Skill Building Workshop for Carers of People with Eating Disorders: Evaluating the Effects on the Participants or Evaluating the Program?

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1. *Introduction*

Eating disorders such as anorexia and bulimia are serious chronic illnesses (Fairburn & Harrison, 2003; Hoek & van Hoeken, 2003), associated with significant physical, psychological, and social impacts (Fairburn & Harrison, 2003; Jacobi, Paul, de Zwaan, Nutzinger, Dahme, 2004; Mehler, Crews, & Weiner, 2004). More specifically, conclusive evidence have demonstrated that caring for someone with an eating disorder such as anorexia and bulimia it is associated with high level of stress, burden, psychological and physical strain and that is often tests carers' coping skills beyond their limits (Karp, & Tanarugsachoc, 2000; Kiriacou, Treasure & Schmidt, 2007; Teasure, Whitaker, Whitney & Schmidt, 2005; Schulz, & Rossler, 2005; Whitney, Haigh, Weinman & Treasure, 2007).

According to the Australian Institute of Health and Welfare (AIHW) (2007), eating disorders are the 2nd cause of hospitalisation in young women in Australia and these disorders are in the ten leading causes of non mortality-related burden of disease within young Australian women aged 15 to 24 years old. Furthermore, eating disorders affect approximately 10 per cent of young Australian women and 1 per cent of young Australian men aged 14 to 24 (AIHW). More specifically, anorexia is the third-most common disease in Australian females aged 15 to 24 (AIHW). Finally, because the age of onset is typically adolescence or early adulthood, individuals who suffer from an eating disorder often rely upon a carer such as a parent or spouse for significant assistance with their recovery and treatment.

Caring for an individual with an eating disorder has been consistently associated with significant burden (Highet, Thompson & King, 2005; Perkins, Winn, Murray, Murphy & Schmidt, 2004; Treasure, Whitaker, Whitney & Schmidt, 2005). This burden is both objective; observable concrete outcomes such as financial costs and negative patient behaviour; as well as subjective; positive and negative feelings associated with the caregiving, such as worry, stress and guilt (Baronet, 1999; Maurin & Boyd, 1990). Numerous factors such as conflict with the sufferer over the eating disorder, attitudes of other family members, levels of social support and interpersonal strains have been shown to be significant predictors of burden (Dimitropoulos, Carter, Schachter, & Woodside, 2008; Kyriacou, Treasure, & Schmidt, 2007). Such factors have been incorporated into a model of carer coping (Schmidt & Treasure, 2006) from which Treasure and associates (Treasure, Smith, & Crane, 2007) have developed a 6 session carer skill-building workshop. The skill-building workshops are designed to improve carers' well-being, coping strategies, and problem-solving skills. In addition, the workshops provide strategies to improve patterns of emotional expression, match carers' goals and expectations to the stage of change of the person they care for is at through teaching them the transtheoretical theory of change and the principles of motivational interviewing. A recent pilot study (Sepulveda, Lopez, Todd, Whitaker, & Treasure, 2008) has shown these workshops to reduce carer distress, level of general caregiver burden and perceived impact of the eating disorder symptoms. While the content of the workshops has been widely disseminated throughout the United Kingdom and developed in to a self-help manual (Treasure et al.), its evaluation is limited to one single study (Sepulveda et al.).

Aims

Therefore, the overall aims of this study were to improve the well-being of carers of a person with an eating disorder and reduce their burden. More specifically, the research question concerned the impacts of participating in a 6 week workshop specifically designed to improve communication, coping, and problem-solving skills of carers of a person with an eating disorder living in Australia.

2. Methods

A non-experimental research design with repeated measures was implemented. Data were collected at three different times. First, data were collected at the beginning (T1) and upon completion (T2) of the workshop series, and six weeks after completing the workshops (T3). Self-reported surveys were used to provide objective data about the communication, coping, and problem-solving skills of carers of a person with an eating disorder. The analysis of the data contributed to explain the impact of the intervention on the well-being and burden reduction of carers of those with an eating disorder. More specifically, data gathered from the self-report surveys provided information about the following variables: expressed emotion (critical comments, and emotional overinvolvement), general health (psychological distress), adaptive and maladaptive coping, nutrition, guilt, dysregulated behaviours, social isolation, importance and confidence in changes being implemented by the person they care for. Also, qualitative comments about the participants' experience were gathered at the end of the workshops. Data were analysed by conducting repeated-measures ANOVAs to determine how the variables changed between each data collection time.

Ethics approval for this study was granted by the Deakin University Human Research Ethics Committee.

2.1. Participants

A total of fifteen persons participated in the workshops. They were all the carer of a person with a diagnosed eating disorder. They were either a close relative, a parent of grand-parent, a partner, or a spouse. Participants were recruited through two eating disorders services and private practitioners, and via a newspaper article. They all resided in a regional area of south east Australia.

2.2. Procedure

Once they accepted to be part of the study, carers participated in six 2-hour workshops held on a weekly basis. The content of the workshop addressed carer's patterns of emotional expression, the transtheoretical theory of change, principles of motivational interviewing to improve communication and increase readiness to change, and the problem solving skills as developed by Treasure and colleagues (2007).

2.3. Data collection

Using a general information sheet, demographic data including age, gender, relationship with the person with the eating disorder, education, and income level were collected as well as information regarding other demands such as other children and employment. Further details regarding the person they are caring for such as their age, gender, symptoms (weight loss, binge eating, exercise, vomiting etc.), treatment including whether they had been hospitalised, the importance that the person change their behaviour and carers confidence their loved one are capable of changing were sought. That type of information was required to fully understand the carers' lived experience and to appreciate their personal views on the eating disorder of the person they care for.

Participants also completed the following four self-reported surveys: the Brief COPE; the General Health Questionnaire; the Eating Disorders Symptom Impact Scale; and the Family Questionnaire.

The *Brief Cope* is a 28 item measure of how carers cope with their caring role; the *General Health Questionnaire* is a 12 item measure of the severity and impact of psychological problems experienced by the carers in the previous 2 weeks; the *Eating Disorders Impact Scale* is a 24 item measure of specific impacts associated with caring for someone with an eating disorder; the *Family Questionnaire* is a 20 item measure of the dimensions of expressed emotion (emotional overinvolvement, and critical comments defined as hostility, and criticism) targeted in the intervention; the *Accommodation & Enabling Scale* is a 33 item Likert scale measuring the extent to which ED behaviours influence or control family life; and finally the *Family Environment Scale* is a 9 item True/False scale measuring amount of openly expressed anger and conflict among family members.

Data were analysed by conducting repeated ANOVAS to determine the level of change over time and measure the effect on participants' general well-being, coping, levels of expressed emotion and the capacity of carers to manage the eating disorder of their loved one.

3. Results

A total of fifteen carers attended series of workshops. There were 10 mothers, 4 fathers, and 1 grand mother. Of these, eighty percent (80%) were living with the person with an eating disorder, twelve out of fifteen were working either part time or full time and all participants had other children. Also, few parents were directly involved with intervention related commitments, with an average of one hour per week dedicated to taking the person they care for to health professionals.

The level of expressed emotion was examined by looking at the number and frequency of critical comments, and level of emotional overinvolvement. At T1, 85.7 percent of carers displayed a high level of emotional overinvolvement, and 64.3 percent of carers reported high levels of critical comments. At T2, the percentage of carers demonstrating high level of emotional overinvolvement had dropped to 66.7 and 61.7 percent of carers reported high levels of critical comments. At T3, scores had decrease for both reported high levels of emotional overinvolvement (53.3%) and reported high scores on critical comments (53.3%). Over time, the level of critical comments decreased, however this result was not significant. The changes reported by the carers about their level of emotional overinvolvement revealed a significant reduction from T1 to T3 ($p < .05$).

The level of psychological distress experienced by carers, as measured by the GHQ-12, was moderate for 57.1 percent of carers, at T1 and 40 percent of carers reported moderate distress at T2 and T3. One carer reported a high level of distress across all time points. While there was a decrease in reported distress over time, this change was not significant.

In terms of coping strategies, carers reported using significantly more adaptive coping strategies from T1 to T2, ($p< .01$) and from T1 to T3 ($p< .01$). There was also a reduction in the use of maladaptive coping strategies, with the change from T1 to T3 approaching significance, ($p= .054$).

When measuring perceived difficulties with the person they care for, as measured by the EDSIS, the level of nutritional difficulties, guilt, dysregulated behaviour, and social isolation reported was low. There were no significant changes in these perceived values over time.

Lastly, there was no change in the importance to carers that their loved one changes, with the level remaining very high. Further, while the level of confidence that carers had that their loved one could change did increase a little over time, this increase was not significant.

3.1. Evaluation of the workshops

Participants also completed an evaluation questionnaire at the end of the series of workshops. Participants were asked to rate the eight following statements: 1) The content was presented clearly; 2) There was sufficient information provided; 3) The workshops were engaging and interesting; 4) The information presented was easy to understand; 5) The material presented was valuable and relevant; 6) The presenters were knowledgeable; 7) I would recommend the workshop to others; and 8) Overall the workshops were of high standard. All items were rated on a 5-point Likert scale (1 = Strongly disagree, 5 = Strongly agree). Overall, the workshops were rated highly with results varying from 4.18 /5 (The information presented was easy to understand) to 4.91/5 (the presenters were knowledgeable; I would recommend the workshop to others; and overall the workshops were of high standard).

4. *Discussion*

This is the first study to investigate the effects of participating in the 6 week workshop series as they were developed by Treasure et al (2007) in regional Australia. Date collected described and quantified such variables as: expressed emotion, critical comments, emotional overinvolvement, general health (psychological distress), adaptive and maladaptive coping, nutrition, guilt, dysregulated behaviours, social isolation, importance for the carers that the person they care for change their behaviour and carers confidence their loved one are capable of changing.

The results of this study indicated a reduction of maladaptive coping and a significant increase in adaptive coping mechanisms. Furthermore, a significant diminution of participants' emotional overinvolvement was observed over the data collection period. The perception of the impact of dysregulated behaviours of their loved ones decreased overtime. In addition, improvements in participants' general well-being and confidence that their loved one could change and improve their overall functioning were found. Therefore, despite the small sample size, the skill-building workshops had significant impacts on carers' functioning and support further studies. However, a study with a larger sample and a control group will increase the power of the result.

Furthermore there was limited information collected with regards to the more global evaluation of the program. Evidence in the literature as well as results from this study have identified the value of skill building activities and support interventions for carers and family members of a person with an eating disorder. However, the evaluation of these interventions, including the evaluation of this skill-building workshop series, has concentrated on measuring the outcomes of the intervention without documenting the other dimension of this program.

This presentation will look closely at this study but will also critique and analyse it through the lens provided by the Gervais' Model of the Dimensions of a Program (1998). This model reflects the effort of modeling and analysing the complex interactions existing between a program, the environment and the individuals involved. It has 5 dimensions (structural, strategic, systemic, operational and specific) that, combined, provide the researcher with a complete image of the program (strengths, limits, the area to develop and to consolidate, etc.). These dimensions take into consideration the multifactorial aspect of the program and provide information about the program as a whole and not only as a succession of interventions offered to the participants. In doing so it is hoped that practitioners will understand the importance of moving evaluation beyond effects of interventions to a comprehensive understanding of program dynamics and dimensions in provision of quality interventions.

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