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Internet-Based Chat Support Groups for Parents in Family-Based Treatment for Adolescent Eating Disorders: A Pilot Study

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Abstract

Objective: This study aims to examine the feasibility and acceptability of an Internet-based chat support group for parents implementing family-based treatment (FBT).

Method: Participants (N = 13) were parents of adolescents with eating disorder who participated in 15 weekly online therapist-guided chat sessions. Sessions focused on encouraging and supporting parental efforts to help their child overcome an eating disorder.

Results: Chat programme satisfaction ratings were high (91.7%). Participants reported looking forward to chat sessions and would recommend the chat to others. The vast majority reported that the chat helped them cope with their child’s eating disorder and to implement FBT. Participants reported feeling that they could talk openly and honestly in sessions and had a sense of belonging to the group. Relatively few technical problems were reported, and the chat was rated as accessible, convenient and easy to use.

Discussion: Findings provide preliminary support for the utility of an online parent chat as an adjunct to FBT. Copyright © 2012 John Wiley & Sons, Ltd and Eating Disorders Association.

Keywords
eating disorders; family-based treatment; online chat; parents; support groups

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Recently published randomized controlled trials (RCT) have shown that treatment of adolescent anorexia nervosa (AN; Lock et al., 2010) and bulimia nervosa (BN; Le Grange, Crosby, Rathouz, & Leventhal, 2007) is more effective when parents are directly involved. For example, family-based treatment (FBT) for AN was found to be superior to adolescent-focused individual treatment at 6- and 12-month follow-up (Lock et al., 2010). Although the first published RCT comparison of FBT for BN and cognitive–behavioural guided self-care for BN found no statistical differences in binge–purge abstinence rates (approximately 40% for both treatment conditions; Schmidt, Lee, et al., 2007), a subsequent study found that FBT for BN was associated with significantly greater binge–purge abstinence and improvements in core BN symptomatology in comparison to supportive psychotherapy at post-treatment and 6-month follow-up (Le Grange et al., 2007). These findings provide empirical indication for the efficacy of FBT, especially for adolescent AN.

Despite its apparent efficacy, the process of implementing FBT has been described by parents as ‘by far the most challenging experience they’ve ever gone through’ (Brown, 2011) and/or prevent their child from binge eating or purging. Indeed, parents ‘absorb the tears, the rage, and the terror of [their] child and the rest of the family’ (Brown, 2011). Surprisingly, in spite of these challenges, support groups for FBT carers are lacking (Collins, 2005).

Greater awareness of carer needs in general has been emphasized in light of findings that carers of individuals with eating disorders have been found to have high levels of psychological distress, burden and expressed emotion secondary to their role as carer (Zabala, Macdonald, & Treasure, 2009). For example, carers of individuals with AN have reported comparable and even greater subjective distress, objective burden and difficulties than carers of individuals with psychosis (Graap, Bleich, Herbst, Scherzinger, et al., 2008; Treasure et al., 2001). Similarly, more than 59% of the carers of individuals with BN reported feeling depressed, ‘burned out’ or physically or mentally ill (Winn, Perkins, Murray, Murphy, & Schmidt, 2004). Commonly reported feelings included helplessness, not knowing how best to respond to their child and fearing that their attempts were more harmful than helpful; extreme reactions included not being able to cope and feeling as though they were ‘going mad’ (Perkins, Winn, Murray, Murphy, & Schmidt, 2004).

Carers’ response to the patient has been shown to influence the outcome of many psychiatric conditions (Schmidt & Treasure, 2006).
In particular, the association between familial expressed emotion (i.e. criticism, hostility and emotional over-involvement; van Furth et al., 1996) towards their child with the eating disorder and treatment dropout or poor outcome is relatively robust (Le Grange, Eisler, Dare, & Hodes, 1992; Szumkler, Eisler, Russell, & Dare, 1985). One study (Le Grange et al., 1992) found that family counselling, in which the parents and the patient were seen separately, was empirically indicated in critical families. Conversely, parental warmth was found to predict good treatment outcome in a recent study (Le Grange, Rienecke Hoste, Lock, & Bryson, 2011).

Indeed, FBT therapists must be aware of many factors that could potentially influence outcome. Specifically, they need to be vigilant of early signs of carer exhaustion and familial criticism as well as encourage carers to express warmth and make positive comments to their child. Additionally, they play a pivotal role in ensuring that carers are provided with the support they need.

Carers of individuals with eating disorders have reported that involvement in a support group, particularly composed of other carers who are in a similar situation caring for an individual with an eating disorder, would help to reduce feelings of isolation as well as provide an opportunity to share experiences and offer advice and reassurance about how to cope with the person in their care (Cottee Lane, Pistrang, & Bryant Waugh, 2004; Graap, Bleich, Herbst, Scherzinger, et al., 2008; Graap, Bleich, Herbst, Trostmann, et al., 2008, Winn et al., 2004). The feasibility and acceptance of various programmes (e.g. ‘multifamily therapy’, Dare & Eisler, 2000; ‘Overcoming Anorexia Online’, Schmidt, Williams, et al., 2007; ‘Maudsley eating disorder collaborative care skills workshops’, Treasure et al., 2007; and ‘Off the C.U.F.F’, Zucker, Marcus, & Bulik, 2006) developed to provide support to carers in managing their child’s eating disorder (e.g. reduce carer distress, help them be aware of and take care of their own needs, enhance self-competency in their carer role, moderate expressed emotion and improve the way they communicate with their child) have been examined. Participation in these programmes has been associated with significant reductions in carer distress and caregiving difficulties (Salamiou, Campbell, Simic, Kuipers, & Eisler, 2005; Sepulveda, Lopez, Macdonald, & Treasure, 2008; Sepulveda, Lopez, Todd, Whitaker, & Treasure, 2008; Treasure et al., 2007) as well as improvements in managing their child’s eating disorder, general parenting skills, parental self-care and caregiving-related burden (Zucker et al., 2006). Moreover, satisfaction ratings of these programmes (including a DVD plus telephone coaching delivery format of the ‘Maudsley eating disorder collaborative care skills workshops’; Sepulveda, Lopez, Macdonald, et al., 2008) have been high (Salamiou et al., 2005; Sepulveda, Lopez, Todd, et al., 2008; Treasure et al., 2007; Zucker et al., 2006).

A recently published study examined the feasibility and acceptability of the workbook materials of a Web-based cognitive-behavioural intervention ‘Overcoming Anorexia Online’ for carers of individuals with AN (Grover et al., 2011). Carer anxiety, depression, negative caregiving-related experiences and expressed emotion were significantly reduced at the end of the study and follow-up. In addition, satisfaction ratings of the intervention were high, and a significant increase in positive caregiving-related experiences was found following participation in this carer intervention. Given the negative influence of expressed emotion on outcome, one study (Uehara, Kawashima, Goto, Tasaki, & Someya, 2001) tested a combined psycho-education/multifamily group specifically designed to decrease expressed emotion. Results of the study included reductions in expressed emotion and increased family cohesion and adaptability.

Carers have expressed a specific wish to connect with fellow carers using synchronous Internet relay chat (IRC) or ‘chat rooms’ (Cottee Lane et al., 2004). Internet-delivered interventions offer several advantages including ease of use, accessibility, flexibility, convenience and time efficiency and cost-efficiency (Bauer, Golkaramnay, & Kordy, 2005; Cook Myers, Wonderlich, Lancaster, & Mitchell, 2004). Additionally, communicating online allows parents to be connected to other users while maintaining anonymity. Indeed, communicating under pseudonyms was found to facilitate openness in one study (Jaffe, Lee, Huang, & Oshagan, 1995), and online group participants have reported developing a sense of community similar to traditional face-to-face groups including high levels of support, acceptance, personal self-disclosure and positive feelings regarding the approach (Kordy, Golkaramnay, Wolf, Haug, & Bauer, 2006). Moreover, Internet-based chat platforms have been shown to effectively deliver eating disorder programming. In addition, high satisfaction ratings of these Internet chat programmes have been reported (Engel & Wonderlich, 2010).

Given the responsibility that parents have in implementing FBT, it would appear that support for FBT parents is especially warranted and that IRC could provide an ideal platform to offer such support. Accordingly, the purpose of this study was to evaluate the technical feasibility and acceptability of a therapist-guided, Internet-based chat support group for parents involved in FBT for adolescent eating disorders.

**Method**

**Participants**

The sample was comprised of parents (N=13), including three couples, 10 different families who were involved in FBT for adolescent AN (Lock & Le Grange, 2012) at The University of Chicago Eating Disorders Program. Internet access and the ability to understand and communicate in English were additional inclusion criteria. Participation of both parents was not required. Adolescents had to be living with their parent(s) or primary caregiver(s). Parents were at various phases of FBT. The presence of active psychosis, mental retardation or the inability to read, write or type were exclusion criteria for the parents. Participants were not paid for taking part in this study, and involvement was voluntary.

**Description of the sample**

Participants were predominantly women (n=10) and Caucasian (n=11; n=2 African-American) with a mean age of 44.9 (SD=6.2, range=38–56) years. All participants were married (one participant was divorced but remarried) and had an average of 2.7 (SD=0.9, range=2–4) children. Participants were well educated; four of 13 had a professional degree (MD, JD), one had a doctoral degree, three had a Master’s degree, four had a 2-year college degree and one had a high school degree. Parents had participated in FBT an average of 2.6 (SD=1.2; range=1–6) months prior to the chat.
programme. Six of the parents had been in a former eating disorder treatment for their child (n=4 individual therapy and n=2 family therapy). For the majority of parents (12/13), this was the first time they had participated in either an Internet-based or face-to-face support group. Most of the participants reported having experience with computers (n=1, 7.7%, ‘very much’; n=8, 61.5%, ‘considerably’; n=2, 15.4%, ‘somewhat’; n=2, 15.4%, ‘a little’) and the Internet (n=3, 23.1%, ‘very much’; n=6, 46.2%, ‘considerably’; n=3, 23.1%, ‘somewhat’; n=1, 7.7%, ‘a little’). All participants had access to the Internet at home, and nine of 13 also had Internet access at work.

**Participants’ children with an eating disorder**

The participants’ children (n=10) ranged in age from 9 to 17 (M=13.3, SD=2.3) years. Eight were girls and two were boys with a mean duration of illness of 9.8 (SD=5.5, range=3-19) months. All met or had met criteria for AN (American Psychiatric Association, 2000).

**Adjunct family-based treatment intervention**

Parents were participating in FBT for AN, and treatment was delivered by three PhD, licensed clinical psychologists. All therapists had extensive experience in implementing FBT (e.g. all received training and supervision from experts in FBT).

**Measures**

The Baseline Demographic Questionnaire is comprised of 17 questions regarding demographic information (e.g. age, marital status), duration of child’s eating disorder, length of time treated with FBT and computer and Internet experience.

The Experience of Caregiving Inventory is a 66-item self-report inventory (Szmucler et al., 1996), which measures caregivers’ appraisal of the caregiving experience. Items refer to the past month and are scored on a 5-point Likert scale (0=never and 4=almost always); a higher score indicates greater severity. Items are organized into 10 subscales; eight subscales focus on the negative aspects of caregiving (caregiver distress): difficult behaviours, negative symptoms, stigma, problems with services, effects on family, the need to provide backup, dependency and loss. Reliability (Cronbach alpha coefficient) ranges from 0.74 to 0.91 have been observed. Two subscales focus on the positive aspects of caregiving (caregiver rewards): positive personal experiences and good aspects of the relationship.

The Eating Disorder Symptom Impact Scale (EDSIS) is a 24-item self-report inventory (Sepulveda, Whitney, Hankins, & Treasure, 2008), which measures the impact of eating disorder symptoms and behaviours on family life. Items refer to the previous month and are scored on a 5-point Likert scale (0=never, 4=almost always). This scale is scored from 0 to 96, with higher scores indicating more negative appraisals. There are four subscales (impact of starvation, guilt, social isolation and dysregulated behaviours) with high internal consistency (0.90).

The Support Questionnaire was developed for use in the study to enquire about the following: (1) sources of support in coping with their child’s eating disorder; (2) sources of support in the use of FBT; and (3) areas of FBT they wanted to receive support or help. Items are rated on a 5-point Likert scale (0=not at all, 1=a little, 2=somewhat, 3=very much and 4=extremely).

**Chat evaluation**

The Before Chat Session Questionnaire is a 10-item questionnaire that assessed the extent to which participation in the last chat session was helpful in the interim period between chat sessions. It was completed prior to each chat session and required participants to rate how often they used particular components learned in the previous chat on a 6-point categorical scale (0=not at all, 1=a little, 2=somewhat, 3=considerably, 4=very much and 5=extremely).

In the After Chat Session Questionnaire and programme evaluation, participants provided an evaluation of each chat session (After Chat Session Questionnaire) following the chat as well as an evaluation of the chat programme at the end of their participation (programme evaluation) on a 6-point categorical scale (0=not at all, 1=a little, 2=somewhat, 3=considerably, 4=very much and 5=extremely). Both the 16-item session evaluation and the 19-item programme evaluation were modifications of a programme evaluation questionnaire used in a prior chat group study (Kordy et al., 2006).

**Procedure**

All eligible parents who were involved in FBT at the University of Chicago were asked to participate in this study. The study protocol was approved by the institutional review board at the University of Chicago. Study procedures were fully described to potential study participants, and written informed consent was obtained. Participants completed assessment inventories online via the Web-AKQUASI programme (Percevic, Gallas, Arikan, Moessner, & Kordy, 2006) at baseline, before and after each chat session, midstudy (completed between sessions 7 and 8) and end of study (following session 15 or at study dropout).

A ‘Frequently Asked Questions’ section that described how to navigate the website and all study procedures (e.g. registering, logging in and out, completing online questionnaires and participating in chat sessions) was provided on the website.

**Support group intervention**

A chat room was specifically arranged for the sessions. Sessions were scheduled at fixed times. Group members met in a virtual room, where they communicated via written messages. The text-based communication was synchronous and in real time. Data were transmitted and stored encrypted. The chat operated under a firewall-protected server. Entry to the programme was password protected, and participants communicated under pseudonyms to ensure confidentiality.

Support groups comprised of two to five (M=3.1, SD=1.0) parents who met at fixed times for 15 (90-minute) sessions. Groups were therapist guided by a licensed clinical psychologist who was trained in FBT for adolescent eating disorders (RBH). Groups were ‘open’, meaning that participants could join at any time. This variety of parents at various stages of FBT was conceptualized as being advantageous in having the parents who were at later stages of FBT provide parents who were just beginning FBT with helpful advice, hope and encouragement as well as confirming that there was indeed a proverbial ‘light at the end of the tunnel’. The chat agenda was set at the beginning of each chat session and was dictated by the current needs of each group.
memories. Sessions were used to encourage and support parental efforts to help their child overcome an eating disorder. In addition, sessions provided parents with an opportunity to express both positive and negative feelings associated with the caregiving process, including sharing stories about past treatment experiences (e.g. residual feelings of being left out of treatment and/or being blamed for causing or contributing to the eating disorder). Although not a formal component of the programme, parents who were in the earlier phases of FBT frequently asked parents who were in the latter phases of FBT how they had managed and coped with the negative feelings (e.g. expressed emotion) associated with the caregiving process. Chat members also suggested more adaptive ways to communicate with and respond to their child with the eating disorder (e.g. via role play). Parents were assisted by fellow parents and the group therapist with problem-solving difficulties they had experienced using FBT, sharing ideas that had helped them to take control of the eating process (e.g. exchanging recipes including a 980-calorie smoothie and a 900-calorie soup!), discussing who to inform about the eating disorder, helping parents choose more proactive coping and managing acute crises. Information about eating disorders (e.g. genetic factors, media influences) also was provided and discussed. Parental advocacy issues including not allowing it to be normative for adolescents to skip school lunches, coaches’ negative comments and media influences as well as adolescent issues were discussed. Frequent checking in regarding how parents were coping emotionally was an ongoing component of the chat programme.

**Statistical analysis**

Descriptive statistics such as percentages, means and standard deviations were calculated. Pre–post effect sizes were calculated by dividing the pre–post mean differences by the pooled standard deviation.

<table>
<thead>
<tr>
<th></th>
<th>Not at all/a little/somewhat</th>
<th>Very much/extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The practical aspects of mealtimes (i.e. making sure we have our child eat enough food to gain weight in AN or regulate our child’s eating in BN)</td>
<td>6/13 (46.2%)</td>
<td>7/13 (53.8%)</td>
</tr>
<tr>
<td>2. Learning how to emotionally cope with the stress associated with mealtimes (i.e. keeping calm)</td>
<td>7/13 (53.8%)</td>
<td>6/13 (46.2%)</td>
</tr>
<tr>
<td>3. Planning meals and snacks (e.g. help with increasing the caloric intake in AN)</td>
<td>5/13 (38.5%)</td>
<td>8/13 (61.5%)</td>
</tr>
<tr>
<td>4. Getting my spouse/partner more involved in helping me implement FBT</td>
<td>11/13 (84.6%)</td>
<td>2/13 (15.4%)</td>
</tr>
<tr>
<td>5. Getting our other children more actively involved in treatment (e.g. have them provide more support to their sibling with the ED)</td>
<td>8/13 (61.5%)</td>
<td>5/13 (38.5%)</td>
</tr>
<tr>
<td>6. Presenting a ‘united front’ (i.e. being in agreement with my spouse/partner about what, when and how much food our child should eat)</td>
<td>7/13 (53.8%)</td>
<td>6/13 (46.2%)</td>
</tr>
<tr>
<td>7. Following through (being consequent) on what we want our child to eat (e.g. not allowing her or him to leave the table until she or he has eaten the food we agreed he or she should eat)</td>
<td>9/13 (69.2%)</td>
<td>4/13 (30.8%)</td>
</tr>
<tr>
<td>8. Preventing our child from getting rid of the food just eaten via self-induced vomiting, laxatives, etc.</td>
<td>11/13 (84.6%)</td>
<td>2/13 (15.4%)</td>
</tr>
<tr>
<td>9. Preventing or monitoring our child’s exercise/activity level</td>
<td>10/13 (76.9%)</td>
<td>3/13 (23.1%)</td>
</tr>
<tr>
<td>10. Separating the ED from our child (i.e. distinguishing who our child is from what the ED makes her or him do)</td>
<td>4/13 (30.8%)</td>
<td>9/13 (69.2%)</td>
</tr>
<tr>
<td>11. Addressing criticism in our family</td>
<td>11/13 (84.6%)</td>
<td>2/13 (15.4%)</td>
</tr>
<tr>
<td>12. Obtaining information about EDs</td>
<td>9/13 (69.2%)</td>
<td>4/13 (30.8%)</td>
</tr>
<tr>
<td>13. Other: ‘managing rages’</td>
<td>12/13 (92.3%)</td>
<td>1/13 (7.7%)</td>
</tr>
</tbody>
</table>

Note: AN, anorexia nervosa; BN, bulimia nervosa; ED, eating disorder; FBT, family-based treatment.
rated as being helpful. See Table 3 for complete results of the session evaluation.

The programme evaluation

Out of a total of 13 participants, nine completed all 15 sessions, two completed seven sessions and two completed less than half of the offered sessions. When asked for the reason why they discontinued their participation, one of the participants stated ‘the group helped me and I did not need any more support’, one participant stated ‘I received everything that I could from the group’, one participant stated ‘I received everything that I wanted from the group’ and one participant did not give any reasons.

Participants reported a high degree of satisfaction (11/12; 91.7%) with the chat programme and would recommend the chat group to another carer or parent (11/12; 91.7%). The vast majority (9/11; 81.8%) of the participants reported that the chat helped them to cope with their child’s eating disorder, and the majority (7/11; 63.6%) reported that the chat helped them implement FBT. Over half (7/12; 58.3%) of participants liked the anonymity of the chat. With respect to the setting, 11/12 (91.7%) liked having one chat a week, eight of 12 (66.7%) liked the 90-minute session duration and five of 11 (45.5%) stated that 15 chat sessions were the right amount. Figure 1 displays the satisfaction ratings at the end of study participation.

Table 2 The Before Chat Session Questionnaire (N=149)

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all/a little/somewhat (%)</th>
<th>Considerably/very much/extremely (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I used the group members’ advice from the last chat about administering FBT.</td>
<td>75.8</td>
<td>24.2</td>
</tr>
<tr>
<td>2. I used the therapist’s advice from the last chat about administering FBT.</td>
<td>64.4</td>
<td>35.6</td>
</tr>
<tr>
<td>3. I found that administering FBT was less stressful.†</td>
<td>59.5</td>
<td>40.5</td>
</tr>
<tr>
<td>4. I felt more hopeful that using FBT would help my child recover from the ED.†</td>
<td>45.3</td>
<td>54.7</td>
</tr>
<tr>
<td>5. I felt more confident in my ability to implement FBT.†</td>
<td>53.4</td>
<td>46.6</td>
</tr>
<tr>
<td>6. I blamed myself less for causing or contributing to the ED.†</td>
<td>83.1</td>
<td>16.9</td>
</tr>
<tr>
<td>7. I felt less alone.</td>
<td>51.0</td>
<td>49.0</td>
</tr>
<tr>
<td>8. I looked forward to the next chat session.</td>
<td>28.9</td>
<td>71.1</td>
</tr>
<tr>
<td>9. My relationship with my child with the ED has improved.†</td>
<td>54.7</td>
<td>45.3</td>
</tr>
<tr>
<td>10. My relationship with my spouse/partner has improved.†</td>
<td>73.5</td>
<td>26.5</td>
</tr>
</tbody>
</table>

Note:
ED, eating disorder; FBT, family-based treatment.
†N=1 missing.
‡N=2 missing.

Table 3 Session evaluation (N=146)

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all/a little/somewhat (%)</th>
<th>Considerably/very much/extremely (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How supported did you feel by the therapist in today’s chat?</td>
<td>4.1</td>
<td>95.9</td>
</tr>
<tr>
<td>2. How supported did you feel by the group members in today’s chat?†</td>
<td>17.9</td>
<td>82.1</td>
</tr>
<tr>
<td>3. How accepted did you feel by the group when you talked about your situation?†</td>
<td>9.7</td>
<td>90.3</td>
</tr>
<tr>
<td>4. How much did the group empathize with your problems and worries in today’s chat?†</td>
<td>19.4</td>
<td>80.6</td>
</tr>
<tr>
<td>5. How much did the therapist’s comments to other group members also apply to you?†</td>
<td>40.7</td>
<td>59.3</td>
</tr>
<tr>
<td>6. How much did group members’ comments to other group members also apply to you?</td>
<td>49.0</td>
<td>51.0</td>
</tr>
<tr>
<td>7. How much of a sense of belonging to the group did you have in today’s chat?†</td>
<td>13.8</td>
<td>86.2</td>
</tr>
<tr>
<td>8. How much were you able to talk to the group openly and honestly in today’s chat?</td>
<td>6.2</td>
<td>93.8</td>
</tr>
<tr>
<td>9. I received additional information about how to use FBT in today’s chat.‡</td>
<td>44.1</td>
<td>55.9</td>
</tr>
<tr>
<td>10. I learned how to handle certain problems I have had in using FBT in today’s chat.†</td>
<td>46.9</td>
<td>53.1</td>
</tr>
<tr>
<td>11. The advice and guidance I received from the therapist in today’s chat was helpful.</td>
<td>14.4</td>
<td>85.6</td>
</tr>
<tr>
<td>12. The advice and guidance I received from the group members in today’s chat was helpful.‡</td>
<td>32.6</td>
<td>67.4</td>
</tr>
<tr>
<td>13. How much did today’s group help you?</td>
<td>21.9</td>
<td>78.1</td>
</tr>
<tr>
<td>14. How satisfied were you with today’s group?†</td>
<td>11.0</td>
<td>89.0</td>
</tr>
<tr>
<td>15. How much did the technical environment limit your ability to express yourself or to self-disclose in today’s chat?</td>
<td>90.4</td>
<td>9.6</td>
</tr>
<tr>
<td>16. Did you experience any technical problems?‡ (yes/no)</td>
<td>77.2</td>
<td>22.8</td>
</tr>
</tbody>
</table>

Note:
FBT, family-based treatment.
†N=1 missing.
‡N=2 missing.
§N=3 missing.
Impact of eating disorder symptomatology on family life and caregiver appraisal of caregiving experience

The prestudy and poststudy results of the EDSIS and the Experience of Caregiving Inventory are presented in Table 4. The highest pre–post effect sizes were found for the EDSIS subscale nutrition ($d = 1.24$) and the EDSIS total score ($d = 1.18$).

Table 4 Pre and post effect sizes EDSIS ($N = 10$) and the ECI ($N = 11$)

<table>
<thead>
<tr>
<th></th>
<th>Pre, $M$ (SD)</th>
<th>Post, $M$ (SD)</th>
<th>$d$</th>
<th>95% CI</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>EDSIS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutrition</td>
<td>13.86 (7.48)</td>
<td>6.22 (4.52)</td>
<td>1.24</td>
<td>[0.29, 2.18]</td>
<td>.017</td>
</tr>
<tr>
<td>Guilt</td>
<td>10.40 (4.35)</td>
<td>7.20 (4.78)</td>
<td>0.70</td>
<td>[0.02, 1.38]</td>
<td>.444</td>
</tr>
<tr>
<td>Dysregulated behaviour</td>
<td>3.90 (3.90)</td>
<td>1.70 (2.16)</td>
<td>0.70</td>
<td>[−0.39, 1.79]</td>
<td>.181</td>
</tr>
<tr>
<td>Social isolation</td>
<td>5.00 (3.43)</td>
<td>3.50 (3.47)</td>
<td>0.43</td>
<td>[−0.46, 1.33]</td>
<td>.299</td>
</tr>
<tr>
<td>EDSIS total score</td>
<td>34.08 (13.62)</td>
<td>18.67 (12.47)</td>
<td>1.18</td>
<td>[0.24, 2.12]</td>
<td>.020</td>
</tr>
<tr>
<td>ECI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficult behaviours</td>
<td>2.68 (0.69)</td>
<td>2.33 (0.99)</td>
<td>0.41</td>
<td>[−0.42, 0.85]</td>
<td>.298</td>
</tr>
<tr>
<td>Negative symptoms</td>
<td>2.24 (0.58)</td>
<td>2.39 (1.01)</td>
<td>−0.18</td>
<td>[−0.69, 0.33]</td>
<td>.441</td>
</tr>
<tr>
<td>Stigma</td>
<td>2.49 (0.65)</td>
<td>1.89 (0.76)</td>
<td>0.85</td>
<td>[0.16, 1.53]</td>
<td>.020</td>
</tr>
<tr>
<td>Problems with services</td>
<td>2.31 (0.70)</td>
<td>2.09 (0.78)</td>
<td>0.29</td>
<td>[−0.35, 0.93]</td>
<td>.332</td>
</tr>
<tr>
<td>Effects on family</td>
<td>2.70 (0.66)</td>
<td>2.12 (0.74)</td>
<td>0.84</td>
<td>[−0.04, 1.71]</td>
<td>.060</td>
</tr>
<tr>
<td>Need to backup</td>
<td>2.05 (0.42)</td>
<td>1.95 (0.52)</td>
<td>0.19</td>
<td>[−0.57, 0.96]</td>
<td>.588</td>
</tr>
<tr>
<td>Dependency</td>
<td>3.24 (1.01)</td>
<td>2.55 (0.75)</td>
<td>0.78</td>
<td>[0.00, 1.55]</td>
<td>.049</td>
</tr>
<tr>
<td>Loss</td>
<td>2.31 (0.87)</td>
<td>2.14 (0.81)</td>
<td>0.20</td>
<td>[−0.53, 0.84]</td>
<td>.554</td>
</tr>
<tr>
<td>Positive personal experience</td>
<td>3.18 (0.75)</td>
<td>3.03 (0.76)</td>
<td>0.20</td>
<td>[−0.66, 1.05]</td>
<td>.583</td>
</tr>
<tr>
<td>Good aspects of relationship</td>
<td>3.45 (0.57)</td>
<td>3.32 (0.53)</td>
<td>0.25</td>
<td>[−0.50, 1.00]</td>
<td>.478</td>
</tr>
</tbody>
</table>

Note.
CI, confidence interval; ECI, Experience of Caregiving Inventory; EDSIS, Eating Disorders Symptom Impact Scale.

*N = 1 missing.

Discussion

The primary aims of this study were to examine the technical feasibility and acceptability of an Internet-based chat programme for parents involved in FBT. The high participant satisfaction ratings provide support for the acceptance of this particular online chat programme. Specifically, participants looked forward to chat sessions and cited accessibility and convenience including not having to manage the logistics of leaving the house to travel to the support group (e.g. not having to arrange for a babysitter) as particular advantages of the chat programme. An additional advantage and helpful aspect of the chat included the opportunity to obtain support from other parents who understood and had ‘been there’ as well as provide support to other parents.

Relatively few problems in operating the chat were reported, and participants noted that the chat programme was easy to use even though only one parent had had prior experience with online chat. The technical environment did not limit the participants’ ability to express themselves. On the contrary, it promoted open and honest communication and self-disclosure, and the anonymity of the chat was cited as a particular advantage, which is in keeping with prior studies (Jaffe et al., 1995; Kordy et al., 2006). Notwithstanding the technical nature of computers and the fact that online communication commonly operates among people who have never met in person, study participants reported that they were able to obtain support and felt accepted by the group members and the therapist and felt as though they belonged to the group. These findings are consistent with the existing literature (Kordy et al., 2006; Salem, Bogar, & Reid, 1997; Winzelberg, 1997) and challenge the notion that a sense of community cannot be built online.

Nevertheless, despite these positive aspects, the computer format was reported to be ‘a bit impersonal’ that did not facilitate getting to know the other participants very well. A telephone conference call was suggested to remedy this issue and create a more personal support group atmosphere. Additionally, a concern regarding the lack of face-to-face dialogue potentially leading to miscommunication was raised. Having the chat moderator provide ‘sound bytes’ or summary statements of the conversation was suggested to have the chat flow more smoothly. Finally, participants preferred when the chat sessions included three or fewer chat members and suggested grouping families according to age of child as well as stage of FBT.

This last suggestion is interesting as we originally theorized that it would be preferable to have groups be mixed with parents of diversely aged children and stages of FBT to allow parents in the earlier stages to obtain a sense of hope from those in the later stages that success with this treatment is possible. However, this finding indicates that parents found it difficult to relate to the challenges faced by parents whose children were at different developmental stages and/or FBT stages. This participant perspective makes sense: parents of a 9-year-old, prepubescent child are presented with very different issues compared with those of a 17-year-old pubertal adolescent. Similarly, parents in the latter phases of FBT (i.e. children are weight restored and eat meals independently with limited parental veto) have dramatically different stresses (e.g. adolescent issues) than parents who are in the first phase of FBT and are solely concentrated on the
challenges associated with the refeeding process. These important age-related and FBT-stage-related differences need to be considered in planning future carer support programmes.

Limitations

It is important to emphasize the pilot nature of this study. The modest sample size and exploratory nature of this study limit the extent to which results can be interpreted and generalized. Moreover, the homogeneity of the sample (e.g. married parents) limits the generalizability of study findings. Replication of this study with a more heterogeneous sample including separated, divorced and/or single parents as well as other carers (e.g. partners, spouses, grandparents) is needed. Without the benefit of a control group, we cannot with confidence attribute improvements reported here to the support group intervention. A larger systematic investigation is warranted before definitive conclusions regarding its efficacy or effectiveness can be made. Findings should therefore be interpreted as preliminary and as a demonstration of the feasibility and acceptability of this particular approach for parents involved in FBT for adolescent AN.

Implications

Study findings indicate that an online carer support programme might be a valuable adjunct to FBT. This has potentially important implications for intervention research and clinical practice. Specifically, the effects of this promising adjunctive approach can now be tested more broadly in controlled research trials. From a clinical practice perspective, findings highlight the important role therapists play in connecting carers, particularly those who are frustrated and display early signs of burn out, to other carers by referring them to carer forums (e.g. ‘Around the Dinner Table’) and/or by encouraging and helping them to form their own support network with other FBT carers.

Parents and other carers as the primary implementers of FBT are not themselves immune to having high expectations and perfectionistic thinking regarding their implementation of FBT. For example, a carer with perfectionistic tendencies might equate a slower rate of weight gain as failure to properly administer this treatment. Consequently, this quest for perfection and overly high standards only serve to further fuel a sense of hopelessness and futility as well as perhaps lead parents, in this state of exasperation, to make critical comments towards their child’s eating disorder. Therapists can help by connecting carers with other FBT carers and developing strategies to make the chat room experience less impersonal and/or by encouraging them to form their own support network with other FBT carers.

Future research

Additional investigation of the provision of support to carers of individuals with eating disorders, in general, as well as those who are involved in FBT, specifically, is needed. For example, two ongoing RCTs are comparing the efficacy of FBT with the ‘Off the C.U.F. F. parent training’ programme (Zucker, Marcus, & Bulik, 2006) and the ‘Overcoming Anorexia Online’ Internet programme (Schmidt, Williams, et al., 2007) with a control intervention. Along these lines, future studies should compare the effectiveness of FBT with and without a parallel parental support group such as Rhodes, Baillee, Brown, and Madden (2008) who found that participation in adjunctive parent-to-parent consultations improved FBT effectiveness (i.e. increased the rate of weight restoration). Published findings from a recently conducted multicenter RCT comparing single-family therapy with multifamily therapy (Dare & Eisler, 2000) will provide valuable information regarding the potential benefits of treating multiple families conjointly. Finally, a comparison of online versus face-to-face support groups also warrants investigation.

The limited scope of this pilot study did not allow for the measurement of improvements in carer psychological distress, burden and expressed emotion. However, future support groups for carers should develop programming to reduce expressed emotion such as the study by Uehara et al. (2001) as well as monitor and modify parental high expectations and perfectionism to facilitate more effective treatment delivery. Finally, subgrouping parents by age of child and stage of FBT to limit age-related and FBT-related differences, examining the content of chat topics in more detail and developing strategies to make the chat room experience less ‘impersonal’ should be studied in future investigations.

Conclusion

Findings from this pilot study suggest that this IRC-based support group for parents is a technically feasible, well-liked, easy-to-operate and convenient medium that enables parents to obtain as well as provide support to other parents involved in FBT. Results of the study showed that the chat helped them cope with the eating disorder and implement FBT, which highlights the importance of providing parallel support to parents who are using FBT. Allowing parents or other carers to participate in this type of...
support during FBT might help moderate psychological distress, burden and expressed emotion as well as facilitate the delivery and effectiveness of FBT.

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REFERENCES


