

What we know — and want to know — about Family Connections: a review from the perspective of lived experience

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Family Connections is a peer-led education, skills, and support program for family members of individuals with borderline personality disorder. Extant literature on Family Connections is limited but consistent in regard to methodology and outcomes, allowing for meaningful cross-study comparison. Despite evidence across studies regarding the program's efficacy, a number of questions remain to be answered. Three possible future research directions were identified from the perspective of family members with lived experience who are also Family Connections peer leaders; examining Family Connections when led by peers, gathering qualitative data about family member's experiences of Family Connections to illuminate additional program benefits, and studying the efficacy of Family Connections for family members of those with other mental health disorders.

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Introduction

Borderline personality disorder (BPD) is a pernicious disorder, full of emotional suffering and high rates of suicidality [1–3]. Family members of individuals with BPD often suffer alongside their loved ones, frequently without access to much needed education and support [4–8]. A number of interventions have been developed for family members of individuals with BPD, but relatively few studies have been conducted to assess their efficacy [9]. According to the most recent systematic reviews of family member interventions [9,10], Family

Connections (FC) is the program with the most evidence for its effectiveness. As a result, some researchers consider FC an essential component in the treatment for BPD [11].

This paper will provide an overview of the evidence for FC by briefly describing the five studies published since the program's inception in 2005, while paying particular attention to the two studies published since 2017. Future research directions will then be discussed based on the perspective of two authors with lived experience (L.C. & D.H.). These authors are in a unique position to provide meaningful insight, given their lived experience perspective as family members of individuals with BPD for whom FC was created who are also actively involved in coordinating FC groups. Recent systematic reviews of family member interventions for BPD — including FC — have called for further and more diverse research [10,12,13]. Therefore, the lived experience perspective presented here could provide meaningful direction for future studies.

Family Connections & Sashbear

FC is a 12-week multi-family education, skills and support program designed to meet the needs of family members of individuals with BPD [14]. FC is modeled structurally after the National Alliance for the Mentally Ill's highly valued Family-to-Family Program [15]. In FC, groups are led by trained family members. The content of the program — developed in consultation with several family members and individuals with BPD — was created by Dr. Alan Fruzzetti and Dr. Perry Hoffman, based on their extensive research and clinical experience [15,16]. FC is regulated and overseen internationally by the National Education Alliance for Borderline Personality Disorder [14]. The content of FC is divided into six modules and includes psychoeducational materials reflecting current literature on BPD and family functioning, as well as relationship and family skills based on Dialectical Behaviour Therapy (DBT) theory [14,34]. By participating in a multi-family program, FC also provides a forum in which participants can build a support network.

The Sashbear Foundation (Sashbear) is a non-profit organization created in 2013 by Lynn Courey and Mike Menu in memory of their daughter Sasha, who suffered from BPD and died by suicide in 2011. Following the loss of their daughter, Courey and Menu trained to become FC peer leaders in institutional settings. In 2014, Courey and

Menu saw an opportunity to bring FC to community-based settings in Canada through Sashbear. The organization began providing FC in Toronto, and in 2016, began providing the program more widely across Canada. To date, Sashbear has provided the FC program to over 5000 families.

Evidence for FC

The inaugural study of FC by the creators of the program in 2005 [14], found that participation in FC significantly reduced family member burden and grief while increasing mastery. The observed changes were sustained three months post-FC, with burden continuing to decrease. Hoffman *et al.*'s replication and extension study in 2007 [16], confirmed initial findings regarding improvements in burden, grief, and mastery, but also reported a decrease in depression. At three-months post-FC, grief scores continued to decrease, burden and depression scores were maintained, while mastery scores decreased [16]. In 2017, Flynn *et al.* [17**] became the first authors to compare the 12-week FC program to a control group, who received a three-week psychoeducational course about BPD. The study methods did not allow for long term follow-up data to be collected for the control group. Participants in the FC group reported similar findings to the inaugural studies (i.e. decreased burden, grief and depression and increased mastery) using a larger sample [17**]. Observed changes persisted at 12–19 months post-program, contributing important knowledge regarding the continued effectiveness of FC. Changes in the same direction were noted for the control group but were insignificant.

In 2019, Liljedahl *et al.* [11**], compared outcomes of the 12-week FC program against a two-weekend intensive FC program; a program that Sashbear also provides. While Liljedahl *et al.* [11**] did not find significant differences between the two types of FC programs, overall a significant reduction in burden, a significant improvement in overall mental wellbeing, and an improvement in family functioning were observed as a result of participation in both types of FC. These improvements were sustained at six to seven-months post-FC. The results from the Liljedahl *et al.* [11**] study are consistent with a study by Rajalin *et al.* from 2009 [18], where the impact of a nine-week adaptation of FC for family members of individuals who had attempted suicide was evaluated and resulted in similar outcomes including decreased burden, as well as improved overall mental wellbeing, quality of life, family functioning and expressed emotion.

The first two Canadian studies examining the impact of FC on family members have been described in the literature [19,20]. In 2018, authors Cameron *et al.* [19], conducted a mixed-methods study examining family member burden, coping, communication and relationships, and in 2019, Henderson *et al.* [20] conducted a

quantitative study evaluating feasibility, caregiver burden, and parenting stress. Both studies have the potential to contribute to a more current and nuanced understanding of the benefits of FC, however the results of these studies have not yet been published. In summary, although evidence for the efficacy of FC for family members of individuals with BPD is strong, there are many questions that remain and a number of future directions to pursue.

Future directions based on lived experience

Examining FC as a peer-led program

FC is described as a peer-led program. The efficacy of peer-led delivery models for family member interventions are well stated in the literature [21,22]. In FC, the peer-led delivery model is posited to allow family members to model non-judgment and to provide examples of skill application from their own experience [14]. However, only the two initial studies on FC by Hoffman *et al.* [14,16], utilized peers as the sole program leaders. In the study by Flynn *et al.* [17**], FC was led by a clinician and co-led either by a secondary clinician or a peer, given the shortage of trained family members at the time the study was conducted. In the study by Liljedahl *et al.* [11**], FC was led by clinicians due to their wide availability within the Swedish mental health system. Therefore, none of the current research on FC has examined program efficacy when provided exclusively by peers as the program was intended.

The paucity of evidence on peer-delivered FC is surprising to us and makes it difficult to generalize evidence regarding the efficacy of the program to organizations like Sashbear that adhere to the peer-led delivery model. From January 2019 to June 2020, all but nine of the 119 FC groups delivered by Sashbear across Canada were led exclusively by peers. The remaining nine groups were led by peers and co-led by clinicians who were interested in learning more about FC and becoming involved with the organization. The importance of the peer-led delivery model is consistently emphasized by participants in the open-ended feedback questionnaires collected by Sashbear. Participants at Sashbear emphasize that they learn more from the peer-led FC groups than they have previously learned in formal counselling programs offered in institutional mental health settings. It seems that group leaders with similar experiences who have compassion for family members are able to create a unique and safe space for sharing and learning. This is a striking contrast to the judgment and stigma families often report with interventions led by mental health clinicians.

As family members ourselves (L.C. & D.H.) — and based on our experience leading FC programs through Sashbear — it seems likely that the peer-led delivery model is a contributing factor to the programs' efficacy and therefore is an important element to include in future research. The

need for research examining FC when delivered by peers has been echoed by other researchers [9,13,17]. Further, Canada's mental health system has embraced FC as an evidence-based program that provides powerful benefits at low cost, primarily because it is delivered by unpaid peers [9,20]. When FC is delivered by clinicians, funding limits the number of groups that can be offered [9]. Therefore, evidence for the efficacy of peer-delivered FC groups could justify directing more resources towards the training and development of peers, thereby increasing the number of families who can access the program.

It is also interesting to note that a number of family members who complete FC often remain involved in the program by becoming peer leaders. From our own experience, the feedback we hear from fellow FC peer leaders, and the literature about the experience of peer facilitation [23], acting as a peer leader can contribute to perceived success and recovery among family members. Possible reasons for this include the ability to continue developing skills and mastery through facilitation, the opportunity to 'pay it forward', and the opportunity to retain a connection with a community of individuals who have shared experience and understanding. Surprisingly, some family members continue as FC leaders even after their loved ones have died by suicide. These families speak of the gift of having had a better relationship with their loved ones after taking FC and before their loved one's death. Their continued involvement in FC seems to be a purposeful way of creating meaning out of tragedy and perhaps healing their own grief. Therefore, in addition to examining the outcomes of FC when led by peers, future research should consider examining the impact of leading FC groups on the peers who chose to do so.

Examining FC qualitatively

All five interventional studies examining the efficacy of FC are quantitative, and three of which examined the same four outcome measures [14,16,17]. Only two studies reported obtaining informal qualitative feedback from family members, however qualitative methodology was not explicitly described in either one [17,18]. To the best of our knowledge, the only study that collected formal qualitative data through the use of focus groups has not published their results [19]. Sashbear collects informal qualitative feedback through the use of open-ended questionnaires, which provide rich illustrations of the way FC impacts people's lives. Through narrative description, family members are able to highlight key outcomes that quantitative data frequently do not capture.

One key theme identified in the informal feedback collected by Sashbear is the change observed in the relationships between family members and their loved one with BPD. In the feedback collected before

participating in FC, family members often report being at the point of estrangement and on the verge of telling their loved one to move out. Twelve weeks later, they have found ways to improve communication and trust and report feeling more connected to their loved one. Interestingly, the study by Liljedahl *et al.* [11] examined family relationships using the Questions About Family Members Scale and the Family Climate Scale but did not find significant improvements in either. However, based on our lived experience as family members and as peer leaders, this shift in familial relationships is one of the most meaningful outcomes of participation in FC. Eliciting qualitative data in future studies may help to illuminate this potential change. Qualitative descriptions may also highlight additional outcomes of FC that have not been examined in the quantitative literature published to date, such as hope [17] and shame [4,19]. Further, qualitative research that seeks to understand how FC benefits family relationships may also indirectly inform our understanding of the impact of FC on the individuals with BPD — something a number of authors have called for [11,13].

Examining FC for family members of individuals with different mental health disorders

FC was created for family members of individuals with BPD specifically. However, in our experience as administrators of Sashbear, many family members seek out the FC program despite not having a loved one with a formal BPD diagnosis. There are many possible reasons for this. Firstly, the 'surplus stigma' associated with BPD can lead to reluctance among clinicians to provide a formal diagnosis [24–26]. Controversy also exists related to the utility of a BPD diagnosis at a young age, despite BPD most often developing during youth [27,28]. Consequently, there may be a number of individuals suffering from BPD who have not been diagnosed [28]. Further, some of the core features of BPD — such as emotion dysregulation — are considered transdiagnostic features of a variety of mental health disorders including depression, anxiety and eating disorders [29–32]. Given that DBT, which was originally created to treat BPD [33], has been found to be effective across many different mental health disorders [34], it is plausible that FC could be effective for a variety of family members for the same reason.

To address the potential barrier to care experienced by family members of loved ones without a BPD diagnosis, Sashbear provides FC to family members of individuals with BPD or related problems including emotion dysregulation, mood lability, self-injury, and relationship difficulties. To date, the majority of research on FC has focused exclusively on family members of individuals with BPD. One study described by Henderson *et al.* [20] is examining FC for family members of youth with concurrent mental health and substance use disorders, but their results have not yet been published. In

order to support wider availability of FC, there is a need for research examining the efficacy of FC for a more diverse population of family members. The Global Alliance for Prevention and Early Intervention for Borderline Personality Disorder (GAP) was created in 2014 and has called for early intervention for families and individuals with subthreshold features of BPD and not just individuals with formal BPD diagnoses [26]. Therefore, future research examining the efficacy of FC for family members of individuals with a wider range of mental health symptoms or diagnoses would support this important call to action.

Conclusion

There is limited but meaningful research regarding the efficacy of FC for family members of individuals with BPD, particularly in regard to improvements in family member burden, grief, mastery, depression, and overall mental wellbeing. It is clear from the research undertaken thus far, and from the perspective of two authors on this paper (L.C. & D.H.) with lived experience as family members and as FC leaders, that not enough is known about FC when delivered by peers as intended. Future studies that elicit qualitative descriptions may enhance our understandings of how FC impacts familial relationships and could possibly illuminate other ways that family members have been impacted by the program that have not been captured quantitatively to date. Lastly, future research should consider examining the efficacy of FC for family members of individuals with diagnoses other than BPD to support wider availability of this impactful program.

Conflict of interest statement

Nothing declared.

CRediT authorship contribution statement

Lynn Courey: Conceptualization, Resources, Writing - original draft. **Doreen Hyndman:** Conceptualization, Resources, Writing - original draft. **Clare Sheasgreen:** Conceptualization, Investigation, Writing - original draft, Writing - review & editing, Project administration. **Elizabeth McCay:** Writing - review & editing.

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