

## RESEARCH ARTICLE

# Collaborative Professional Education for Carers of Those with Eating Disorders

Cris Haltom<sup>1\*</sup>, Rebecca Ribeiro<sup>2</sup> & Nancy Potter<sup>3</sup>

<sup>1</sup>Dept. of Psychology, Ithaca College, Ithaca, NY, USA

<sup>2</sup>Binghamton University, State University of New York, Binghamton, NY, USA

<sup>3</sup>Cornell Cooperative Extension of Tompkins County, Ithaca, NY, USA

### Abstract

This paper describes the effectiveness of a 6-hour education programme to provide skills, knowledge and support to carers about how to best support patients with eating disorders. Based on a philosophy of mutual and ongoing support and learning, this programme brought together community groups of professionals, carers and advocates to present and participate in the programme. Pretest and post-test measures of the programme's effectiveness were administered to 81 participants ( $N=81$ ) across multiple-programme presentations in different locations in the USA. A paired form of analysis showed significant effect sizes on carers' knowledge, skill and understanding of eating disorders. Copyright © 2011 John Wiley & Sons, Ltd and Eating Disorders Association.

### Keywords

anorexia nervosa; bulimia nervosa; childhood; family therapy; eating disorder not otherwise specified

### \*Correspondence

Cris Haltom, PhD, Dept. of Psychology, Ithaca College, Ithaca, NY 14850, USA. Tel: +1 607-272-6750; Fax: +1 607-266-6414.

Email: [cris@lightlink.com](mailto:cris@lightlink.com), [cce2@cornell.edu](mailto:cce2@cornell.edu)

Published online in Wiley Online Library ([wileyonlinelibrary.com](http://wileyonlinelibrary.com)) DOI: 10.1002/erv.1129

## Introduction

The focus of eating disorder education has been to increase knowledge and understanding of eating disorders with an eye to prevention and enhanced therapeutic outcomes. Educational approaches are known and accepted as part of eating disorder treatment. Specifically, the needs of carers for eating disorder education have been identified in evolving research data documenting the high level of distress experienced by those caring for individuals with eating disorders (Haigh & Treasure, 2003; Kyriacou, Treasure, & Schmidt, 2008; Perkins, Winn, Murray, Murphy, & Schmidt, 2004; Treasure et al., 2001; Winn, Perkins, Murray, Murphy, & Schmidt, 2004; Zabala, Macdonald, & Treasure, 2009). Prolonged negative and difficult behaviours endemic to eating disorders (Pope et al., 2006) such as rejection of carer's help (Kyriacou et al., 2008) and patient comorbidities (Hudson, Hiripi, Pope, & Kessler, 2007; Kaye et al., 2004) contribute to the aversive impact of eating disorders on carers. Further, carers' misunderstanding about eating disorders can lead to damaging patterns of family interaction such as overprotection, criticism and hostility (Whitney et al., 2005; Whitney, Haigh, Weinman, & Treasure, 2007). Carers have been found to have expressed need for mutual support, skills-building for how to best provide support for a loved one and more and earlier access to information about the nature and aetiology of eating disorders (De la Rie, van Furth, De Koning, Noordenbos, & Donker, 2005; Haigh & Treasure, 2003; Surgenor, Rau, Snell, & Fear, 2000; Winn et al., 2004). The American Psychiatric Association

(2006) and the Worldwide Charter for Action on Eating Disorders (Academy for Eating Disorders, 2006) addressed the difficulty parents and carers have in obtaining sufficient information to feel confident in supporting their loved ones, by recommending up-to-date educational information about eating disorders which are available and accessible to carers.

Sepulveda, Lopez, Macdonald, and Treasure (2008) conducted research on DVD-based and telephone-based skills training for carers. Positive carer outcomes included changed carer attitudes toward eating disorders, improved communications with those with eating disorders and reduced parent distress. That Sepulveda et al. (2008) found carers had difficulty applying imparted knowledge to their individual circumstances points to the importance of providing eating disorder education supplemental to professional treatment.

### Mission of the Parent Partner Program™

The primary mission of Parent Partner Program™ (PPP) (Haltom et al., 2008) was to supplement treatment by providing carers with skills, knowledge and understanding to support people with eating disorders to move toward recovery. Carers were defined as family and friends of those with eating disorders (Treasure, Sepulveda et al., 2007; Treasure, Smith, & Crane, 2007). Based on a philosophy of mutual and ongoing support and learning, a secondary mission of this programme was to bring together a community of expert professionals, carers and advocates to copresent a programme which reflected multifaceted, integrated treatment.

## History of the Parent Partner Program™

The content of PPP was developed by a collaboration of community education and health care experts from mental health, medical and nutrition fields. Its content covered topics reflected in evidence-based treatments and findings by experts in the field of eating disorders. The programme approach was based on family and parent empowerment research conducted by Bronfenbrenner, Cochran and Cross (Cochran & Henderson, 1986) who found all families have strengths, and parents should be given positive recognition for being experts on their children.

## The format and protocol of the programme

Parent Partner Program™ included lectures, accompanying Power Point slides, case study video clips, group discussion and interaction (question/response) with presenters. A PPP manual ensured consistent programme content was delivered to participants. It streamlined the organization of multiple-programme presenters by assembling and sequencing workshop materials.

The programme was delivered in two consecutive sessions, each lasting 3 hours. Participants completed pretest and post-test evaluations. The programme was divided into four consecutive parts: introduction and mental health aspects (2 hours), medical aspects (1 hour), nutrition aspects (1.5 hours) and a caretaker/advocate presentation (1.5 hours). Each section followed a manualized format and was presented by a health care professional representing his/her profession or a caretaker. Within a particular discipline and community, team members were interchangeable and rotated across successive presentations. Professional health care presenters were volunteers with at least 1 year's experience treating eating disorders within a comprehensive, interdisciplinary treatment team. Specific precautions were taken to protect the confidentiality and anonymity of participants. Case studies provided in the manual alleviated the need for presenters to use their own examples that might compromise confidentiality.

## Method

Participants included 81 carers for those with eating disorders. Carers included parents, friends, siblings, other relatives and a few professionals. No demographic data was collected to distinguish the type of carer. Matched pretest and post-test data were collected for carers from 2007 through 2008. Unmatched data were excluded from the evaluative analysis. Data were collected from seven PPP presentations in four cities in New York State, USA. Participants were informed that the programme was adjunctive to treatment, not a substitute for treatment, and that knowledge provided was not a substitute for specialized training in the treatment of eating disorders.

## Assessment measure

A 14-item questionnaire (Appendix 1) was developed by Dr Cris Haltom. Questions were designed to assess the following in carers: confidence in their knowledge about eating disorders, ability to collaborate with a multidisciplinary treatment team, confidence in their loved one's treatment, understanding of their role and ability to support their loved one in treatment,

motivation to support/participate in treatment and understanding of ways they might be affected by a loved one's illness. Participants were instructed to think of those with eating disorders as 'loved ones' regardless of their relationship to the person(s) with eating disorders. Responses to questions 1 through 13 (Appendix 1) were measured using a 5-point Likert scale with 1 indicating 'disagree strongly' and 5 indicating 'agree strongly.' Question 14 (Appendix 1) was measured by indicating 'yes' or 'no' to whether the programme was helpful. If 'yes', space was provided for a written answer to 'how' the programme was useful.

Questions were chosen for their importance to carer education based on (1) preprogramme, carer focus groups, (2) documented knowledge of education topics in which carers have expressed interest (De la Rie et al., 2005; Rosenvinge, Skårderud, & Thune-Larsen, 2003; Surgenor et al., 2000), (3) documented information about the impact of eating disorders on carers (Treasure, Sepulveda et al., 2007), (4) familial factors thought to influence treatment outcomes (Lock, Le Grange, Agras, & Dare, 2001; Treasure, Sepulveda et al., 2007) and (5) 2 years of pilot testing and evaluation of PPP.

## Results

Two-tailed paired sample *t*-tests were used to examine the statistical significance of differences between pretest and post-test scores on each of 13 questions from 81 participants (Table 1). Cohen's *d* coefficients were calculated for each question as an indicator of the strength of effect of PPP on participants' knowledge from pretest to post-test. Cohen's *d* was defined as the difference between two means (post-test/pretest) divided by the pooled standard deviation for the data for each question.

Results showed statistically significant changes from pretest to post-test on all 13 Likert-scale questions. All changes were highly significant ( $p < .001$ ) except for question 13 ( $p = .019$ ), a measure of participants' motivation to support/participate in a loved one's treatment. Effect size was medium to large in all areas except participant's motivation (Cohen's  $d = .28$ ). A closer examination of participant responses indicated a small effect size for question 13 as a result of preexisting, high levels of pretest motivation (mean score = 4.62 out of a possible 5) compared with post-test levels (mean score = 4.81). This suggested respondents who attended the programme had a preexisting, high level of motivation to support treatment with little room for change.

Results of question 14 showed all respondents found the programme helpful. Respondents' written comments reflected increased knowledge about eating disorders and their treatment (20 respondents), increased knowledge about how to support someone with an eating disorder (eight respondents), increased knowledge and appreciation for interdisciplinary treatment (five respondents), a sense of sharing support for carers as a result of caretaker presentations (five respondents), enjoyment of speakers' expertise and presentation ability (four respondents) and increased understanding and empathy for the person with an eating disorder (two respondents).

## Discussion

Although other eating disorder education programmes have been used as a standard part of treatment, PPP is unique in that it is

**Table 1** Post-test/pretest means, standard error of means, *t*, paired differences d.f., paired differences two-tailed significance and Cohen's *d* (pretest to post-test effect size) for paired sample *t*-test analyses

Question	Mean post-test/pretest	Standard error of means	<i>t</i>	Paired differences d.f.	Two-tailed significance	Cohen's <i>d</i> effect size
1	1.111	.108	10.260	80	.000	1.14
2	1.609	.132	12.150	77	.000	1.38
3	1.282	.114	11.265	77	.000	1.28
4	.370	.081	4.553	80	.000	.51
5	.449	.104	4.327	68	.000	.52
6	1.068	.128	8.346	72	.000	.98
7	1.160	.110	10.516	80	.000	1.17
8	.962	.116	8.286	77	.000	.94
9	1.194	.112	10.661	79	.000	1.19
10	1.231	.129	9.554	79	.000	1.07
11	1.256	.121	10.356	79	.000	1.16
12	1.335	.133	10.356	78	.000	1.13
13	.189	.079	2.408	73	.019	.28

multidisciplinary both in content and presentation, and its manualized form makes it portable from community to community. PPP successfully and effectively brought together a community of professionals, carers and advocates to organize and copresent the programme in an atmosphere of collaboration, mutual learning and support among carers, treatment professionals and advocates.

Several methodological limitations, however, must be noted when evaluating the results of the current study. First, lack of demographic data about participants made it difficult to distinguish programme effectiveness for different types of carers. Second, programme effectiveness was assessed using self-report measures, which were not corroborated with assessment from another source. Third, we were unable to assess why participant response rate was lower on two questions reflecting confidence in a loved one's treatment team and ability to talk knowledgeably to a treatment team. It is possible that

these test items were awkward for any participating treatment professionals. Fourth, this study did not include a nonexposed control group. Lastly, this study did not examine the effectiveness of the programme on treatment outcomes. Future evaluation of PPP's effectiveness might address these limitations.

## Acknowledgements

This study was supported by the New York State Comprehensive Care Centers for Eating Disorders, contract 2020781, New York State Dept. of Health, Division of Chronic Disease Prevention and Health Bureau of Health Risk Reduction. Dr Haltom completed this study while acting as the Eating Disorder Community Education Liaison for the Western New York Comprehensive Care Centers for Eating Disorders.

## REFERENCES

- Academy for Eating Disorders. (2006). Worldwide Charter for Action on Eating Disorders. <http://www.aedweb.org/source/Charter> [Last accessed 27 July 2010].
- American Psychiatric Association. (2006). Practice guidelines for the treatment of patients with eating disorders (3rd edn). In *American Psychiatric Association practice guidelines for the treatment of psychiatric disorders*. Washington, DC: American Psychiatric Publishing, Inc., pp. 1097–1222.
- Cochran, M., & Henderson, C. R. Jr. (1986). *Family matters: Evaluation of the parental empowerment program: Summary of a final report to the national institute of education*. Cornell University, Ithaca, NY: Cornell University Department of Human Development.
- De la Rie, S. M., van Furth, E. F., De Koning, A., Noordenbos, G., & Donker, M. C. H. (2005). The quality of life of family caregivers of eating disorder patients. *Eating Disorders: The Journal of Treatment and Prevention*, 13, 345–351.
- Haigh, R., & Treasure, J. L. (2003). Investigating the needs of carers in the area of eating disorders: Development of the carers' needs assessment measure (CaNAM). *European Eating Disorders Review*, 11, 125–141.
- Haltom, C., Travis, S., DeSilva, A., Uphoff, M., Popenoe, J., Potter, N., et al. (2008). Parent partner program: Helping family, friends and carers understand eating disorders. Manual distributed by Gurze Publications ([www.gurze.com](http://www.gurze.com)), Carlsbad, CA.
- Hudson, J. I., Hiripi, E., Pope, H. G., & Kessler, R. C. (2007). The prevalence and correlates of eating disorders in the national comorbidity survey replication. *Biological Psychiatry*, 61, 348–358.
- Kaye, W. H., Bulik, C. M., Thornton, L., Barbarich, N., Masters, K., & Price Foundation Collaborative Group. (2004). Comorbidity of anxiety disorders with anorexia and bulimia nervosa. *The American Journal of Psychiatry*, 161, 2215–2221.
- Kyriacou, O., Treasure, J., & Schmidt, U. (2008). Understanding how parents cope with living with someone with anorexia nervosa: Modelling the factors that are associated with carer distress. *The International Journal of Eating Disorders*, 41, 233–242.
- Lock, J., Le Grange, D., Agras, W. S., & Dare, C. (2001). *Treatment manual for anorexia nervosa: A family-based approach*. New York: Guilford Publications, Inc.
- Perkins, S., Winn, S., Murray, J., Murphy, R., & Schmidt, U. (2004). A qualitative study of the experience of caring for a person with bulimia nervosa. Part 1: The emotional impact of caring. *The International Journal of Eating Disorders*, 36, 256–268.
- Pope, H. G., Lalonde, J. K., Pindyck, L. J., Walsh, T., Bulik, C., Crow, S., et al. (2006). Binge eating disorder: A stable syndrome. *The American Journal of Psychiatry*, 163, 2181–2183.
- Rosenvinge, J. H., Skårderud, F., & Thune-Larsen, K. (2003). Can educational programmes raise clinical competence in treating eating disorders? Results from a Norwegian trial. *European Eating Disorders Review*, 11, 329–343.
- Sepulveda, A., Lopez, C., Macdonald, P., & Treasure, J. (2008). Feasibility and acceptability of DVD and telephone coaching-based skills training for carers of people with an eating disorder. *The International Journal of Eating Disorders*, 41, 318–325.
- Surgenor, L. J., Rau, J., Snell, D. L., & Fear, J. L. (2000). Educational needs of eating disorder patients and families. *European Eating Disorders Review*, 8, 59–66.
- Treasure, J., Murphy, T., Szmukler, G., Todd, G., Gavan, K., & Joyce, J. (2001). The experience of caregiving for severe mental illness: A comparison between anorexia nervosa and psychosis. *Social Psychiatry and Psychiatric Epidemiology*, 36, 343–347.

Treasure, J., Sepulveda, A. R., Whitaker, W., Todd, G., Lopez, C., & Whitney, J. (2007). Collaborative care between professionals and non-professionals in the management of eating disorders: A description of workshops focused on interpersonal maintaining factors. *European Eating Disorders Review*, 15, 24–34.

Treasure, J., Smith, G., Crane, A. (2007). *Skills-based learning for caring for a loved one with an eating disorder: The New Maudsley Method*. London: Routledge.

Whitney, J., Murray, J., Gavan, K., Todd, G., Whitaker, W., & Treasure, J. (2005). Experience of caring for someone with anorexia: Qualitative study. *The British Journal of Psychiatry*, 187, 444–449.

Whitney, J., Haigh, R., Weinman, J., & Treasure, J. (2007). Caring for people with eating disorders: Factors associated with psychological distress and negative caregiving appraisals in carers of people with eating disorders. *The British Journal of Clinical Psychology*, 46, 413–428.

Winn, S., Perkins, S., Murray, J., Murphy, R., & Schmidt, U. (2004). A qualitative study of the experience of caring for a person with bulimia nervosa. Part 2: Carers' needs and experience of services and other support. *The International Journal of Eating Disorders*, 36, 269–279.

Zabala, M. J., Macdonald, P., & Treasure, J. (2009). Appraisal of caregiving burden, expressed emotion and psychological distress in families of people with eating disorders: A systematic review. *European Eating Disorders Review*, 17, 338–349.

## Appendix 1

### Preworkshop and postworkshop questionnaire

Code: \_\_\_\_\_ (If no code is assigned, make up and use same code for preworkshop and postworkshop questionnaires.)

Date: \_\_/\_\_/\_\_ (Please fill in.)

Your responses to this questionnaire are confidential and identify you only as a coded number in the upper right hand corner.

Circle the number that best reflects your view, at this moment, of each statement. A score of '1' indicates you 'disagree strongly' and '5' indicates you 'agree strongly'.

1. I can identify ways in which family/friend behaviours can encourage or perpetuate eating disorders. 1 2 3 4 5
2. I know what treatment involves for my loved one. 1 2 3 4 5
3. I understand my role in my loved one's recovery. 1 2 3 4 5
4. I can identify ways in which our culture and the media contribute to eating disorders. 1 2 3 4 5
5. I am confident in my loved one's treatment team. 1 2 3 4 5
6. I can talk knowledgeably to my loved one's treatment team about her or his treatment. 1 2 3 4 5

7. I can identify the nature of eating disorders beyond problems with eating. 1 2 3 4 5
8. I can identify ways in which I may be affected by my loved one's eating disorder. 1 2 3 4 5
9. I am confident that I can talk knowledgeably to my loved one about eating disorders. 1 2 3 4 5
10. I can identify the nutritionist's role in my loved one's treatment. 1 2 3 4 5
11. I can define the physician's role on my loved one's treatment. 1 2 3 4 5
12. I can define the psychotherapist's role in my loved one's treatment. 1 2 3 4 5
13. I am motivated to support and/or participate in my loved one's treatment. 1 2 3 4 5

I found the Parent Partner Program™ helpful. Yes\_\_\_\_. No\_\_\_\_. If yes, please specify how:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Thank you for your participation.