Eating Disorders in Childhood and Adolescence: Caregiver Distress as a Maintaining Risk Factor for Prolonging Eating Disorder Symptoms

Final Outcomes Report

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Executive Summary

Caregivers of individuals struggling with mental health difficulties experience significant distress from caring for the identified patient. For carers of patients struggling with anorexia nervosa, the burden of care was even said to be comparable to caring for someone with psychosis. Prolonged stress in the caregiver not only results in poorer mental health in the carer, it may also affect the caregiver’s ability to cope and care for the patient, serving as a maintaining factor for prolonging eating disorder symptoms.

The purpose of the present study was to examine the relationship between caregiver distress and eating disorder symptom severity among adolescents receiving treatment for an eating disorder in a pediatric clinical setting. The study hypothesized two mediation models, where patient eating disorder symptoms was expected to be related to caregiver distress, with patient expressed emotion mediating this relationship. Further, it was also hypothesized that caregiver distress would contribute to the maintenance of patient eating disorder symptoms, and that caregiver expressed emotion would mediate this relationship. To capture this information, the present study entailed collecting data from patients and their caregivers who completed relevant psychometrics at intake to the program.

As the present study did not find a significant correlation between caregiver expressed emotion and patient eating disorder symptom severity, it was not possible to test the proposed mediational models. However, some interesting significant correlations between multiple variables were noted. These findings are discussed.
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Introduction

Caring for others struggling with chronic health conditions can be a stressful experience. Studies have shown that caregivers of patients struggling with mental health difficulties experience significant distress when caring for a loved one (Schene, Wijngaarden & Maarten, 1998). The same observation was found among caregivers of patients struggling with eating disorders (Winn et al., 2007). Notably, the burden of care experienced by family members of people struggling with anorexia is said to be comparable, if not more stressful, than caring for someone with struggling psychosis (Santonastaso, Saccon & Favaro, 1997; Treasure et al., 2001).

The relationship between caregiver and the identified patient can greatly affect a caregiver’s experience, determining the level of distress they experience. For carers of individuals with cancer, a distressed relationship has been associated with negative caregiver experiences (Nijboer et al., 1999; Das Chagas Medeiros, 2000). Further, the quality of the patient-carer relationship has predicted burden in carers of those with rheumatoid arthritis (Nijboer et al., 1999; Das Chagas Medeiros, 2000).

When considering dimensions of the interaction between caregiver and the identified patient, specifically expressed emotion (EE), high EE has been found to predict carer distress levels in diverse patient populations (Vaughn & Leff, 1976; Scazufca & Kuipers, 1996; Wagner et al., 1997; Winn et al., 2007). Caregivers with high levels of negative EE have been reported to have higher levels of burden and poor psychological health (Scazufca & Kuipers, 1996; Wagner et al., 1997). In eating disorder patient populations specifically, high levels of EE among relatives of individuals struggling with Anorexia Nervosa was found to be related to distress in caregivers and other family members (Schmidt & Treasure, 2006). Furthermore, patient reports of EE have been found to predict negative experience of caregivers of adolescent patients with bulimia (Winn et al., 2007).

Prolonged stress resulting from the demands of caregiving may have important implications for both caregivers and the identified patients. The primary outcome consistently associated with negative caregiver experience is poor psychological health (Winn et al., 2007; Nijboer et al., 1999). This has important implications as the distress felt by caregivers may impact the quality of care they are able to provide to loved ones experiencing mental health difficulties. The relationship with close others, as measured by EE, has been shown to influence outcomes of many psychiatric conditions (Schmidt & Treasure, 2006). Further, high EE is a well-replicated predictor of relapse across many different psychiatric disorders (Butzlaff & Hooley, 1998). Studies have found greater symptom severity among patients with schizophrenia and post-traumatic stress disorder to be related to increased caregiver distress levels (Schene, Wijngaarden & Maarten, 1998; Calhoun, Beckham & Bosworth, 2002). With eating disordered patients, there is good evidence suggesting that outcome of AN is also influenced by the emotional reactions of close others (Schmidt & Treasure, 2006). Several studies have found that EE affects adherence to treatment and outcome in AN (Eisler et al., 2000,1997; Stice, 2002; Szmukler et al., 1985). Given the small, but consistent,
evidence, existing literature suggests that the type of interpersonal interaction captured in the EE construct may be a causal maintaining factor in AN (Schmidt & Treasure, 2006). It has been postulated that high EE may be an expression of well-intentioned but ineffective attempts on behalf of the family to care for their ill relative (Hooley & Campbell, 2002).

Because of the interconnecting nature of the caregiver-patient relationship, the link between the caregiver experience and patient outcomes must be explored as it has important implications for patient treatment and prognosis. Understanding how caregiving experience affects a patient’s course of treatment will allow us to better tailor treatment provided to youth struggling with eating disorders.

The Present Study

To date, the evidence supporting the role of various factors as maintaining factors is limited. The present study examined the relationship between caregiver distress and eating disorder symptom severity among adolescents receiving treatment for an eating disorder in a pediatric clinical setting. The study hypothesized that patient eating disorder symptoms was related to caregiver distress, with patient expressed emotion mediating this relationship. Further, it was also hypothesized that caregiver distress contributes to the maintenance of patient eating disorder symptoms, and that caregiver expressed emotion would mediate this relationship. The goal of the study is to better understand eating disorders and how caregiver-patient relationship can affect patients’ course of treatment. It is hoped that findings will improve the patient care of children and youth struggling with an eating disorder by allowing clinicians to better support patients and their families during the course of treatment.

Method

Participants
Children and youth up to the age of 18 diagnosed with an eating disorder (e.g. Anorexia Nervosa, Bulimia Nervosa, Eating Disorder Not Otherwise Specified) and seen by the
Pediatric Eating Disorders Program at McMaster Children’s Hospital in Hamilton, Ontario, were asked to participate in this study. The program provides services to children and adolescents up to the age of 18 who require multi-disciplinary assessment and treatment for an eating disorder. Services at the program include medical management, assessment, consultation, family therapy, individual therapy, group therapy, and nutritional counseling. Team members include pediatricians, psychologists, a psychiatrist, social workers, and a registered dietician.

In total, the study group comprised of 106 children and adolescents, 93.2% of whom were females (mean age=14.77 years, SD=1.73 years). Thirty-two percent of patients met DSM-IV (APA, 2004) diagnostic criteria for Anorexia Nervosa, 14.3% for Bulimia Nervosa and 46.9% for Eating Disorder-Not Otherwise Specified. Eighty-nine percent of patients lived with their parent(s), 1.9% lived with another family member and 3.9% had other living arrangements (foster care, group home, etc.)

As not all participants completed all measures, the sample size was allowed to vary depending on the analysis conducted. Participants who did not complete all measures were not excluded from the study, as doing so would result in an unnecessarily reduced sample size.

**Procedure**

Patients treated by the Pediatric Eating Disorders Program at McMaster Children’s Hospital were asked to complete a series of self-report questionnaires related to caregiver distress, expressed emotion and eating disorder symptom presentation and severity. All packages were completed at time of intake into the program. From these questionnaires, relevant data was extracted and analyzed as aggregated data. Statistical analyses were completed in order to test the hypothesis of this study.

**Measures**

Items and subscales from the measures detailed below were used in the present study.

**Eating Disorder Inventory-3 (EDI-3) (Garner, 2004).** The EDI-3 assesses behavioural and symptomatic patterns of eating disorders, such as Anorexia Nervosa and Bulimia Nervosa. To assess eating disorder symptom severity, three of the twelve subscales of the EDI-3 were considered: Bulimic Symptoms (7 items), Drive for Thinness (7 items), and Body Dissatisfaction (9 items). The EDI-3 has established internal consistency, criterion-related validity, and convergent and discriminant validity for all subscales (Garner, 2004; Garner et al., 1983). The three EDI-3 subscales were used to assess patient eating disorder symptom severity.

**Family Attitude Scale (FAS) (Kavanagh et al., 1997).** The FAS contains 30 questions that assess the patient/family member’s amount of criticism and hostility. The internal consistency of the instrument is high and high expressed emotion is significantly correlated with a higher FAS score (see Humbeeck et al., 2002). Concurrent validity has also been established with the State-Trait Personality Inventory (STPI, Spielberger et al., 1983, cited in Kavanagh et al., 1997). The FAS has been established as a reliable
and valid indicator for measuring critical aspects of family attitudes, reflecting the state of psychological health of families (Kavanagh et al., 1997; Fujita et al., 2002). Items 5, 8, 9, 14 and 19 of the FAS were used to measure caregiver expressed emotion as these items specifically pertained to caregiver’s behaviors in particular.

Perceived Criticism Scale (PC) (Hooley & Teasdale, 1989). The PC consists of 12 items measuring the intensity of perceived criticism by the respondent mother, father and siblings. In addition, respondents are also asked how critical they were of these family members using the same scale. The PC demonstrates excellent discriminant validity and moderate convergent validity (Riso et al., 1995). Items numbered 1 and 5 were selected to measure caregiver expressed emotion and 2 and 6 were selected as they pertain specifically to patient expressed emotion.

Eating Disorders Symptom Impact Scale (EDSIS) (Sepulveda, Whitney, Hankin & Treasure, 2008). The EDSIS contains 24 items that measure caregivers’ appraisal of the personal impact that the eating disorder symptoms and behaviours of the patient have upon their own well-being. The EDSIS focuses on four factors: conflict at home over nutrition, parental guilt concerning the notion that their action may have caused the illness, patient dysregulated behaviour and caregiver social isolation. The EDSIS is the first questionnaire designed specifically to measure specific caregiving burdens experienced by family members caring for a person struggling with an eating disorder. The EDSIS demonstrates acceptable reliability and moderate convergent validity with the Experience of Caregiving Inventory (ECI), General Health Questionnaire (GHQ-12) and Children Global Assessment Scale (CGAS) (Sepulveda, Whitney, Hankin & Treasure, 2008). The guilt, nutrition and social isolation subscales were used to measure caregiver distress. Items 10 and 13 were used to measure patient expressed emotion.

Eating Disorders Program Questionnaire (PEDQ). Items developed by the Pediatric Eating Disorders Program, which pertained to parental teasing and criticism, were also considered to reflect caregiver expressed emotion.

Measurement Properties
As caregiver and patient expressed emotion were both assessed using items from multiple measures, their test properties were explored prior to their use. Particular items thought to best reflect the required constructs were chosen from each measure. The items taken from EDSIS and PC used to assess patient expressed emotion exhibited good internal consistency (Cronbach’s α =0.56). A factor analysis supported the separation of caregiver expressed emotion construct into two constructs: namely caregiver expressed emotion and caregiver criticism. The items taken from FAS used to assess caregiver expressed emotion exhibited good internal consistency (Cronbach’s α =0.62) and items taken from PC and PEDQ used to assess caregiver criticism also exhibited good internal consistency (Cronbach’s α =0.82).
Data Analyses

Statistical analyses were performed using SPSS for Windows version 15.0. Descriptive data was produced to determine the prevalence of clinically significant scores in relevant psychometrics among the patients seen by the Pediatric Eating Disorders Program. Descriptive statistics were examined for all variables considered. All variables were analyzed to determine if data was normally distributed (Behrens, 1997).

Pearson Product-Moment Correlations were used to examine the hypothesized relationships among variables. This involved the examination of all correlations between each of the variables, including eating disorder symptom severity (drive for thinness, bulimic symptoms, body dissatisfaction), caregiver distress (nutrition, guilt, social isolation), caregiver expressed emotion (expressed emotion, criticism), and patient expressed emotion. If the above-mentioned variables correlated with one another, stepwise multiple regressions were planned to test each of the proposed models.

As proposed by Baron and Kenny (1986), four criteria needed to be met in order for caregiver expressed emotion to be a mediator of caregiver distress and eating disorder symptom severity: (1) caregiver distress should be significantly associated with caregiver expressed emotion; (2) caregiver distress should be significantly associated with eating disorder symptom severity; (3) caregiver expressed emotion should be significantly associated with eating disorder symptom severity; and (4) controlling for caregiver expressed emotion, the association between caregiver distress and eating disorder symptom severity should be reduced or be no longer significant. The Sobel test (1982) was used to determine whether the reduction in the association between caregiver distress and eating disorder symptom severity was significant. The above criteria (Baron and Kenny, 1986) and the Sobel test (1982) are considered a valid and reliable method of testing for mediation.

Similarly, for the second proposed mediation model, four criteria needed to be met in order for patient expressed emotion to be a mediator of eating disorder symptom severity and caregiver distress: (1) eating disorder symptom severity should be significantly associated with patient expressed emotion; (2) eating disorder symptom severity should be significantly associated with caregiver distress; (3) patient expressed emotion should be significantly associated with caregiver distress; and (4) controlling for patient expressed emotion, the association between eating disorder symptom severity and caregiver distress should be reduced or be no longer significant. The Sobel test (1982) was used to determine whether the reduction in the association between eating disorder symptom severity and caregiver distress was significant.

Results

Descriptive Statistics

Descriptive analyses yielded means and standard deviations for the main variables:
Table 1: Mean Raw Scores and Standard Deviations for All Variables

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Distress</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Isolation (SI)</td>
<td>102</td>
<td>8.60</td>
<td>3.68</td>
</tr>
<tr>
<td>Guilt (G)</td>
<td>104</td>
<td>10.89</td>
<td>2.91</td>
</tr>
<tr>
<td>Nutrition (N)</td>
<td>102</td>
<td>17.52</td>
<td>3.81</td>
</tr>
<tr>
<td>Caregiver Expressed Emotion (EE)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Expressed Emotion (EE)</td>
<td>68</td>
<td>8.38</td>
<td>4.01</td>
</tr>
<tr>
<td>Caregiver Criticism (C)</td>
<td>19</td>
<td>16.89</td>
<td>8.66</td>
</tr>
<tr>
<td>Eating Disorder (ED) Symptom Severity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drive for Thinness (DT)</td>
<td>104</td>
<td>14.12</td>
<td>10.12</td>
</tr>
<tr>
<td>Bulimic Symptoms (B)</td>
<td>106</td>
<td>7.78</td>
<td>8.56</td>
</tr>
<tr>
<td>Body Dissatisfaction (BD)</td>
<td>103</td>
<td>21.63</td>
<td>13.10</td>
</tr>
<tr>
<td>Patient Expressed Emotion (EE)</td>
<td>101</td>
<td>8.95</td>
<td>3.47</td>
</tr>
</tbody>
</table>

**Main Effects**

Pearson’s Product Moment correlations were conducted in order to verify whether the variables of interest were related.

Table 2: Pearson’s Product Moment Correlations

<table>
<thead>
<tr>
<th></th>
<th>Caregiver Distress</th>
<th>Caregiver EE</th>
<th>ED Symptom Severity</th>
<th>Patient EE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SI</td>
<td>G</td>
<td>N</td>
<td>EE</td>
</tr>
<tr>
<td>Caregiver Distress</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Isolation (SI)</td>
<td>1</td>
<td>.459**</td>
<td>.483**</td>
<td>.530**</td>
</tr>
<tr>
<td>Guilt (G)</td>
<td>.459**</td>
<td>1</td>
<td>.338**</td>
<td>.384**</td>
</tr>
<tr>
<td>Nutrition (N)</td>
<td>.483**</td>
<td>.338**</td>
<td>1</td>
<td>.379**</td>
</tr>
<tr>
<td>Caregiver Expressed Emotion</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver EE</td>
<td>.530**</td>
<td>.384**</td>
<td>.379**</td>
<td>1</td>
</tr>
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<td>Caregiver Criticism</td>
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<td>-.157</td>
<td>.005</td>
<td>.318</td>
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<tr>
<td>Eating Disorder Symptom</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drive for Thinness (DT)</td>
<td>-.180</td>
<td>-.031</td>
<td>.280**</td>
<td>-.070</td>
</tr>
<tr>
<td>Bulimic Symptoms (B)</td>
<td>-.015</td>
<td>.012</td>
<td>-.138</td>
<td>-.107</td>
</tr>
<tr>
<td>Body Dissatisfaction (BD)</td>
<td>-.134</td>
<td>.033</td>
<td>-.172</td>
<td>-.025</td>
</tr>
<tr>
<td>Patient Expressed Emotion</td>
<td>-.047</td>
<td>.286**</td>
<td>.088</td>
<td>.107</td>
</tr>
</tbody>
</table>

* Correlation is significant at the 0.05 (2-tailed)
** Correlation is significant at the 0.01 (2-tailed)

**Higher Order Analysis: Mediation Models**

As the first three criteria required to test mediation were not met, further regression analyses to test the proposed mediation models were not carried out.
Conclusions and Recommendations

Although there was no support for the proposed mediation models, several significant correlations between different variables were found.

The significant correlation found between patient drive for thinness and conflict over nutrition in the home implies that caregivers of patients with strong motivations to stay thin experience more conflict with the identified patient regarding food and nutrition. As drive for thinness among eating disordered patients implies a fixation on controlling and limiting nutritional intake, it is reasonable to expect that caregivers would naturally respond by encouraging the patient to eat more. Such divergence in perceptions about what is considered adequate nutrition would likely cause conflict in the home regarding the matter.

The significant correlation found between patient body dissatisfaction and patient expressed emotion indicates that youth who have greater levels of body dissatisfaction also express greater negative emotions towards caregivers. In previous research, depressed mood and body dissatisfaction have been shown to be strongly correlated (Holsen, Kraft & Roysamb, 2001). It is possible that depressed mood itself contributes to both body dissatisfaction and expressed emotion, thus explaining their correlation. It is further possible that biological abnormalities induced by malnutrition cause patients to become more irritable and depressed (Laessle, Schweiger & Pirke, 1988), which may in turn also contribute to both body dissatisfaction and expressed emotion.

Consistent with a study by Winn and colleagues (2007), a significant relationship was found between caregiver distress and patient expressed emotion. In particular, our findings indicate that patients who show greater negative affect towards their caregivers have caregivers who feel greater guilt about their child’s illness. Interestingly, our study found only one aspect of caregiver distress, guilt, to significantly correlate with patient expressed emotion. This may be because the guilt felt for the belief that they may have caused or contributed somehow to the patient’s suffering is a fundamental element to caregivers experiencing distress. Patients’ expressed emotions may lead a parent to feel responsible for their child’s suffering or be interpreted as indication that they are not providing their child with appropriate care, as they are unable to alleviate their child’s apparent suffering. It is also possible that the content of patients’ expressed emotion is critical of the parent or designed to illicit guilt (e.g. blaming his or her wellbeing on the carer). Guilt represents an internal burden, affecting the caregiver’s own self-esteem. In contrast, other indicators of caregiver distress such as conflict regarding nutrition and social isolation represent more external aspects of caregiver burden. This may explain why they were not found to correlate with patient expressed emotion.

Further, findings indicate that caregivers who are critical of their children are more likely to have children who express greater negative emotions towards them. Given that directionality is not evident when correlations are found, this may be a bidirectional relationship. For example, the patient may internalize caregivers’ critical comments made towards them, and associated distress may be directed outwards. However, given
the findings of this study, parent expressed emotion does not appear to be related to their level of criticism, thus parental distress is not a possible mediator in this relationship.

Consistent with studies by Scazufca & Kuipers (1996), Dossetor and colleagues (1994) and Wagner and colleagues (1997), caregiver expressed emotion was found to be significantly associated with caregiver distress. In our study where caregiver distress was characterized by social isolation, guilt and nutrition, the same correlation was found with caregiver expressed emotion. As the caregiver experiences greater distress from caring for the identified patient, the carer also expresses greater negative sentiments towards the patient. As proposed by Hooley & Campbell (2002), it is thought that expressed emotion is a result of a well-intentioned but ineffective attempt for caregivers to provide care for the identified patient. It is important to note that unlike the aforementioned studies, our current study sampled an eating disordered patient population.

Unlike studies regarding caregivers of adult patients experiencing mental health difficulties, our findings regarding caregivers of youth patients experiencing eating disorders did not find a relationship between patient symptom severity and caregiver distress. The differing results may be due to the differing characteristics of the study populations, our study pertaining to an adolescent eating disordered population, while the literature is based mainly on the adult population regarding other mental health disorders. Furthermore, our study differed in its method of measuring expressed emotion in taking items from multiple measures instead of using one measure, such as the Level of Expressed Emotion (Cole, Shahe & Kazarian, 2006).

The unexpected study findings may also be accounted for by a theory presented by Laliberte and colleagues (1999). Laliberte and colleagues (1999) argue that general family variables do not necessarily relate directly to the patient’s psychopathology. For eating disorder patients, Laliberte and colleagues proposed that specific family process variables pertaining to eating and nutrition, as opposed to more general family process variables, would be more powerful in predicting disordered eating behaviours. The present study’s unexpected findings may be explained by the fact that general rather than specific relationship variables between the caregiver and the patient were used. It will be important for future research to explore more specific family variables related to issues of body image, food and nutrition.

Despite the fact that the proposed hypothesis was not supported, it is clear that many aspects of the patient-caregiver relationship are correlated in a meaningful way. It is therefore important to explore other angles of this dynamic relationship to understand the factors that could affect and prolong patient eating disorder symptoms. In the future, longitudinal analyses of data may be helpful in determining the directionality of the relationships demonstrated above. Longitudinal data would also allow for a consideration of how caregiver distress changes as treatment progresses.
Next Steps

The next step for this project is the dissemination of research findings and knowledge exchange, as outlined below. The next steps in my career are also detailed below, in regards to future plans.

Knowledge Exchange Plan

To date, I have given a presentation to other research assistants on the process of applying for a research grant, as well as the steps necessary in developing research methodology. Acquired knowledge, specifically the present study’s findings, will be formally presented to staff members of the Pediatric Eating Disorders Program in the fall.

Future Plans

As stated in the application for this undergraduate research grant previously, I plan to pursue medical school following graduation, specializing in pediatric psychiatry. I am currently waitlisted at the University of Queens School of Medicine. I have also completed my study for the diabetes transition clinic at the McMaster Children’s Hospital as part of my thesis project and presented findings at the poster presentation in Toronto at the Society of Adolescent Medicine Conference this past April. A manuscript for the study is currently being prepared for submission to the Journal of Adolescent Health later this month. Furthermore, it is intended that results from the comorbidity study I have worked on in the past will be submitted to a scholarly journal in the near future.
References


