

Evaluation of a Web-Based Skills Intervention for Carers of People with Anorexia Nervosa: A Randomized Controlled Trial

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ABSTRACT

Objective: To investigate the feasibility and usefulness of an online information and skills development intervention for carers of individuals with anorexia nervosa (AN) and individuals with AN.

Method: Thirty-seven carers and seventeen individuals with AN were recruited; carers completed the intervention Overcoming Anorexia Online (OAO), with random allocation to receiving additional clinician guidance (OAO-G) or no guidance (OAO-NoG). Level of expressed emotion, distress, depressive symptoms, experience of caregiving, and impact of eating disorder symptoms were assessed in carers and perceptions of changes in their carers' expressed emotion were assessed in individuals with AN. Participants completed questionnaires at pre-intervention, post-intervention and 3-month follow-up.

Results: Significant reductions were found for carer intrusiveness, negative experiences of caregiving, and the impact of starvation and guilt. Within group effect sizes suggested mixed findings with respect to whether greater benefits were conferred for carers receiving clinician guidance. Decreases in perceived intrusiveness of the carer by the individual with AN were associated with a large effect size.

Discussion: Results demonstrate the feasibility and usefulness of an online intervention for carers. Further examination of the efficacy of the intervention for both carers and individuals with AN is warranted. © 2013 Wiley Periodicals, Inc.

Keywords: anorexia nervosa; carers; intrusiveness; web-based; intervention

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Introduction

Carers of individuals with anorexia nervosa (AN) often feel underequipped to deal with the illness.¹ Group-based carers' skill workshops reduce carer distress, high-expressed emotion (EE), and care-giving burden associated with eating disorder (ED) symptoms^{2–4} and research has begun to explore the usefulness of web-delivered support. Two studies have examined the program "Overcoming Anorexia Online" (OAO), which combines systemic and cognitive behavioral principles. A pilot study⁵ provided carers with workbooks that were completed in conjunction with 20 min of clinician guidance (e-mail or telephone) per week. Results showed significant improvements in carer anxiety and depression, negative

experiences of caregiving, the impact of ED symptoms, and carer EE, maintained at 3-month follow up. The second study⁶ compared the efficacy of an online version of OAO in conjunction with clinician guidance to a control group receiving ad hoc support only. The former produced significantly greater decreases in carer anxiety and depression. The benefit of providing access to additional clinical guidance has not previously been evaluated with OAO as with other programs.⁷ An important omission to date across any such programs is quantitative evaluation of the experience of the individual with AN.^{5–7} The present study aimed to (1) provide preliminary information on the efficacy of OAO with and without clinician guidance for carers and (2) assess perceptions of the individual with AN of their carer's levels of EE over the intervention.

Method

Participants and Recruitment Procedure

Carers ($N = 37$) were recruited via the Web sites of consumer support associations across Australia in addition to the Somerset and Wessex ED Association in the United Kingdom. The study was also advertised via "Facebook" to a variety of Groups that were active and related to recovery from AN, caring for an individual with AN, or generally carer-related. Inclusion criteria required that carers

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spoke English fluently and were presently caring for a person experiencing AN. All carers were directed to a web address; after giving consent, carers were sent a letter providing them with details on how to access their Time 1 (T1) questionnaire, which was hosted on the Web site. Once the carer was recruited, the family member with AN was invited to participate, of which 17 gave their consent to be involved. The Flinders University Social and Behavioural Research Ethics Committee approved this study.

Design

Participants were asked to complete questionnaires at baseline prior to intervention commencement (T1) and randomization at the end of the intervention (T2) and at 3-month follow-up (T3). The primary outcome measure was completed by both the carer and the individual with AN (the later were sent a hard copy of each of their questionnaires at the same specified assessment times as their carer). Secondary measures were completed by the carers only.

Intervention

All participants received the OAO intervention, both web-based and hard copies (the latter were provided as backup to the web material). These seven modules have been previously described elsewhere.⁵ Carers were also given hard copies of an additional two workbooks, providing them with information on how to take care of their own well-being (Workbook 8) and additional information on treatments and resources (Workbook 9). Participants were randomly assigned to receive the OAO modules either with no additional guidance (OAO-NoG), or with additional guidance (OAO-G),⁵ which was provided by e-mail or telephone by a Masters level trainee psychologist once a week. They had a period of 7 weeks to complete these modules before the T2 questionnaire.

Measures

The primary outcome measure was the 38-item Level of EE Scale⁸ completed by carers to rate their own EE and by AN sufferers to indicate their perception of their carer's EE. A four-point response scale was presented, with higher total scores indicating higher levels of EE. The secondary outcome measures included the General Health Questionnaire-28,⁹ the Medical Outcome Study Short Form Scale,¹⁰ the Depression Anxiety Stress Scales-21,¹¹ the 25-item Eating Disorder Symptom Impact Scale,¹² and the Experience of Care Giving Inventory¹³ assessing both the positive and negative experiences.

Results

Participant Flow

Only 37 carers entered the study between October 2010 and August 2012, out of them 4 (11%) were male

and 31 (83%) lived with the person with AN. Participant flow is shown in **Figure 1**. While only 27 (73%) completed T2 questionnaires, in all 30 (81%) went on to complete the intervention and completed at least two of the three waves of assessment. Seven carers withdrew and five individuals with AN withdrew after T1 (three from OAO-NoG and two from OAO-G).

Carer Analyses

Of the 27 carers who completed their T2 questionnaires, only 10% had spent no time completing the online modules, whereas 74% of those who had engaged in the modules reported completing at least 50% of the content, and 95% reported finding the modules at least "Quite Useful." The five carers who did not access the Web site reported this was because of difficulty accessing a computer or the OAO Web site, or not having enough time to spend on the internet.

No significant baseline differences were found between the carers in the two groups on any of the measures. Using linear mixed modeling (**Table 1**), two interactions approached significance ($p < 0.10$), one for quality of life (showing sustained improvement for OAO-G) and the other for the impact of guilt (with OAO-NoG experiencing the largest decreases). Three significant main effects of time were observed: intrusiveness and impact of starvation decreased for both groups, with OAO-G and OAO-NoG showing the largest decreases, respectively. Negative experiences of caregiving decreased in both groups, with the largest decrease associated with OAO-NoG. There was a significant main effect of group for irritability, where the guidance group had significantly improved scores compared to the no guidance group at T3.

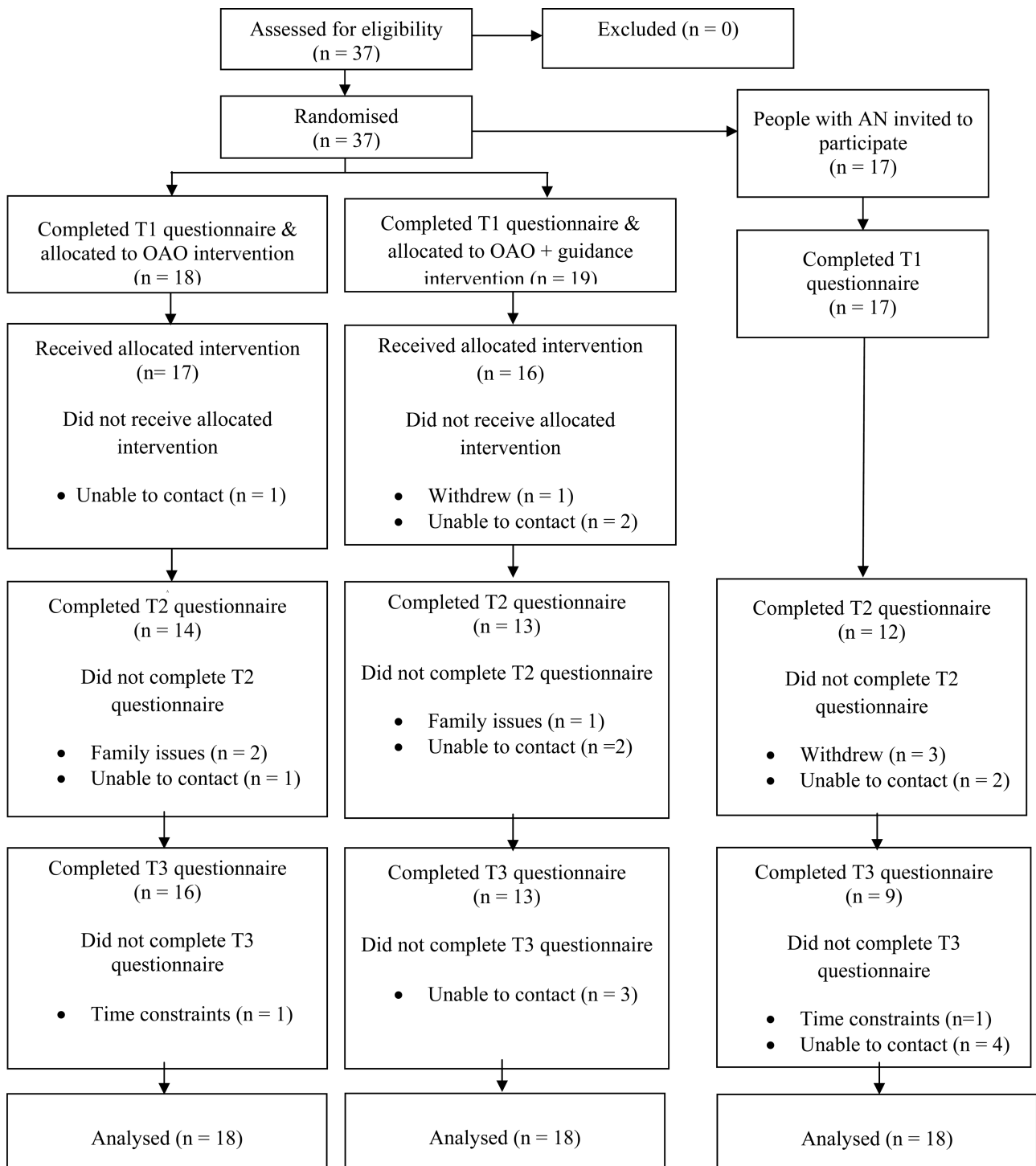
Perceived EE by the Individual with AN

Ratings of the individual with AN's perception of their carer's EE over time did not show a significant reduction, with T1-T3 effect sizes (Cohen's d) for the subscales and total scale ranging from 0.10 to 0.61. This latter result pertained to the intrusiveness subscale, where a paired samples t -test showed that reductions approached significance, $t(8) = 2.12$, $p = 0.07$, $ES = 0.70$. There was a positive correlation between changes in perceived EE over time between the carer and the person with AN reports ($r = 0.55$; $p = 0.001$).

Discussion

The usefulness of OAO is suggested by significant reductions for carer intrusiveness, negative experiences of caregiving, and the impact of starvation and guilt. However, we had a lower than expected recruitment rate. While the reason for this is unknown, it may represent a recruitment bias which could impact on the generalizability of the results, and may reflect a lack of acceptability of the Web site. With respect to the second aim of this study we found that individuals with AN did not perceive that their carer's levels of EE had significantly changed

FIGURE 1. CONSORT flow diagram of participants through each stage of the study.



over the intervention. However, the effect size of the decrease in intrusiveness was large, mirroring the significant improvements carers perceived. These findings are consistent with qualitative improvements identified by AN sufferers in previous research.¹⁴ Further quantitative

research should be utilized to investigate the impact of interventions of carers on the person receiving care.

A number of limitations of the current study exist. The sample size was inadequate to statistically inform us as to whether the provision of clinical guidance is important

TABLE 1. Estimated means (M), standard errors (SE), and effect sizes (ES) comparing changes in the two groups over time

Measure (baseline α)	OAO-NoG					OAO-G				
	M (SE)			ES		M (SE)			ES	
	(T1)	(T2)	(T3)	T1-T2	T1-T3	(T1)	(T2)	(T3)	T1-T2	T1-T3
LEE (0.94)	2.09 (0.10)	2.03 (0.08)	2.12 (0.08)	0.07	0.11	1.99 (0.10)	1.86 (0.08)	1.80 (0.08)	0.50	0.60
Intrusiveness ^a (0.93)	2.50 (0.14)	2.20 (0.16)	2.30 (0.12)	0.48	0.29	2.42 (.14)	2.10 (0.16)	2.04 (.12)	0.69	0.79
Criticism (0.88)	1.79 (0.12)	1.96 (0.10)	1.99 (0.10)	0.41	0.47	1.81 (0.11)	1.81 (0.10)	1.73 (0.11)	0.13	0.25
Irritability ^b (0.78)	2.29 (0.13)	2.18 (0.11)	2.30 (0.12)	0.19	0.01	1.97 (0.13)	1.90 (0.11)	1.80 (0.13)	0.28	0.44
Lack of emotional support (0.70)	1.78 (0.11)	1.77 (0.10)	1.87 (0.09)	0.10	0.25	1.76 (0.11)	1.61 (0.10)	1.62 (0.10)	0.41	0.33
GHQ-28 (0.93)	2.77 (0.13)	2.78 (0.15)	2.90 (0.13)	0	0.23	2.86 (0.14)	2.91 (0.15)	2.91 (0.15)	0.09	0.09
SF-36 ^c (0.85)	61.73 (3.39)	57.10 (3.86)	60.32 (4.54)	0.32	0.10	59.92 (3.35)	64.75 (3.87)	64.76 (4.87)	0.34	0.34
DASS-21 (0.90)	29.00 (4.09)	27.92 (4.85)	24.45 (4.57)	0.06	0.26	23.26 (4.00)	19.03 (4.86)	17.92 (4.92)	0.25	0.31
EDSIS (0.85)	35.94 (3.34)	31.15 (3.80)	29.08 (4.06)	0.34	0.49	37.79 (3.25)	36.06 (3.76)	36.13 (4.23)	0.13	0.11
Starvation ^a (0.89)	17.52 (1.36)	14.10 (1.96)	13.13 (1.91)	0.61	0.79	18.74 (1.29)	16.66 (1.92)	15.59 (1.07)	0.37	0.57
Guilt ^{a, c} (0.78)	10.33 (1.23)	8.39 (1.31)	7.11 (1.24)	0.38	0.63	9.36 (1.20)	9.25 (1.26)	9.23 (1.28)	0.02	0.03
Social isolation (0.85)	6.36 (0.86)	5.53 (1.02)	5.06 (0.84)	0.23	0.36	6.73 (0.83)	6.09 (0.99)	6.01 (0.88)	0.18	0.20
Bulimic behaviors (0.70)	3.89 (0.92)	3.11 (1.07)	3.70 (1.23)	0.20	0.05	3.63 (0.89)	3.89 (1.06)	5.11 (1.26)	0.07	0.39
ECI negative ^a (0.90)	104.89 (6.54)	81.76 (8.68)	80.99 (9.26)	0.84	0.87	101.16 (6.37)	90.21 (8.64)	98.41 (9.68)	0.40	0.10
ECI positive (0.90)	26.89 (2.20)	25.80 (2.73)	25.65 (2.22)	0.12	0.13	30.63 (2.14)	30.40 (2.71)	27.21 (2.25)	0.02	0.36

ES=Cohen's *d*; LEE = Level of Expressed Emotion; GHQ-28 = General Health Questionnaire (scaled version 28-items); DASS-21 = Depression, Anxiety and Stress Scales – 21-item; SF-36 = Medical Outcomes Study: 36-Item Short Form Survey; EDSIS = Eating Disorder Symptom Impact Scale; ECI = Experience of Care-Giving Inventory.

^aSignificant main effect of time.

^bSignificant main effect of group.

^cTime × group interaction <0.10.

for improving outcome of the intervention, with post hoc power calculations suggesting that the study was only adequately powered (0.77) to find large effect size difference (Cohen's *d* = 0.80). Additionally, significant main effects of time and group showed mixed results in terms of which group received the benefit. Therefore, the question of whether provision of additional support for carers completing self-help interventions needs to be further pursued with studies powered to detect small to moderate effect sizes. Second, carers received both hard copies and web-based access, and we are unable to disentangle the effects related to these different mediums. Third, in previous evaluations of this program, carers have been given more time to use the variety of skills taught, 2–4 months,⁵ and the follow-up period was also shorter than previously (3 months vs. 6 months⁶). It is possible that these time periods were too short for carers to effectively utilize the skills taught, potentially diluting the efficacy of the intervention. Fourth, guidance was provided by two trainee clinicians, with substantially less experience than those delivering guidance in previous evaluations.^{5,6} Specialist care in AN may be important, perhaps more so than in other eating disorders. Alternatively, it may be effective to have expert carers provide the guidance.

In conclusion, this study has demonstrated the feasibility of a carer skills intervention in AN. It was effective in improving carer levels of intrusiveness, negative experiences of caregiving, the impact of starvation and guilt, and providing preliminary support for positive impacts of the intervention on people with AN. These findings suggest that continued investigations of self-help programs that are adequately powered will provide further useful information as to the benefits of these approaches and ways of increasing their impact.

CW and US are authors of OAO, hold IPR rights and receive royalty on commercial sales.

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