relational approach could help their loved one with BPD also helped them to cultivate a sense of self-acceptance.

Family psychoeducation programs rely on family members engagement as part of an identified patient's treatment, focused on changes the family member can make that support the treatment target outcomes. Hoffman & Fruzzetti (2007) highlight the value of family education programs in empowering family members to learn and develop their own understanding, even when their loved one is not in therapy or receiving treatment for BPD. This was borne out in interviews, with participants highlighting how their sense of ability to affect change was bolstered by the fact that they were doing something for themselves, as well as their loved one, that did not depend on their loved one's actions or ability to engage with services or treatment.

The importance of validation and empowerment for carers was drawn out by the current study, highlighting that many improvements remain to be made in the medical and mental health care service

systems which focus mostly on the person with the diagnosis. As a minimum, carers need to be seen and valued as individuals and not only has a support to someone with BPD.

In their trial of Kindred, Gleeson et al. (2021) found that carers engaged less with content that was designed to improve their own well-being in preference to content that would improve their understanding and relationship with the young person. This was flagged as an important area for development and improvement in future iterations of Kindred, such as making clearer links between the benefits of self-care and ability to support a loved one. In their review of interventions that incorporate significant others in BPD treatment, FitzPatrick et al. (2019) highlight that disorder-specific interventions that target BPD in the context of close relationships appear to be the most effective in addressing BPD pathology, significant other distress and distress in close relationships. This included an important aspect of focusing on the benefit of significant other support to both themselves and their loved one with BPD.

Attention to environments and interpersonal systems, including the way family and individual relationships shape lives in different ways was revealed as an integral part of the learning experience. Bernardon & Pernisce-Duca (2012) highlight that 'narrative therapy is based on the premise that stories, and not fixed realities, shape our lives' (p.244), and Bateman and Fonagy (2019) emphasise the importance of self-experience and bring understood by others as essential for learning, change and seeing from others' perspectives. Findings from interviewees highlighted, in a slightly different way, these storytelling and perspective-shifting aspects of relational support that foster deeper appreciation and understanding of alternative narratives and relational possibilities. Participants expressed deep appreciation for the way relational support and the F&F group allowed them to 'hear' hard truths and aspects of their stories of loving someone with BPD that they otherwise would not have been able to engage with. This opened doors for them to reshape and redirect the story of how they cared for and approached their relationships with loved ones, and themselves.

The concept of recovery as it applies particularly for people with BPD and their loved ones cannot be separated from relationships and relational domains of life. Fitzpatrick, Liebman and Monson (2021) point to a significant lack of attention in the research literature to the interpersonal elements of how BPD pathology is maintained in adulthood, particularly in the context of informing BPD interventions and treatment targets. The connection between intrapersonal and interpersonal functioning is a promising area for positive support and intervention.

The literature provides evidence that services targeting relational support, and a group/community within which to interact and practice skills, provides valuable support to family and friends of people with BPD. Involvement in family and friend interventions was associated with decreases in burden, and improved understanding of how to manage their relationship with a loved one.

Family programs are especially important to consider as families often have difficulty gaining access to mental health services to support their needs and finding family therapists who understand their loved one's needs (Hoffman & Fruzzetti, 2007). A similar experience has been reported by partners of people with BPD, who report that support systems for family members do not meet their specific needs (Greer & Cohen, 2018; Mannion et al., 1994).

6. Concluding comments

This study highlighted the importance of ongoing and expanding research into experience and effectiveness of relational support for family and friends of people with BPD. Participants in our project expressed heartfelt gratitude and optimism that relational support was an area under investigation, and emphasised the need for more and ongoing research. Reporting on the process of adapting DBT for families, Hoffman et al. (2005) also reported willingness and explicit appreciation of research and development of programs to assist family members.

The ongoing nature of the *BPD Community* F&F group, and the opportunity to practice skills, receive empathic, informed but firm feedback, was central for many of the participants. Relating to the unique challenges that carers face in the day-to-day relationships with loved ones, this opportunity to draw on an established and constant source of information, support and compassion represents a particular strength of the *BPD Community* F&F group and approach to recovery and wellbeing. Peoples' relationships are not time-limited, and the access to an ongoing group environment and peers navigating the same relational challenges was emphasised as grounding and extremely important to interview participants. One participant described their extended time attending group, and the changes they had experienced in their relationship with a loved one with BPD as a result. They also emphasised that giving their time was an invaluable way they could continue to be part of a community and continue their practice of developing understanding, skills, and support networks.

The literature revealed no research or interventions addressing anything beyond family or romantic relationships of people with BPD. Interventions for friends, children and siblings was not examined, though some interview participants in the current study represented these groups and our interviews with them highlighted the importance of addressing their needs as an area for future exploration and intervention.

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8. Appendices

The following appendices provide additional information regarding the following aspects of the project:

8.1 Detail of final articles included in review

8.2 Interview guiding questions

8.1. Detail of final articles included in review

Author(s) & year	Title	Aim(s) and design of study	Participants	Measures	Methods/analysis	Country
Barr, Townsend & Grenyer (2020)	Using peer workers with lived experience to support the treatment of borderline personality disorder: a qualitative study of consumer, carer and clinician perspectives	Explore perceptions and models of peer support for BPD from the perspectives of consumers, carers and mental health professionals. Qualitative research.	12 consumers, 12 carers and 12 mental health professionals	N/A	Reflexive thematic analysis within a phenomenological methodology	Australia
	Key findings All groups emphasised the hope, connection and validation that peer workers provided. Two models of peer support work emerged with differences regarding the level of integration or complementarity to mental health teams.					
Bateman & Fonagy (2019)	A Randomized Controlled Trial of a Mentalization-Based Intervention (MBT-FACTS) for Families of People With Borderline Personality Disorder	Measure change in adverse incidents reported by family member, well-being, empowerment, burden and levels of anxiety and depression for immediate or delayed MBT-FACTS (Mentalisation-Based Families and Carers Training and Support) intervention. Randomised controlled trial.	56 family members/significant others living with/supporting people with a diagnosis of BPD	Recording and brief description of critical events 7 days before and during intervention (using designed event report sheet). Weekly self-report measures before, during and at 3-month follow-up: Beck Depression inventory; Spielberg State-Trait Anxiety Inventory; Burden Assessment Scale; Warwick-Edinburgh Mental Well-being Scale; SCORE-15 index of family function and change; and Family Empowerment Scale.	Aggregated measure of weekly average adverse incidents; linear mixed-effects models to test intervention differences at 3 weeks, 6 weeks and follow-up. Questionnaire data, 7 time points using linear mixed-effects models.	UK
	Key findings Both groups showed improvement on measures of depression, total anxiety and burden; immediate-intervention group experienced more empowerment and sense of well-being than delayed intervention group. MBT-FACTS reduced reported adverse incidents for families.					
Bernardon & Pernice-Duca (2012)	Integrating Recovery and the Narrative Attachment Systems Perspective to Working Through Borderline Personality Disorder	Advocates for systemic family-based treatment approach using narrative attachment therapy and reflective functioning. Literature review/summary.	N/A	N/A	Not listed	United States
	Key findings Attachment theory, narrative therapy and reflective functioning provide a useful framework to explore and explain changes in relationships and personal identity and functioning in relation to BPD and family.					

Author(s) & year	Title	Aim(s) and design of study	Participants	Measures	Methods/analysis	Country
Carter, Sired & Gordon (2015)	Evaluation of borderline personality disorder awareness workshops for service users and carers	Evaluate usefulness of BPD awareness workshops for service users and carers. Outcome study.	30 workshop participants (45% service users, 55% carers/family members)	eKALM self-report questionnaire (adapted from Personality Disorder Knowledge, Attitudes and Skills Questionnaire) Feedback forms, open-ended questions	Paired-samples t-tests (e-KALM) Thematic analysis (Feedback forms)	UK
	Key findings Workshops provided validating and safe learning environments, and opportunity to meet others in similar situations. Workshops acted a catalyst for a learning journey regarding BPD, self-discovery and future planning for change.					
Ekdahl, Idvall & Perseius (2014)	Family Skills Training in Dialectical Behaviour Therapy: The Experience of the Significant Others	Describe significant others' experience of DBT-FST (Dialectical Behaviour Therapy Family Skills Training), pre-post life situations and levels of anxiety and depressive symptoms. Descriptive mixed methods.	70 significant others with a parental relationship to children undergoing DBT treatment in a child- and adolescent psychiatry unit	Hospitals Anxiety and Depression Scale (HAD) Open question, free text questionnaires Group interviews	Qualitative content analysis, descriptive and inferential statistics	Other: Sweden
	Key findings Life before DBT-FST was a struggle, with DBT-FST providing hope for the future, strategies helpful in daily life. Anxiety and depressive symptoms significantly decreased for those with high initial levels.					
Fitzpatrick, Wagner & Monson (2019)	Optimizing Borderline Personality Disorder Treatment by Incorporating Significant Others: A Review and Synthesis	Reviews the empirical support for interventions that incorporate significant others in BPD treatment in addressing three potential treatment targets: (a) BPD pathology, (b) significant other distress, and (c) close relationship distress. Systematic review.	N/A	N/A	Systematic search of PUBMED, MEDLINE and PsycINFO Estimates of magnitude of effect	Canada
	Key findings Interventions that incorporate SOs may be able to more directly and effectively target BPD and the interpersonal context, expediting and optimising individual interventions. Disorder-specific or SO-assisted formats may provide improved outcomes for all involved.					

Author(s) & year	Title	Aim(s) and design of study	Participants	Measures	Methods/analysis	Country
Flynn et al (2011)	Family Connections versus optimised treatment-as-usual for family members of individuals with borderline personality disorder: non-randomised controlled study	Compare the effectiveness of FC with an optimised treatment-as-usual (OTAU) program for family members of individuals with BPD and introduce a long-term follow up. Randomised controlled trial.	80 family members (FC n=51, OTAU n=29) of individuals with BPD.	The Burden Assessment Scale (BAS) Grief Assessment Scale (GAS) Revised Centre for Epidemiologic Studies Depression Scale (CES-D) Personal Mastery SCALE (PMS)	Linear mixed-effects models	Ireland
	Key findings FC participants showed significant improvement on all measures, while OTAU participants showed some but not significant change in the same direction.					
Gleeson et al (2020)	A pilot trial of moderated online social therapy for family and friends of young people with borderline personality disorder features	Evaluated the acceptability, usability and safety of Kindred, a novel online intervention for carers of young people with BPD. Pilot outcomes study.	17 adult carers, 8 young people with BPD	Post-Study Usability Questionnaire (PSSUQ) Experience of Care-giving Inventory (ECI) Perceived Stress Scale Kessler Psycho-logical Distress Scale (K-10) Parental Adolescent Communication (PAC) Scale Assessment of Quality of Life - 4 Dimensions 12 of the self-report items (S1-S12) of the World Health Organization Disability Assessment Schedule 2.0. 3 items of the self-report Sheehan Disability Scale Coping Inventory for Stressful Situation-Specific Coping 3 items of the self-report Personality Disorder Knowledge Attitudes and Skills Questionnaire Borderline Symptom List (BSL-23) Ecological momentary assessment (EMA) at baseline and follow-up	Descriptive statistics, paired samples t-tests and Cohen's d for repeated measure. Analyses of cortisol in hair were performed according to the established protocol by Davenport et al. (2006). Semi-structured interviews, thematic analysis.	Australia
	Key findings Carer burden, stress, expressed emotion, family communication, quality of life, functioning, coping and perceived knowledge of BPD improved at follow-up. Kindred was shown to be acceptable, usable and safe.					

Author(s) & year	Title	Aim(s) and design of study	Participants	Measures	Methods/analysis	Country
Greer & Cohen (2018)	Partners of Individuals with Borderline Personality Disorder: A Systematic Review of the Literature Examining Their Experiences and the Supports Available to Them	Investigated the experiences of romantic partners of adult individuals with BPD and the interventions designed to support them. Systematic review.	N/A	Systematic search (13 articles pertaining to partner experience, 9 to interventions)	Thematic analysis	Canada
	Key findings Themes of partner experiences: emotional challenges, dual roles, and lack of control. Interventions addressed only a small portion of sub-themes identified in partners' experiences. Development and evaluation of more partner-oriented programming should focus on psychoeducation, peer support, individual- and relationships-based skills development.					
Grenyer et al (2019)	A Randomized Controlled Trial of Group Psychoeducation for Carers of Persons With Borderline Personality Disorder	RCT of 'Staying Connected' psychoeducation program for carers of someone with BPD. Randomised controlled trial	Carers of someone with BPD randomised into intervention (n=33) or waitlist (n=35)	Pre/post questionnaires and satisfaction ratings, 12 month follow up McLean Screening Instrument for BPD-Carer Version (MSI-BPD-C) Burden Assessment Scale (BAS) Dyadic Adjustment Scale-4 (DAS-4) Family Empowerment Scale (FES) Mental Health Inventory-5 (MHI-5) The Family Questionnaire (TFQ)	Multilevel modelling approach (SPSS-19 Linear Mixed Models)	Australia
	Key findings Intervention participants reported sustained improvements in dyadic adjustment with their relative, increased empowerment and reduced expressed emotion. Perceptions of increased ability to play an active role were also reported. Structured programs for carers effective extend interventions and address high burden.					
Gunderson et al (1997)	Families of borderline patients: A psychoeducational approach	Describes changes in understanding of borderline personality disorder psychopathology and changes in healthcare system and treatment. Describes McLean psychoeducational approach. Literature review and program description.	N/A	Camberwell Family Interview	Description	United States
	Key findings Families report increased communication by 6 months after starting psychoeducation, and feeling less burdened. Psychoeducational multiple family group (PE/MFG) approach appears appropriate to early phases of long-term treatment.					

Author(s) & year	Title	Aim(s) and design of study	Participants	Measures	Methods/analysis	Country
Hoffman & Fruzzetti (2007)	Advances in Interventions for Families with a Relative with a Personality Disorder Diagnosis	Describes family psychoeducation (FPE) and family education (FE) programs that have been shown to be useful for families, focusing on BPD programs Literature review/summary.	N/A	N/A	Description	United States
	Key findings Most often associated with DBT, family psychoeducation programs and family education programs are becoming more available to relatives of someone with BPD. Early studies suggest these programs benefit family members and may be beneficial to their relatives with BPD as well. More research and funding are needed to develop, evaluate and improve more programs					
Hoffman et al (2005)	Family Connections: A Program for Relatives of Persons With Borderline Personality Disorder	Assessed changes in family members who participated in Family Connections. Outcomes study.	44 participants from 34 families	Burden Assessment Scale Perceived Burden Scale Revised Center for Epidemiologic Studies Depression Scale (CES-D) Grief Scale	Hierarchical linear modelling	United States
	Key findings Levels of burden and grief decreased, and mastery increased from pre- to post-Family Connections. No changes in depression observed.					
Hoffman, Fruzzetti & Buteau (2007)	Understanding and engaging families: An Education, Skills and Support Program for relatives impacted by Borderline Personality Disorder	Reports on replication and extension of Family Connections. Outcomes study.	Family Connections participants (n=55)	Burden Assessment Scale Perceived Burden Scale Revised Center for Epidemiologic Studies Depression Scale (CES-D) Grief Scale	Hierarchical linear modelling	United States
	Key findings Participants showed improvements on all measures. At program completion, male and female outcomes were comparable except for grief, with women remaining higher than men.					
Hoffman, Fruzzetti & Swenson (1999)	Dialectical Behavior Therapy - Family Skills Training	Describes Dialectical Behavior Therapy - Family Skills Training. Program description.	N/A	N/A	N/A	United States
	Key findings					

Author(s) & year	Title	Aim(s) and design of study	Participants	Measures	Methods/analysis	Country
	DBT-FST aims to: 1) provide all family members an understanding of borderline behavioral patterns in a clear, nonjudgmental way; 2) enhance the contributions of all family members to a mutually validating environment; and 3) address all family members' emotion regulation and interpersonal skills deficits					
Krawitz et al (2016)	Family Connection in New Zealand and Australia: an Evidence-Based Intervention for Family Members of People with Borderline Personality Disorder	Provides an overview of the history, content and current Australasian status of Family Connections. Descriptive.	N/A	N/A	Description	New Zealand
	Key findings Family Connections has been shown to be effective in addressing distress and morbidity for family members of people with BPD. Family Connections has been delivered at time of writing in the United States for nearly 15 years, New Zealand for seven years, and in Australia for one year with 650 people on the waiting list.					
Mannion et al (2022)	Pilot project for a recovery-oriented, DBT-informed skill-building education course for families of adults with borderline personality, bipolar or major depressive disorders	To assess the Getting Off the Emotional Roller Coaster Skill-Building Family Education Course (GOER Family Course). Quasi-experimental.	270 (intervention = 217, control = 53) family members of a person diagnosed with emotion regulation disorder	Self-report questionnaires at pre- and post-intervention (or time equivalent) Burden Assessment Scale (BAS) Self-Assessment of Attitudes, Knowledge and Skills (SAAKS) (adapted from SMI Family Self-Efficacy Scale)	Descriptive statistics, t-tests, one-way ANCOVA	United States
	Key findings The intervention was effective in reducing caregiver burden, and attitudes, knowledge and skills showed improvement in the intervention group. Particularly where inaccurate diagnoses and ineffective treatment of a loved one with emotion regulation disorder is occurring, this intervention filled an important gap in resources for families. Adaptation to virtual learning is highlighted for future development.					
Marschke (1997)	An alternative support model for family members of the mentally ill: modifying dialectical cognitive-behavioural skill building (DBT)	Provide an overview of literature on family intervention programs Identify, accept and appeal to characteristics shared by and unique to patients and family members, and apply and modify DBT accordingly. Literature review/pilot study.	8 family members of patients with emotional disorders (Borderline Personality Disorder, Obsessive Compulsive Disorder, Manic-Depressive Disorder)	Not reported	Not reported	United States

Author(s) & year	Title	Aim(s) and design of study	Participants	Measures	Methods/analysis	Country
	Key findings Dialectical cognitive-behavioural Skill Building (DBT), with minor modifications, resonates and is applicable to family members of patients with emotional disorders. The model appeals to health rather than pathology, provides skills to address problems rather than diagnoses, and holds a dialectical or relationship-based view of reality and mental illness rather than adhering to a linear framework. Family members receive support, learn specific and applicable relationship-based skills, and have the opportunity to develop self-awareness and interpersonal effectiveness.					
Mayoral et al (2020)	Development of an early intervention program for adolescents with emotion dysregulation and their families: Actions for the treatment of adolescent personality (ATraPA)	Present an adaptation of DBT-A, Actions for the Treatment of Adolescent Personality (ATraPA) to the Spanish health system. Descriptive study.	Adolescents aged 13-17 with borderline personality disorder or traits, or severe emotion dysregulation, and their families	N/A	N/A	Other: Spain
	Key findings Presents ATraPA program, including ATraPA-TAI (intensive outpatient treatment), ATraPA-FAL (Families on the border) and group of alternatives. ATraPA-FAL is specific to parents of adolescents not taking part in ATraPA-TAI.					
Miller & Skerven (2017)	Family Skills: A Naturalistic Pilot Study of a Family-Oriented Dialectical Behavior Therapy Program	Evaluated the effectiveness of Family Skills. Outcomes study.	70 family members of a person with BPD participating in Family Skills Programs	Beck Depression Inventory II Beck Hopelessness Scale Brief Symptom Inventory Burden Assessment Scale	Descriptive, statistical and clinical significant analysis.	Unites States
	Key findings Depression, hopelessness and interpersonal sensitivity decreased significantly from pre- to post-intervention, with clinically significant change observed.					
Pearce et al (2017)	Evaluation of a psychoeducational group intervention for family and friends of youth with borderline personality disorder	Evaluate Making Sense of Borderline Personality Disorder (MS-BPD). Outcomes study.	23 family and friends of a young person with BPD		Paired-samples t-tests	Australia
	Key findings Participants reported significantly decreased levels of subjective burden and increased knowledge of BPD, however, objective burden and distress did not change. A brief group-based psychoeducation program benefits family and friends of young people with BPD in areas of subjective burden and knowledge, and findings are supportive of proceeding with further studies including RCT.					
Penney (2008)	Family Connections An Education and Skills Training Program for	Describes Family Connections and provides a group leader's perspective and reflections.	Experienced Family Connections group leader	N/A	Reflective	United States

Author(s) & year	Title	Aim(s) and design of study	Participants	Measures	Methods/analysis	Country
	Family Member Well Being: A Leader's Perspective	Descriptive and reflective.				
	Key findings Key insights provided include: early intervention and treatment need to focus more on youth; while knowledge is gained, most importantly family members will learn skills for themselves and their own well-being; leaders must recognise the last 2 weeks as a transition period for the group, allow time for discussion and help prepare for life after FC; time period of the program is limiting, and ideally would be available to family members as long as needed.					
Ratnaweera, Hunt & Camp (2021)	A Qualitative Evaluation of Young People's, Parents' and Carers' Experiences of a National and Specialist CAMHS Dialectical Behaviour Therapy Outpatient Service	Explored the experiences of young people and their parents/carers of a DBT service. Qualitative research.	Young people in DBT treatment (n=18) and their parents (n=7)	N/A	Thematic analysis	Switzerland
	Key findings Identified themes for young people included a new way of living, better understanding of self, new skills, person-centred approach, and relationships with others. They reported improvements in BPD symptoms following DBT. Identified themes for carers included f improved relationships, feeling supported, improved quality of life, and time/timing.					
Smith (2008)	BPD and the Need for Community: A Social Worker's Perspective	Emphasise the importance of a community/systems approach, and presents the Borderline Centre at McLean Hospital as a case study. Descriptive and reflective.	N/A	N/A	Descriptive and reflective	United States
	Key findings Emphasises need for community for family and friends as well as patients and those treating BPD, and the modelling of individual, family and community level relationships. The organisational model presented includes a holding environment, and incorporates combined treatment approaches for patients and families (e.g., DBT, DBT-FST, FC and Multiple Family Group). Families supported for as long as needed in group work, and provided ongoing monthly workshops with experts.					

8.2. Interview guiding questions

1. Can you tell me a little bit about yourself and how you are involved in BPD Community?

2. We are really interested in the idea of relational support that BPD Community is developing. Do you have any thoughts about this that come to mind straight away?

3. **What has your experience, if any, been of relational support through BPD Community? How has this made a difference to you?**
You might think about this compared to experiences with other social groups/with the health system.

4. **Do you feel relational support and sense of community are different things for you? Can you tell me a little about this?**

5. People with lived experience of BPD often report a sense of isolation. How do you think relational support might be able to help address this?

6. Thinking about the different social groups you are part of, which is most important to you, and why?
You could think about family, friendship circles, workplace colleagues or other social groups you are part of such as online groups or communities.

7. Which social group do you rely on the most, and why?
This might be different to the group you think is most important to you, or it might be the same. Is this related to sense of community for you, and how? Or How is this related to a sense of community for you?

8. Which social group have you put the most emotional energy into?
You could think about positive or negative emotions (e.g., hope, expectation, anger, resentment). Is this related to sense of community for you? Or How is this related to a sense of community for you?

9. Thinking about the groups or people you feel supported by, can you tell us a little bit about before and after you felt supported by this group or person? What was different for you?
*What made the **most** difference to you, and how?*

10. **Do you have any thoughts about how a model that focuses on relational support and community can be better used to help people with lived experience of BPD?**
What has worked for you, what hasn't worked so well.

11. We've looked at therapeutic support for people with a BPD diagnosis. In this interview we're interested in thinking about family and friends of people with BPD like you, and your understanding or thoughts about the support available for you. **What is your understanding of the support available to family and friends of people with BPD, and how do you feel about it?**
What are your thoughts about would most support you, or that future support could focus on?

12. Is there anything else you would like to say about relational support for the BPD community?

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