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# The influence of carer fear and self-blame when supporting a loved one with an eating disorder

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#### **ABSTRACT**

Carers often feel disempowered and engage in behaviours that inadvertently enable their loved one's ED symptoms and yet little is known regarding these processes. This study examined the relationships among fear, self-blame, self-efficacy, and accommodating and enabling behaviours in 137 carers of adolescents and adults with ED. The results revealed that fear and self-blame predicted low carer self-efficacy in supporting their loved one's recovery as well as the extent to which carers reported engaging in recovery-interfering behaviours. The relevance of these findings are discussed in the context of family-oriented ED therapies and highlight the importance for clinicians to attend to and help to process strong emotions in carers, in order to improve their supportive efforts and, ultimately, ED outcomes.

#### Introduction

There is mounting evidence in support of carer involvement in the treatment of eating disorders (ED) across the lifespan. In children and adolescents, randomized clinical trials provide robust findings supporting the active involvement of parents in the context of family-based therapy (FBT; see Downs & Blow, 2013; Lock, 2011, for a review). FBT engages parents as key resources in the therapy and the FBT clinician is tasked with empowering parents to adopt a primary role in their child's treatment process. Parental self-efficacy is emerging as a variable of particular interest in FBT. In a qualitative study exploring the core principles of FBT for

adolescents with anorexia nervosa, clinicians identified parental self-efficacy as most necessary for positive outcome (Dimitropoulos, Freeman, Lock, & Le Grange, in press). In the context of research, Lafrance Robinson, Strahan, Girz, Wilson, and Boachie (2013b) reported that through the course of adapted FBT for adolescents with ED, positive changes in parental self-efficacy predicted reductions in their child's ED, depression, and anxiety symptoms, which were maintained at 3 and 6 months post treatment. Byrne, Accurso, Arnow, Lock, and Le Grange (2015) mirrored and extended these findings. The results of their study revealed that increases in parental self-efficacy predicted adolescent weight gain, whereas increases in self-efficacy in the adolescents themselves did not.

Among adult populations, the New Maudsley Model (NMM) also enlists the family in actively supporting their loved one throughout the recovery process, while targeting carer anxiety and burden in order to decrease the negative impact of these states on helping behaviors (Treasure, Smith, & Crane, 2007; Whitney et al., 2012). Specifically, and among other interventions, carers are trained in the use of communication tools influenced by principles of motivational interviewing to help support their loved one to engage in the tasks of recovery. Macdonald, Murray, Goddard, and Treasure (2011) investigated the impact of a NMM skills-based training program for carers of adults with ED. Carer skills training was associated with an increase in carer self-efficacy as well as with reductions in carer distress, anxiety and burden, the latter of which are hypothesized to have the potential to maintain ED symptoms (Macdonald et al., 2011). A second study examining the outcomes of an NMM self-help intervention for carers of adults with an ED revealed that carer self-efficacy was related to improvements in both carer distress in terms of anxiety and depressive symptomology, as well as to client outcomes, including ED functioning and symptoms (Goddard, Macdonald, & Treasure, 2011).

Emotion-focused family therapy (EFFT; Lafrance Robinson, Dolhanty, & Greenberg, 2013a) is another model of family therapy in which parents and carers are regarded as essential partners in the treatment process and they are recruited as recovery and emotion coaches to support their loved one, regardless of age. An integral part of the treatment model also includes attending to and supporting the processing of strong carer emotion—that is any emotional reaction, such as fear or self-blame, that could potentially interfere with parental self-efficacy and caregiving efforts. The results of a pilot study examining the outcomes of a 2-day EFFT group for parents of children (of any age) with an ED revealed a decrease in parental fears and self-blame over time, as well as an increase in parental self-efficacy (Lafrance Robinson, Dolhanty, Stillar, Henderson, & Mayman, 2014). Parents also reported feeling more determined to engage in behaviors supportive of their child's behavioural and emotional recovery.

#### **Emotion and self-efficacy**

The impact of emotions and their relationship to self-efficacy are clearly important to consider in the context of family-oriented therapies for ED. A wealth of research has shown that affect is associated with self-efficacy (Bandura, 1977; Forgas, Bower, & Moylan, 1990; Heimpel, Wood, Marshall, & Brown, 2002), including in the caregiving domain. When carers experience intense emotion (e.g., fear), they lose access to their caregiving instincts, acquired knowledge, and learned skills (Siegel, 2010). For instance, in the context of ED treatment, carers may resist implementing treatment tasks such as reintroducing challenging foods, if they fear that doing so may lead their child to stop eating all together, or worse that the distress associated with the intervention could lead them to becoming suicidal. This failure to comply in the parent is thought to be related to both the feared outcome (suicidality) as well as a crippling fear that they will not be able to handle the crisis that may ensue (low self-efficacy) should they implement the agreedupon interventions in the face of their loved one's resistance.

Parental self-blame appears similarly to rob the parent of their capacity to engage in recovery tasks effectively. The field of ED has emerged from a long history of parental blame (Mondini, Favaro, & Santonastaso, 1996) and despite a general consensus among clinicians that parents do not cause ED, many parents blame themselves for having caused the illness (Lafrance Robinson et al., 2014) and for not seeking help soon enough (Perednia & Vandereycken, 1989). In fact, many parents fear they are to blame and that others will blame them and so it is possible that fear and self-blame are in fact separate but related processes that negatively influence carers' capacity to help.

The present study examined the manner in which carer fear and selfblame influence carer self-efficacy and accommodating and enabling behaviours. We predicted that carer fear and self-blame would predict carer empowerment and accommodating and enabling behaviours. That is, we expected that the more caregivers felt fear about their loved one's illness and the more they blamed themselves, the less empowered they would feel to help their loved one with recovery and the more likely they would be to engage in behaviours that contribute to the maintenance of the illness.

#### Method

#### **Participants**

A parent intervention was delivered to parents of adolescent and adult children with EDs at eight sites in various treatment settings (hospital, community mental health, and private practice) across Canada. The sample included 137 participants, including 126 biological parents (87 mothers), eight step-parents (three step-mothers), two romantic partners, and one relative. Carers were recruited in several ways to participate in an intervention for ED. Posters were displayed at reception desks of eating disorder clinics and therapists approached (a) carers involved in their loved one's ED treatment, (b) parents of adult clients who were not currently involved in treatment, and (c) parents of adolescents or adults who were on a waiting-list for treatment. The measures were administered to the participants in a group setting and were completed by paper and pencil. Measures were administered in the same order and in the same manner across study sites, prior to the commencement of the intervention. Participants were given as much time as they needed to complete the measures. Data collection typically took between 30-45 minutes to complete. No exclusion criteria were used.

The mean age of the affected individual was 18 years (SD = 5.06) and ranged from 12-41 years. Carers were recruited from a variety of different settings (private practice, hospital, and community mental health agencies). Nineteen percent of carers had a loved one on the waitlist for ED treatment, 56.2% of carers had a loved one involved in active treatment for an ED for an average of 1 year (range from 2 weeks to 8 years), while 18.2% of families were engaged in services not specific to an ED. Primary symptoms of concern were reported to include restricting in 84.7% of cases, bingeing in 39.4% of cases, over-exercising in 48.2% of cases, purging in 34.3% of cases, and use of laxatives in 7.3% of cases, while 12.4% reported other symptoms (examples include self-harm, misuse of insulin, and involuntary spitting). In terms of symptom onset, according to caregiver report, 56.2% of loved ones first displayed ED symptoms less than 1 year ago, 14.6% between 1 and 2 years ago and 12.4% more than 2 years ago (ranged from 2 to 20 years).

#### Measures

#### Carer Fear Scale

Fear was measured with the Carer Fear Scale. The Carer Fear Scale is a newly developed measure designed to assess the degree to which carers feel vulnerable to fears that can interfere with their ability to refeed their child and interrupt ED symptoms (Lafrance Robinson, 2014). Items were developed on the basis of clinical experience and carer feedback. Carers were asked to rate on a 7-point Likert scale (ranging from *not at all likely* to *extremely likely*) the extent to which they feel vulnerable to four different fear items when supporting their child's behavioural recovery. Sample items include "Fear of breaking down or burning out throughout the process" and "Fear of pushing my child too far with treatment and leading her to depression, running away or suicide." Scale total scores can range from 7 to 28 ( $\alpha = .71$ ). A higher total scale score on this measure indicates a higher level of carer fear related to their engagement in recovery tasks.

#### Carer Self-Blame Scale

Self-blame was measured with the Carer Self-Blame Scale. This scale was designed to assess the degree to which carers feel they are to blame for their child's ED (Lafrance Robinson, 2014). Items for this scale were also developed on the basis of clinical experience and carer feedback. Carers were asked to rate on a 7-point Likert scale (ranging from not at all likely to extremely likely) the extent to which they felt responsible for their child's ED. Sample items include "Fear of being blamed or to blame" and "My worst fears will have come true—I will be to blame" as well as "Others will blame me." Scale total scores can range from 7 to 14 ( $\alpha = .80$ ). A higher total scale score on this measure indicates a higher level of self-blame with respect to their child's ED.

#### Carer self-efficacy

Carer self-efficacy or empowerment was assessed using a revised version of the Parent versus Anorexia Scale (PvA; Rhodes, Baillie, Brown, & Madden, 2005).2 The PvA was designed to study parental self-efficacy, that is the "ability of a [carer] to adopt a primary role in taking charge of the [eating disorder] in the home setting for the purpose of bringing about the recovery of their loved one" (Rhodes et al., 2005, p. 401). Seven items make up the scale and these are rated on a 5-point Likert scale (from strongly disagree to strongly agree). Scale total scores range from 7 to 35. A lower scale score indicates a lower level of self-efficacy whereas a higher scale score indicates a higher level of self-efficacy. Sample items include "I feel equipped with specific strategies for the task of bringing about the complete recovery of my loved one in the home setting" and "It is more my responsibility than my loved one's to bring him/her to a healthy weight." The scale yields adequate psychometric properties (Rhodes et al., 2005).

### Accommodation and Enabling Scale for Eating Disorders

The Accommodation and Enabling Scale for Eating Disorders (AESED; Sepulveda, Kyriacou, & Treasure, 2009) is a 33-item self-report scale developed to measure the degree to which carers engage in behaviours that may accommodate and enable the symptomology of a relative with an ED. The total scale score can range from 0 to 138. A higher score indicates a higher level of accommodating and enabling of ED symptoms. This measure also consists of five subscales: Control of Family (sample items: Does your child's eating disorder control cooking practice and ingredients you use? Control the choices of food that you buy?); Reassurance Seeking (sample items: Does your child engage any family member in repeated conversations asking for reassurance about whether she/he will get fat? About whether it is safe or acceptable to eat a certain food?); Meal Ritual (sample items: Do any family members have to accommodate to what tableware is used? What time food is eaten?); Turning a Blind Eye (sample items: Do you choose to ignore aspects of your child's eating disorder...such as if food disappears? Money is taken?); and Avoidance and Modifying Family Routine (sample items: Have you modified your leisure activities because of your child's needs? Have you modified your family routine because of your child's symptoms?). All items are rated on a 5-point Likert scale (from never to daily) except item 24, which is rated on an 11-point Likert scale (from none at all to completely). This scale yields adequate psychometric properties (Sepulveda et al., 2009).

#### Results

#### Predictor variables and dependent measures

The mean for carer fear was 4.55 (SE = .12) and 2.94 (SE = .15) for carer selfblame, suggesting that carers experienced a moderate degree of fear and selfblame (see Table 1). The total mean on the Parents versus Anorexia scale (PvA) was 18.09 (SE = .33) and comparable to self-efficacy scores of other carers studied (Byrne et al., 2015; Girz et al., 2013; Lafrance Robinson et al., 2014), suggesting similarly low self-efficacy across this diverse group of participants (see Table 1). The total mean on the Accommodating and Enabling scale (AESED) was 54.43 (SE = 2.57), which is similar to other carer samples (Goddard et al., 2011; Grover et al., 2011b) and suggests considerable accommodating/enabling of ED symptoms (see Table 1).

## The link between carer fear and self-efficacy and accommodating and enabling behaviours

We predicted that carer fear would predict both carer self-efficacy and accommodating and enabling behaviours. To assess this, we conducted two separate regression analyses. In the first analysis, carer fear was the predictor variable and self-efficacy was the dependent variable. In the second regression analysis, carer fear was the predictor variable and accommodating/

Table 1. Means and standard errors for dependent variables: carer fear, carer self-blame, carer self-efficacy, accommodating and enabling behaviours.

	Mean	SE
Carer fear	4.55	.120
Carer self-blame	2.94	.154
Self-efficacy	18.09	.33
Accommodating and enabling behaviours	54.32	2.57
Control of family	8.98	.38
Reassurance seeking	12.60	.74
Meal ritual	5.65	.55
Turning a blind eye	2.93	.32
Avoidance/modifying	24.36	1.14

Table 2. Regression results for carer fear on carer self-efficacy and accommodating and enabling behaviours and each of the AESED subscales.

	b	T	р	$R^2$
Self-efficacy	24	-2.77	.006	.06
Accommodating and enabling behaviours	.36	3.68	<.001	.13
Control of family	.22	2.47	.015	.05
Reassurance seeking	.24	2.67	.009	.06
Meal ritual	.17	1.86	.07	.03
Turning a blind eye	.13	1.39	.17	.02
Avoidance/modifying	.40	4.39	<.001	.16

Note. Predictor in both cases is carer fear.

enabling behaviours was the dependent variable. We found that fear negatively predicted carer self-efficacy: the more fear carers had, the less empowered they felt (results for these analyses are reported in Table 2). We also found that fear positively predicted accommodating/enabling behaviours: the more fear carers felt, the more likely they were to engage in accommodating/ enabling behaviours with their child.

Given that each AESED subscales assesses a unique aspect of accommodating and enabling behaviours within the household, such as reassurance seeking or modifying family routines, we sought to explore the unique relationships between carer fear and each of the AESED subscales. Regression analyses were conducted using fear as the predictor variable and each of the subscales of the AESED as the dependent variables. Given that strong emotions are suspected to have a negative impact on caregiving efforts by leading carers to engage in behaviours that maintain their child's symptoms (Goddard et al., 2011a; Schmidt & Treasure, 2006), we expected that carer fear would positively predict each of the AESED subscales. We found that fear positively predicted the following subscales: control of family, reassurance seeking and avoidance/modifying behaviours (results are in Table 2). The more fear carers experienced the more likely they were to allow their loved one's ED to control the family, the more likely they were to allow their loved one to engage in reassurance seeking behaviours and the more likely they were to modify the family routine. There was a marginal effect for the link between fear and meal rituals: the stronger their fear the more carers allowed their loved one's ED to alter the family's meal rituals. Carer fear did not predict turning a blind eye to symptoms.

# The link between carer self-blame and self-efficacy and accommodating and enabling behaviours

We also expected that carer self-blame would predict both carer self-efficacy and accommodating/enabling behaviours. We conducted a second set of regression analyses with carer self-blame as the predictor variable and carer self-efficacy and accommodating/enabling behaviours as the two dependent

Table 3. Regression results for carer self-blame on carer self-efficacy and accommodating and enabling behaviours and each of the subscales of the AESED.

	b	Т	p	R <sup>2</sup>
Self-efficacy	27	-3.10	.002	.07
Accommodating and enabling behaviours	.25	2.50	.01	.06
Control of family	.19	2.17	.03	.04
Reassurance seeking	.15	1.64	.11	.02
Meal ritual	.21	2.29	.02	.04
Turning a blind eye	.07	.75	.46	.005
Avoidance/modifying	.21	2.12	.04	.04

Note. Predictor in both cases is carer self-blame

variables. The same phenomenon was found as with carer fear. Carer selfblame negatively predicted carer self-efficacy and positively predicted accommodating/enabling behaviours (results for these analyses are reported in Table 3). Thus, the more carers blamed themselves, the less empowered they felt and the more they engaged in accommodating/enabling behaviours with their loved one.

Next, we looked at the link between carer self-blame and each of the subscales of the AESED. We found that carer self-blame positively predicted control of family, accommodation of meal rituals, and avoidance/modifying family routine (results are in Table 3). The more carers blamed themselves the more likely they were to allow their loved one's ED to control the family, the more likely they were to accommodate meal rituals and the more likely they were to modify the family routine. Carer self-blame did not significantly predict reassurance seeking although the link was in the expected direction (the more carers blamed themselves, the more they allowed their loved one to engage in reassurance seeking behaviours). As with fear, carer self-blame did not predict turning a blind eye to symptoms.

#### Discussion

The results of the current study indicated that the more fear carers reported, the less empowered they felt about actively supporting their loved one's ED recovery and the more likely they were to engage in recovery-interfering behaviours. The same phenomenon was observed with carer self-blame. The more carers blamed themselves, the less empowered they felt and the more they reported engaging in accommodating and enabling behaviours. Those accommodating and enabling behaviours that were most vulnerable to the influence of fear and self-blame included the degree to which the ED was allowed to control the family (e.g., how food is prepared), the modification of meal rituals (e.g., what tableware is used), the avoidance and modifications of routines (e.g., work schedule or leisure activities), and reassurance seeking (e.g., asking about whether s/he looks fat in certain clothes).

Our findings contribute to the literature by demonstrating a clear link between fear and self-blame in carers and low self-efficacy, lending support to the hypothesis that these emotional experiences can lead the carer to become inflexible and reactive, losing access to their instincts and acquired skills (Siegel, 2010). These findings also lend support to the Cognitive-Interpersonal Maintenance Model of Eating (Goddard et al., 2011a; Schmidt & Treasure, 2006), which suggests that carers can experience high emotional arousal that can then lead them to engage in behaviours that can inadvertently maintain their loved one's illness. Our study empirically demonstrates that in the face of strong emotions such as fear and self-blame, carers are in fact more likely to accommodate and enable ED symptoms. Given that considerable attention is being paid to the active role of carers in the treatment of ED across the lifespan, it is important for researchers and clinicians alike to become cognizant of the link between carer emotion and therapy-interfering behaviours. This is especially true since emotions are amenable and accessible for change, and they can be evoked and transformed in the context of brief psychotherapy (Greenberg & Paivio, 2003). When clinicians attend to and process carer fear and self-blame, the carer can become better equipped, and their loved one better supported. Until now, there have been no studies that point to the ways in which this process can be facilitated and we believe this is reason for hope.

The results relating to self-blame are consistent with FBT, NMM, EFFT, and other family therapy models for ED, in that they highlight the importance for clinicians to reduce carer self-blame in the context of treatment (Lafrance Robinson et al., 2013a; Lock & Le Grange, 2012; Treasure, Schmidt, & Macdonald, 2009). Family-oriented ED therapies make recommendations regarding how to accomplish this therapeutic task such as lifting or reassuring self-blame in both FBT and in NMM (Lock & Le Grange, 2012; Treasure et al., 2009). In EFFT, and in line with emotion theory, there is active processing of the presenting emotions in carers (Lafrance Robinson et al., 2013a). When carers present with self-blame, for example, the self-blame is actively attended to, expressed, and the person's emotions are validated. In fact, working through the self-blame becomes the main focus of the session, given the belief that if not fully processed, it will continue to lead to unspoken dynamics that will negatively influence the carer's ability to support their loved one effectively, and can in fact lead to therapy-interfering behaviors.

In this study, the additional finding that increased parental fear actually reduces carer empowerment begs the question as to whether the increasing of parental anxiety in the context of FBT may have the potential to work in the opposite manner and paradoxically decrease the parent's ability to feel empowered. In FBT, the therapist works to prompt parental action, and thereby increase empowerment, by increasing "anxiety" around the impact

of the ED and the potential serious consequences of failing to act quickly to restore normal eating and physical health (Lock & Le Grange, 2012). The discussion of the balance or tension between raising parental anxiety in the service of mobilizing to action on the one hand, and reducing parental fears to increase empowerment or self-efficacy on the other, can be considered in light of the principles of motivational interviewing, fundamental in the NMM (Treasure et al., 2009), and in particular how these principles relate to selfefficacy. A core principle of MI is to "develop discrepancy." The caveat, however, is that in the context of low self-efficacy such as that found in individuals with ED and their families, the appropriateness of this principle is re-evaluated (Treasure & Ward, 1997). This is because increased discrepancy, or heightened awareness of and concern about one's circumstances, in the face of low self-efficacy in regard to one's ability to change them, is seen to increase a hopeless despair due to the perceived incapacity and lack of confidence in the ability to change. In other words, when carer self-efficacy is low, raising anxiety for the purpose of mobilization could have the opposite effect than what was intended.

Because anxiety and other strong emotional states also lead to a heightened state of physiological arousal, and high physiological arousal leads to decreased access to instincts and learned skills, we would argue that raising anxiety in carers who are already anxious, or even emotionally activated whether overtly or covertly—would be counter-productive. For example, if a parent is afraid their involvement will anger their child and this fear is already immobilizing, further heightening anxiety may further rob the carer of their innate capacity to respond in a calm way that conveys both support and confidence.

The question would then be: are these two constructs of parent anxiety in FBT and parental fears in EFFT the same or different animals? In FBT, the goal is to incite urgency to act in parents by increasing anxiety around health concerns (Lock & Le Grange, 2012). In EFFT, the identified fears are a mix of fears of the serious consequences of their loved one's health status and emotional fears including fears of pushing their child too hard and losing her in some way, as well as fears in the parent that they have done something to damage her and cause the illness (Lafrance Robinson et al., 2013a). What again can offer hope to the field is that engaging in emotional tasks that reveal parental fears that have until now laid more "dormant," and processing them, can free the parent from both types of fears.

In light of these findings, it will be very important for clinicians across the disciplines to resist the urge to discount the appropriateness of carer involvement when the carers present as emotional, disempowered, or even when they engage in behaviours that bluntly interfere with treatment. This may be especially pertinent in the context of adult treatment since there is a belief in the field that some adult clients should move towards a more independent recovery especially when their carers present as unsupportive. These clinical presentations do not in fact suggest that the carers in question are unable or unmotivated. Rather, the results of this study suggest that these carers are quite likely paralyzed by, or acting out of fear or self-blame. Most importantly, we believe that the results of this study can serve to renew our faith and belief in the ability for all carers to transform feelings of defeat, fear and debilitating self-blame in order to contribute actively and positively to their loved one's recovery, and thus improve long-term outcome.

#### **Notes**

- 1. Services included independent counselling, unspecified outpatient services and psychological treatment for another mental illness.
- 2. The revision of the scale was minor. Statements referring to "anorexia" were revised to reflect the different eating disorder symptoms.

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