

A SELF-HELP INTERVENTION FOR CAREGIVERS OF PEOPLE DIAGNOSED WITH AN  
EATING DISORDER

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**Title**

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**DOCTOR OF NURSING PRACTICE**

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## **ABSTRACT**

The purpose of this evidence-based practice project was to support caregivers of patients with eating disorders by delivering an evidence-based intervention designed to decrease caregiving burden and illness maintaining behaviors at a regional eating disorder and weight management center (EDWMC). Based on the Cognitive Interpersonal Maintenance Model, the intervention developed by Treasure and colleagues (2006) was shown to improve caregivers' sense of self-efficacy, interaction with their loved ones, and their loved ones' outcomes. After receiving the training materials, caregivers of previous studies reported decreases in caregiving burden and illness maintaining behaviors. Furthermore, patients with caregivers who received the intervention also improved their body mass indexes (BMI) in a previous study.

For this project, caregivers were referred to the co-investigator by clinical psychologists. After screening for eligibility and providing consent, recruited caregivers were provided with the training materials (online videos and a self-help manual) and instructed to review them at their own pace for six weeks. A reminder email was sent to them weekly to complete the intervention. In addition to completing the validated questionnaires at baseline and post-intervention, caregivers virtually participated in an exit interview for evaluation. The Burden Assessment Scale, Accommodation and Enabling Scale for Eating Disorders, and Family Questionnaire were utilized to evaluate caregiving burden, accommodating and enabling behaviors, and levels of expressed emotions, respectively. The project data analysis indicated that implementing the intervention decreased the average scores for caregiving burden, accommodating and enabling behaviors, and expressed emotions. Furthermore, caregivers were satisfied with the intervention and provided positive feedback about the project. During the exit interviews, caregivers indicated that they desired a support group for future projects.

Based on an in-depth literature review and project findings, continuing intervention implementation is recommended for the EDWMC. In the future, healthcare providers, in collaboration with clinical psychologists, may consider offering these training materials developed by Treasure and colleagues to caregivers of patients with eating disorders. Furthermore, clinics may consider offering a support group for emotional support and skill practice. Healthcare providers may improve the outcomes of both caregivers and patients by addressing the needs of the caregivers and approaching illnesses holistically.

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## **DEDICATION**

To my wife Anna Condon and daughter Evaline Condon.

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## LIST OF ABBREVIATIONS

AESED.....	Accommodating and Enabling Scale for Eating Disorder
AN.....	Anorexia Nervosa
BAS.....	Burden Assessment Scale
B.N.....	Bulimia Nervosa
CaNAM.....	Carers Needs Assessment Measure
CASK.....	Caregiver Skills
CDI.....	Children’s Depression Inventory
CIMM .....	Cognitive Interpersonal Maintenance Model
CINAHL .....	Cumulative Index to Nursing and Allied Health Literature
Cochrane .....	Cochrane Database of Systematic Reviews
DASS .....	Depression Anxiety and Stress Scale
EBP .....	Evidenced-Based Practice
ECHO.....	Experienced Carers Helping Others
ECI.....	Experience of Caregiving Inventory
E.D. ....	Eating Disorder
EDEG-A.....	Eating Disorder Examination Questionnaire-Adolescent
EDSIS .....	Eating Disorder Symptom Impact Scale
EDWMC .....	Eating Disorder and Weight Management Center
E.E.....	Expressed Emotions
GHQ-12.....	General Health Questionnaire
HAD .....	Hospital Anxiety and Depression Score
KEDS .....	Knowledge of Eating Disorder Scale

LEE .....Level of Expressed Emotion Scale  
MASC .....Multi-Dimensional Anxiety Scale for Children  
OSFED .....Other Specified Feeding and Eating Disorder  
PSS .....Perceived Stressed Level  
PVA.....Parents Versus Anorexia Scale  
RCT.....Randomized Controlled Trial  
SCDMH .....South Carolina Department of Mental Health

## CHAPTER ONE. INTRODUCTION

According to the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition, “eating disorders are characterized by a persistent disturbance of eating that impairs health or psychosocial functioning” (as cited in Yager, 2018, para 1). Although diagnostic criteria are available to diagnose eating disorders, some abnormal eating behaviors will not fit into the diagnostic criteria. In general, the types of eating disorders include anorexia nervosa, bulimia nervosa, binge eating disorders, other specified feeding and eating disorders, avoidant restrictive food intake disorder, rumination disorder, and unspecified feeding or eating disorders (Anxiety and Depression Association of America, n.d.). Regardless, any type of eating disorder may cause serious physical, psychological, and social complications. Therefore, eating disorder behaviors should be promptly addressed before complications worsen.

Goddard, Macdonald, and Treasure (2011) indicated that caregivers are often the first individuals to help their loved ones toward receiving treatment. Furthermore, caregivers usually remain with the sufferers throughout the illness and into recovery. Although caregivers are often the first individuals to encourage their loved ones to seek treatment and could potentially aid in the recovery process, they could also be maintaining eating disorder behaviors if they are not adequately educated or supported (Treasure & Schmidt, 2013). Caregivers of people with eating disorders were found to experience increased anxiety, burden, depression, and decreased quality of life (Anastasiadou et al., 2014; Las Hayas et al., 2014; Martin et al., 2015). These psychological complications could predispose the caregivers to cope ineffectively with maladaptive behaviors. Therefore, caregivers require education and support in their caregiving to maintain a therapeutic and supportive relationship with the sufferers (Goddard, Macdonald, & Treasure, 2011).

## **Background and Significance**

Although eating disorders may have many serious complications, treatments are available for a full recovery. A report from 2014 stated that 60% of people with eating disorders make a full recovery with treatment (Farrar, 2014). Attempts were made to pursue more recent statistics in the literature to strengthen the claim, but none were found during the literature review. Regardless, 20% of people with anorexia nervosa died prematurely without treatment (South Carolina Department of Mental Health, n.d.). South Carolina Department of Mental Health (SCDMH) estimated that 8 million Americans have eating disorders. Not only do eating disorders affect women, but they can also affect men. Around 10 – 15% of people with anorexia nervosa or bulimia nervosa are male (SCDMH, n.d.). Therefore, encouraging someone with an eating disorder to receive treatment is vital in reducing the mortality rate. The National Institute for Health and Care Excellence (2017) recommended family involvement in treating child and adolescent eating disorders to improve patient care. Furthermore, Treasure and Schmidt (2013) pointed out that sufferers spend significantly more time with the caregivers than with the treatment team. Therefore, educating and supporting caregivers may help them facilitate the recovery process.

However, Martin and colleagues (2015) revealed in their research that caregivers of patients diagnosed with eating disorders were identified to have a higher caregiving burden than caregivers of patients diagnosed with depression and schizophrenia. As a result of increased levels of distress, caregivers may display a high level of expressed emotions (E.E.), such as criticizing eating disorder behaviors, overprotecting the sufferers from assuming responsibilities or making decisions, and acting frustrated toward the sufferers (Sepulveda et al., 2010; Treasure & Schmidt, 2013). Also, caregivers may accommodate eating disorder behaviors in attempts to



avoid family conflicts. For instance, caregivers may organize their lives around sufferers' meal rituals, provide repeated reassurance about body image, and accommodate an excessive exercise routine (Sepulveda et al., 2009). These behaviors could perpetuate or worsen eating disorders (Sepulveda et al., 2009; 2010; Treasure & Schmidt, 2013).

### **Project Purpose**

Caregivers of patients diagnosed with an eating disorder (E.D.) often feel overwhelmed with the time-consuming and emotion-draining nature of caring for a loved one with an E.D. Unfortunately, the needs of the caregivers are often neglected. Therefore, the current project seeks to provide resources (i.e., *The Skilled-based Caring for a Loved One with an Eating Disorder: The New Maudsley Method* self-help manual and streaming access to the video content from Dr. Treasure's DVDs) to caregivers of individuals with E.Ds. These resources have been shown to improve caregivers' sense of self-efficacy and interaction with their loved ones and patient outcomes. The purpose of this evidence-based practice (EBP) improvement project is to support caregivers of patients diagnosed with anorexia nervosa (AN), bulimia nervosa (BN), and other specified feeding or eating disorder (OSFED) by delivering an empirically-supported intervention designed to decrease the caregiving burden and illness maintaining behaviors.

## **Measurable Objectives**

This EBP improvement project focused on decreasing caregiving burden and illness-maintaining behaviors by providing an evidence-based self-help intervention to caregivers of individuals diagnosed with AN, BN, and OSFED. In accordance with these goals, the measurable objectives for this project:

- 1) Participating caregivers of E.D. patients will experience a decrease in caregiving burden from before to after the intervention, evidenced by a decrease in the scores collected from the Burden Assessment Scale (BAS).
- 2) Participating caregivers will demonstrate a decrease in accommodating and enabling behaviors (e.g., repeatedly reassuring patients regarding their body image or accommodating ritualistic eating habits) from before to after the intervention, evidenced by a decrease in the scores collected from the Accommodating and Enabling Scale for Eating Disorders (AESED).
- 3) Participating caregivers will demonstrate a decrease in expressed emotions from before to after the intervention, evidenced by a decrease in the scores collected from the Family Questionnaires (FQ).

## CHAPTER TWO. LITERATURE REVIEW

An in-depth literature review was conducted utilizing the Cochrane Database of Systematic Reviews (Cochrane), Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsychInfo. A systemic screening process was applied to the resulting articles. A Prisma flow diagram that delineates the screening process is provided in Appendix A. The use of keywords, “eating disorder AND caregiver AND burden,” yielded an irrelevant result while searching with Cochrane. Therefore, a different set of keywords, “eating disorder AND caregiver,” was then applied. However, the modified search resulted in four irrelevant systemic reviews. Although no relevant systematic review was found in this database, 89 research articles were identified. After screening through the 89 research articles, seven were included in the literature review.

In addition, CINAHL and PsychInfo were also utilized for the search of evidence. The use of keywords, “interventions AND carers AND eating disorders,” were applied to the search in both databases. Furthermore, the search limited the results to full-text, peer-review, and published within the last five years from 2016 to 2020. Initially, CINAHL resulted in 177 articles, and PsychInfo resulted in 46 articles. After screening the titles and abstracts, five articles were left from CINAHL, and three articles were left from PsychInfo for the full-text review. At the end of the screening process, all eight articles were included in the literature review.

Additionally, research articles were acquired from other sources (i.e., hand searching, google scholar, subject-matter expert). 13 research articles from other sources were included in the literature review at the end of the screening process. After conducting an in-depth literature review, the following topics will be discussed: types of interventions, strategies of delivery of

caregiver-based interventions, the impact of interventions on caregivers, and the impact of interventions on patients.

### **Types of Interventions**

Over the years, interventions have been developed to support and educate caregivers of people with an eating disorder. According to Treasure and colleagues (2015), caregivers are defined as “individuals who provide unpaid help and support” to people that are in need (p. 368). The literature revealed several interventions that aim to support caregivers in their caregiving roles. However, they have different foci and underlying theories (Gisladdottir et al., 2016; Sepulveda et al., 2019; Treasure et al., 2015).

Researchers have developed several theoretical models and related interventions to identify and intervene in key caregiver factors that could maintain eating disorder behaviors. However, one theoretical model that has gathered the most robust research attention and empirical support is the Cognitive Interpersonal Maintenance Model (Goddard et al., 2013; Treasure & Schmidt, 2013). In 2006, Schmidt and Treasure proposed the Cognitive Interpersonal Maintenance Model (CIMM) to explain the maintaining and causative factors for anorexia nervosa. In later research, Treasure and Schmidt gathered more empirical evidence to support and clarify the model (Treasure & Schmidt, 2013).

According to the CIMM, the shared familial cognitive and socio-emotional factors such as obsessive-compulsive and anxious-avoidant traits could contribute to the cause and maintenance of anorexia nervosa (Treasure & Schmidt, 2013). These personality traits foster pro-anorexia nervosa beliefs and behaviors. Therefore, individuals with these personalities are more vulnerable to anorexia nervosa. Furthermore, family members who share these personality traits

are more likely to react to the symptoms of eating disorders with a high level of E.E. and accommodating behaviors that could further perpetuate the disordered eating.

Based on the interpersonal elements of the CIMM, the Maudsley Model of Collaborative Caring manual was developed and utilized initially in a workshop pilot study (Sepulveda, Lopez, et al., 2008). The intervention covered principles of motivational interviewing to improve communication and to promote positive patient behavioral changes. Caregivers' maladaptive behaviors, such as displaying a high level of E.E., were also addressed in the intervention. Besides the Maudsley Model of collaborative care, the intervention is also known as Experienced Carers Helping Others (ECHO) and the New Maudsley Method (Goddard, Macdonald, Sepulveda, et al., 2011; Treasure et al., 2015). This review refers to this intervention as the New Maudsley Method to stay consistent with the self-help manual's title and avoid confusion between Maudsley family-based therapy and the Maudsley Model of collaborative caring.

### **Strategies of Delivery of Caregiver-Based Interventions**

Furthermore, different strategies for delivering the interventions were identified in the literature. A meta-analysis by Hibbs and colleagues (2015) presented different strategies of delivering the interventions: workshops, guided self-help with books, self-help with books, online guided self-help, and online self-help. One study utilized DVDs to educate the caregivers about their caregiving roles (Quadflieg et al., 2017). Meanwhile, other studies utilized a combination of DVDs, books, and different amounts of coaching sessions over the phone (Hibbs et al., 2018; Hodsoll et al., 2017; Salerno et al., 2016). These studies revealed that self-help with books and DVDs might be the most feasible, beneficial, and require the least number of resources to deliver the caregiver-based interventions (Hibbs et al., 2015; 2018; Hodsoll et al., 2017; Salerno et al., 2016).

After hand-searching the research articles, which adopted the self-help with books strategy, from the meta-analysis by Hibbs and her colleagues (2015), the delivery strategy was identified the same as utilizing a combination of DVDs and a book. This type of delivery strategy is also known as the ECHO intervention (Hibbs et al., 2018; Hodson et al., 2017; Salerno et al., 2016). The ECHO intervention could be self-help or include coaching sessions (Goddard, Macdonald, Sepulveda, et al., 2011). Although other delivery strategies could produce significant and sustainable caregiver burden alleviation and distress improvement, only the ECHO intervention reduced E.E. significantly at post-intervention and follow-up in the studies (Hibbs et al., 2015).

Although the New Maudsley Method was first piloted in a workshop setting, the original delivery strategy involved six 2-hour workshops over three months (Sepulveda, Lopez, et al., 2008). More time and resources are required for the original delivery strategy compared to the ECHO intervention delivery strategy. Several studies attempted to reduce the time required to deliver the New Maudsley Method in a workshop setting (Jenkins et al., 2018; McEvoy et al., 2019; Spettigue et al., 2015). In a shorter workshop delivery strategy, caregivers could still increase their caregiving knowledge, skills, and self-efficacy. However, E.E. was not significantly reduced in the studies (Hibbs et al., 2015; McEvoy et al., 2019).

Instead of multiple workshops, the ECHO intervention delivery strategy required fewer resources and time from the caregivers and the treatment team. According to Goddard, Macdonald, Sepulveda, and colleagues (2011), every caregiver received written material and five DVDs covering theoretical models and caregiving skills. Some caregivers in the study received additional guidance through weekly telephone calls from a former caregiver or a senior clinical nurse from the eating disorder unit. The total length of the ECHO intervention delivery strategy

was six weeks. Not only was the ECHO intervention delivery strategy able to produce significant improvement in caregiving anxiety, depression, and maintaining behaviors, but it was also able to provide positive patient outcomes (Goddard, Macdonald, Sepulveda, et al., 2011; Hibbs et al., 2018; Hodsoll et al., 2017; Salerno et al., 2016). Thus, the ECHO intervention delivery strategy is the most feasible, beneficial, and requires fewer resources than other delivery strategies.

## **The Impact of Interventions on Caregivers**

### **Psychological Distress**

According to the literature, anxiety, burden, depression, negative caregiving experience, and stress were some psychological distresses experienced by the caregivers of someone with an eating disorder (Dimitropoulos et al., 2019; Goddard, Macdonald, Sepulveda, et al., 2011; Linacre et al., 2016; Salerno et al., 2016). The effects of psychological distress on the caregivers are detrimental to them and the patients. In response to high levels of distress, caregivers could perpetuate eating disorder behaviors with a high level of E.E. and accommodating behaviors (Goddard, Macdonald, Sepulveda, et al., 2011). Therefore, providing interventions that alleviate caregiver psychological distresses may benefit both the caregivers and the patients.

Delivering the New Maudsley Method via an ECHO format had shown to decrease caregivers' psychological distress (Goddard, Macdonald, Sepulveda, et al., 2011; Hibbs et al., 2018; Salerno et al., 2016). After six weeks of implementing the New Maudsley Method via an ECHO format, Goddard, Macdonald, Sepulveda, and colleagues (2011) identified a significant decrease in the Hospital Anxiety and Depression score (HAD) among 153 caregivers. Before the intervention, 33% of the caregivers scored two standard deviations away from the norm. At post-intervention, the percentage decreased to 22%. The percentage of caregivers who scored outside

the two standard deviations further decreased to 17% at a 3-month follow-up. These findings were clinically significant post-intervention and at follow-up.

In another study with the same delivery strategy and content, Hibbs with colleagues (2018) identified a significant decrease in the Eating Disorder Symptom Impact Scale (EDSIS) compared to the control group. EDSIS is a scale with 24 items that measure caregiving burden. A decrease in EDSIS correlates to a decrease in caregiving burden. At discharge, the EDSIS scores for caregivers in the ECHO group were significantly lower than the control group with a small negative effect size. Furthermore, Salerno and colleagues (2016) identified a decrease in the Depression Anxiety and Stress Scale (DASS) at the one-year follow-up for the ECHO group. The control group had a slight increase in the DASS score. The mean DASS score for the ECHO group decreased from 34.58 at baseline to 32.27 at post-intervention. Meanwhile, the mean DASS score for the control group increased from 29.24 at baseline to 31.61 at post-intervention.

Besides ECHO interventions, psychoeducational workshops, skills-based workshops, and web-based interventions effectively reduced psychological distress (Dimitropoulos et al., 2019; Hoyle et al., 2013; Linacre et al., 2016; McEvoy et al., 2019; Sepulveda et al., 2019). According to Sepulveda and colleagues (2019), psychoeducational workshops developed based on Fairburn's curriculum were found to be comparable to the skilled-based workshops developed by Treasure and her colleagues. The General Health Questionnaire (GHQ-12) and the Experience of Caregiving Inventory (ECI) measured the workshops' efficacy. At post-intervention, a marginally significant improvement ( $p < 0.1$ ) was shown in GHQ-12 and ECI-negative for psychoeducational and skilled-based workshops. A decrease in GHQ-12 and ECI-negative scores is associated with decreased psychological distress and negative caregiving appraisal, respectively. Furthermore, both groups had a statistically significant improvement ( $p < 0.05$ ) in



ECI-negative at follow-up. Both workshop programs helped mitigate caregivers' negative caregiving experiences and their psychological distress after six two-hour workshops.

Even though workshop intervention effectively addressed caregivers' psychological distress, it was not suited for caregivers with time constraints and geographical barriers. Grover and colleagues (2011) developed an off-line psychoeducational intervention based on systemic cognitive behavior therapy to address these concerns. They offered interactive workbooks in printed format and clinical support through weekly email or telephone counseling. After the intervention, caregivers' levels of anxiety and depression decreased significantly ( $p < 0.1$ ) with large effect sizes of 0.65 and 0.59, respectively. Although Dimitropoulos and colleagues (2019) suggested that participants prefer in-person workshops in their study, interactive workbooks and online interventions may be more accessible. Furthermore, Dimitropoulos and colleagues (2019) did not find a statistical difference in caregivers' outcomes between the web-based intervention and workshop intervention.

### **Knowledge and Skills**

According to Haigh and Treasure (2003), families of people with anorexia nervosa often express to the treatment team that they are not provided with enough information about the illness and practical skills to take care of their loved ones who suffer eating disorders. Furthermore, the lack of understanding about the illness could negatively affect the relationship between the caregivers and individuals with eating disorders (Goddard, Macdonald, & Treasure, 2011). Nevertheless, workshop and ECHO delivery strategies are available to increase caregivers' knowledge, self-efficacy, and skills (Hodsoll et al., 2017; Jenkins et al., 2018; McEvoy et al., 2019; Spettigue et al., 2015).

Jenkins and colleagues (2018) identified that the New Maudsley method could be delivered within a day through a 7-hour workshop in a nonexperimental study design. In this study, 77 caregivers' self-efficacy was measured by the Parents Versus Anorexia scale (PVA), and caregiver skills were measured by the Caregiver Skills (CASK) scale. After a 7-hour workshop, the study showed a significant increase in both caregivers' self-efficacy ( $p < 0.001$ ) and caregiving skills ( $p < 0.001$ ). The effect size was 0.46 for PVA and a range from 0.53 to 0.86 for CASK subcategories.

A randomized controlled trial (RCT) evaluated the efficacy of a 2-hour workshop combined with bi-weekly telephone support to improve caregivers' eating disorder knowledge and self-efficacy (Spettigue et al., 2015). The New Maudsley method was delivered through a 2-hour workshop, and a DVD was provided to the caregivers before their child's initial comprehensive assessment at the unit. After the workshop, caregivers were followed up with bi-weekly telephone support during the waiting period before their child was presented to the eating disorder unit for the initial assessment. This randomized controlled trial utilized the PVA and Knowledge of Eating Disorder Scale (KEDS) to measure caregivers' self-efficacy and knowledge, respectively. Moreover, the Children's Depression Inventory (CDI), Multi-Dimensional Anxiety Scale for Children (MASC), and Eating Disorder Examination Questionnaire-Adolescent (EDEQ-A) were utilized to assess children's depression, anxiety, and eating disorder symptoms, respectively. Although these children did not present to the unit with a significant improvement in any measured outcome, caregivers did present to the unit with a significant increase in self-efficacy ( $p < 0.001$ ) and caregiving knowledge ( $p < 0.001$ ).

McEvoy and his colleagues (2019) conducted an RCT and attempted to deliver the New Maudsley method with two 2.5-hour workshops a week apart. McEvoy and his colleagues

utilized the Carers Needs Assessment Measure (CaNAM) to ascertain caregiving knowledge. They also utilized the CASK to assess caregiving skills in this study. The CaNAM score in the intervention group improved significantly ( $p < 0.001$ ) from before to after the intervention with a large effect size (-1.05). The CASK score also improved significantly ( $p < 0.001$ ) in the intervention group from before to after the intervention with a large effect size (-0.76). However, no significant improvement in the patient outcomes was identified in this study. Although both RCTs could deliver the New Maudsley method shorter than the original workshop delivery strategy, neither study significantly improved patient outcomes.

Unlike the workshops mentioned earlier, a randomized pilot trial produced positive patient outcomes with the ECHO delivery strategy (Hodsoll et al., 2017). Further details related to patient outcomes from this strategy are addressed in a later section. In this pilot study, the researchers mailed the New Maudsley manual and the DVDs to the caregivers. Besides the educational materials, the caregivers received ten sessions of telephone support from a clinical psychologist. Each session of telephone support lasted between 30 and 60 minutes. A year from the baseline assessment, the ECHO group revealed a moderate improvement (E.S. = 0.4) in caregiving skills. While workshops efficiently increased caregiving knowledge, self-efficacy, and skills, the ECHO strategy addressed patient and caregivers' outcomes.

## **Behaviors**

Besides mitigating psychological distress and increasing caregiving knowledge, the New Maudsley method also decreased unhelpful behaviors. The literature identified some negative caregiving behaviors thought to maintain the illness. Behaviors such as overprotecting patients from assuming responsibilities, criticizing patients about the illness, reassuring patients' body

image excessively, accommodating eating rituals, and enabling unhealthy exercise regimes were shown to maintain eating disorders (Goddard, Macdonald, Sepulveda, et al., 2011).

Some interventions in the literature were identified to decrease negative caregiving behaviors (Dimitropoulos et al., 2019; Hibbs et al., 2015; Hibbs et al., 2018; Hoyle et al., 2013; McEvoy et al., 2019). In 2011, Grover and her colleagues developed an interactive intervention for caregivers of people with anorexia nervosa. Unlike the New Maudsley Method, this intervention was based on the systemic cognitive-behavioral approach. The intervention focused on providing information on eating disorders, encouraging self-monitoring for the eating disorder behaviors, promoting caregiver self-care, and educating on anorexia nervosa symptoms management. In the study, Grover and colleagues utilized the Level of Expressed Emotion Scale (LEE) to assess 27 caregivers' expressed emotion from before to after the intervention. The scores for the LEE improved significantly ( $p = 0.04$ ) with a medium effect size (0.49) from baseline to post-intervention.

Furthermore, Dimitropoulos and colleagues (2019) adapted the intervention developed by Grover and her colleagues. Although the content was the same as the original intervention, Dimitropoulos and colleagues changed the delivery format to a 2-day workshop. They compared the online delivery format with the 2-day workshop to evaluate their feasibility and efficacy. In their study, Dimitropoulos and colleagues (2019) found a small between-group effect size. However, the findings were not statistically significant. As a result, both online and workshop interventions had similar efficacy. Online and workshop interventions reduced the mean score for the Accommodating and Enabling Scale for Eating Disorders (AESED) by 6.97 and 6.64, respectively. They also reduced the mean score for the Family Questionnaire (FQ) by 2.5 and

3.41, respectively. Therefore, both interventions reduced the participants' enabling behaviors and levels of expressed emotions (e.g., criticism and emotional over-involvement).

Aside from a systemic cognitive-behavioral approach, the New Maudsley method effectively reduced the illness maintaining behaviors. After six weeks of intervention through the ECHO delivery format, Goddard, Macdonald, Sepulveda, and colleagues (2011) identified a significant improvement in caregivers' accommodating behaviors and expressed emotions. This study utilized AESED and FQ to measure accommodating behaviors and expressed emotions, respectively. The AESED score decreased significantly (mean difference = - 9.1,  $p < 0.001$ ) and the FQ score also decreased significantly (mean difference = -0.3,  $p = 0.002$ ) after the intervention. Also, Hibbs and colleagues (2018) identified an improvement in expressed emotions. They also identified an improvement in the time spent with the patients through the ECHO delivery format. Hibbs and colleagues (2018) conducted an RCT, which revealed a significant decrease ( $p = 0.05$ ) in the time spent taking care of the patients with a medium effect size (-0.34) six months after the intervention. Moreover, the RCT revealed a significant decrease in FQ ( $p = 0.05$ ) with a small effect size (-0.25) six months after the intervention.

Even though the intervention developed by Grover and her colleagues was effective in decreasing caregivers' maladaptive behaviors such as high expressed emotions and accommodating behaviors, studies did not record any reduced time spent with the patients. Meanwhile, the New Maudsley method delivered through an ECHO format reduced caregivers' time spent with the patients. Furthermore, the ECHO delivery strategy did not require many resources from the treatment team. Thus, the New Maudsley method delivered through an ECHO format could be a more effective and efficient way to improve caregiving behaviors.

## **The Impact of Interventions on Patients**

Caregiver-oriented interventions did not only improve caregivers' mental health, knowledge, and behaviors, the interventions also improved patient outcomes (Hibbs et al., 2018; Hodsoll et al., 2017; McEvoy et al., 2019). Hodsoll and colleagues (2017) found that the New Maudsley method delivered in an ECHO format improved patient BMI, hospital admission rates, peer issues, and increased pro-social behaviors. A later study by Hibbs and colleagues (2018) found that patients whose caregivers participated in the ECHO delivery format had a reduced level of eating disorder psychopathology and improved quality of life at six months post-discharge. Similar to a previous study by Hodsoll and colleagues (2017), patients in this study by Hibbs et al. (2018) were also shown to have fewer inpatient bed days 7 – 12 months after discharge.

However, two studies in the literature showed mixed findings from the workshop delivery format (McEvoy et al., 2019; Spettigue et al., 2015). McEvoy and colleagues' (2019) study showed a decrease in patient depression but increased patient anxiety. Even though both measures were not statistically significant, they could be clinically significant. In addition, another study by Spettigue and colleagues (2015) found no difference in patient anxiety and depression between the intervention group and the control group. The mixed findings could be a result of the lack of intensity in the interventions. Both workshops in the studies were less than three hours each session. One of the studies had only one session of a 2-hour workshop (Spettigue et al., 2015). Meanwhile, the other study had only two sessions of 2.5-hour workshops (McEvoy et al., 2019).

## **Conclusion**

In summary, the literature revealed caregiver-oriented interventions could reduce caregiver psychological distress (Dimitropoulos et al., 2019; Goddard, Macdonald, Sepulveda, et al., 2011; Hibbs et al., 2018; Linacre et al., 2016; McEvoy et al., 2019; Salerno et al., 2016; Sepulveda et al., 2019), increase caregiving knowledge and skills (Jenkins et al., 2018; McEvoy et al., 2019; Spettigue et al., 2015), and decrease illness-maintaining behaviors (Dimitropoulos et al., 2019; Hibbs et al., 2015; Hibbs et al., 2018; McEvoy et al., 2019; Treasure & Nazar, 2016).

Furthermore, the literature has shown that the ECHO delivery format was found to be effective for patients in reducing eating disorder psychopathology, increasing quality of life, improving BMI, reducing peer issues, promoting pro-social activities, and decreasing inpatient bed days after discharge (Hibbs et al., 2018; Hodson et al., 2017; Treasure & Nazar, 2016). Although the positive effects on caregivers are well documented, further research is needed to identify the impact of caregiver-oriented interventions on people with eating disorders. Most research articles focused on caregivers' outcomes. Regardless, the literature supports implementing caregiver-oriented interventions for caregivers of people with eating disorders.

## **Theoretical and Conceptual Framework**

### **The Iowa Model of Evidence-Based Practice**

The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Healthcare (Refer to Appendix B) is commonly recognized for its applicability and ease of use by multidisciplinary team members (Melnik & Fineout-Overholt, 2018). This model helped facilitate a self-help intervention for caregivers of people diagnosed with eating disorders in a regional eating disorder treatment center (Refer to Appendix C). Permission to utilize this evidence-based practice model was obtained from the University of Iowa Hospitals and Clinics

(Refer to Appendix D). According to Melnyk and Fineout-Overholt (2018), this model offers guidance for healthcare clinicians in making decisions about clinical practices that could impact healthcare outcomes. Additionally, this model guides healthcare clinicians in making clinical decisions through a multi-step change process with a series of feedback loops. After addressing these feedback loops, the evidence-based decision-making process is strengthened using this theoretical framework (Melnyk & Fineout-Overholt, 2018).

***Problem and Knowledge Focused Triggers***

- Caregivers of people diagnosed with an eating disorder demonstrate illness maintaining behaviors as a result of an increased level of caregiving burden (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013)
- Research revealed a decrease in illness maintaining behaviors and caregiving burden with the implementation of interventions based on the Cognitive Interpersonal Maintenance Model for caregivers of people diagnosed with an eating disorder (Hodsoll et al., 2017; McEvoy et al., 2019)

**I. Topic priority for the organization:**

- Directors from Sanford Eating Disorder and Weight Management Center (EDWMC) were informed about the empirically supported self-help interventions for caregivers of people diagnosed with eating disorders. They expressed their desire to implement interventions to alleviate the caregiving burden and mitigate illness maintaining behaviors. According to the outpatient E.D. clinic director, she could list multiple caregivers of different patients that would benefit from this EBP improvement project (T. Meyer, personal communication, August 14, 2020).



## II. Form a Team:

- The team consisted of the co-investigator, NDSU faculty, clinical psychologists, unit managers, and staff from Sanford EDWMC. As a co-investigator, my role was to facilitate the recruitment process, screen for participation eligibility, provide weekly reminders (email messages) to complete training materials, and evaluate the results after implementation. The supervisory committee members were as follows:

**Table 1**

*Supervisory Committee Members*

Name	Role	Contact Information
Dean Gross	Chair	dean.gross@ndsu.edu
Stephen Wonderlich	Committee Member	Stephen.Wonderlich@SanfordHealth.org
Lauren Schaefer	Committee Member	Lauren.Schaefer@SanfordHealth.org
Heidi Saarinen	Committee Member	heidi.saarinen@ndsu.edu
Kristi Steffen	Graduate Appointee	kristine.steffen@ndsu.edu

## III. Assemble and Analyze Relevant Research:

- A literature review and synthesis were completed, with the research indicating an adequate base of information to continue with the next step of piloting the change in practice. Empirical findings supported that Janet Treasure and her colleagues had developed a self-help intervention to directly address illness maintaining behaviors and caregiving burden (Goddard, Macdonald, Sepulveda, et al., 2011). The intervention could benefit caregivers of patients diagnosed with eating disorders at EDWMC.

## IV. Pilot the Change in Practice:

- After the supervisory committee and EDWMC approval, the dissertation team submitted the project to the Institutional Review Board (IRB). The project did not

initiate until approval was granted from the IRB. Refer to Appendix E and F for the IRB approval. Project outcomes were determined, and baseline data were collected. Implementation of the intervention was planned for September 2020 and would end when caregivers of 6 patients or more had completed their six weeks of intervention.

**V. Integrate and Sustain the Practice Change and Disseminate Results:**

- After caregivers had completed the self-help intervention, results collected from the project were disseminated at North Dakota State University and Sanford Eating Disorder and Weight Management Center through PowerPoints and poster board presentations. Training materials were provided to Sanford EDWMC at no cost to integrate and sustain the practice change.

**Cognitive Interpersonal Maintenance Model**

The Cognitive Interpersonal Maintenance Model (CIMM) was first proposed in 2006 by Ulrike Schmidt and Janet Treasure. The model explained the intrapersonal and interpersonal factors that could cause or maintain anorexia nervosa (AN). These factors included “perfectionism/cognitive rigidity, experiential avoidance, pro-Anorectic beliefs, and the response of close others” (Schmidt & Treasure, 2006, p. 343). In 2013, Treasure and Schmidt provided more empirical evidence to support and clarify the CIMM research (Refer Appendix G for permission to use the CIMM figures). This research revealed that people with strong attention to detail and a weak ability to switch between tasks (i.e., set-shifting) are at a higher risk of developing AN.

According to Treasure and Schmidt (2013), people with AN would often interpret social signals inaccurately due to the effects of starvation. People with AN tend to pay more attention to negative facial expressions while avoiding compassionate expressions (Treasure & Schmidt,

2013). After adaptations were made based on the new clinical and behavioral evidence, the CIMM has become more complex and comprehensive.

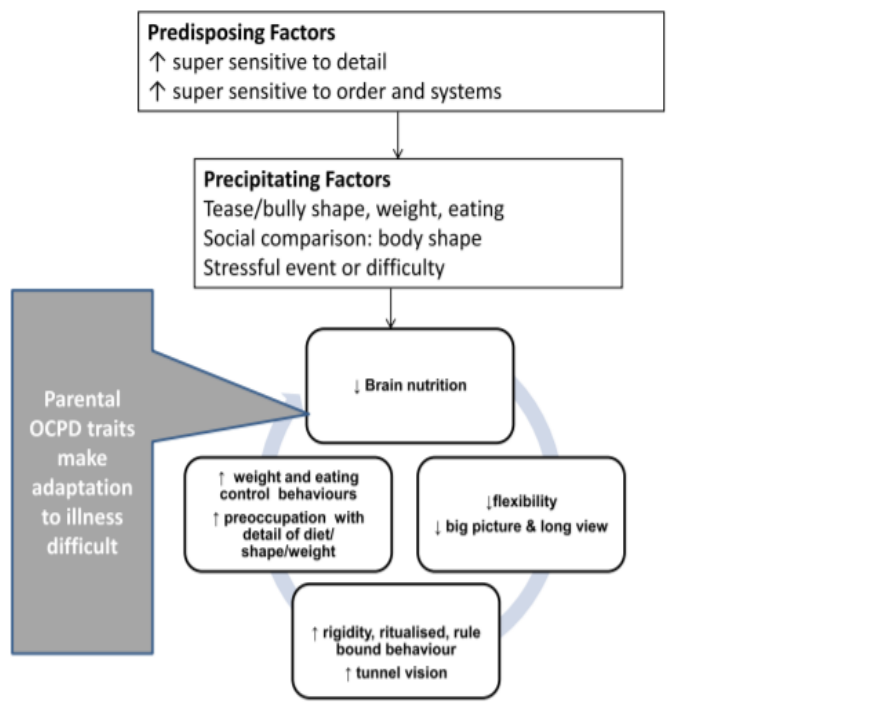
### **Perfectionism/Cognitive Rigidity**

When the CIMM was first proposed, avoidant and obsessive-compulsive personality traits were considered vulnerabilities to AN's development (Schmidt & Treasure, 2006). People with these traits tend to be more perfectionistic and rigid in their ways of thinking. They are afraid of making any mistakes. Therefore, eating anything outside of their self-imposed "safe" food is considered a mistake and can cause extreme negative emotions.

After gathering new evidence, Treasure and Schmidt (2013) included weak set-shifting, strong attention to detail, and weak central coherence (i.e., inability to see the big picture) to develop the vulnerability traits or maintain AN. Among these traits, weak central coherence and weak set-shifting are developed during starvation, when the brain lacks adequate nutrients for proper functioning. As a result, people with these traits become more focused on dieting behaviors and harder to break existing dieting rules.

**Figure 1**

*A Diagrammatic Formulation of Obsessive-Compulsive Personality Disorder Traits*



*Note.* This figure was produced by Treasure and Schmidt in 2013. This open-access article is distributed under the terms of the creative commons CC BY license, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

**Social Impairment/Experiential Avoidance**

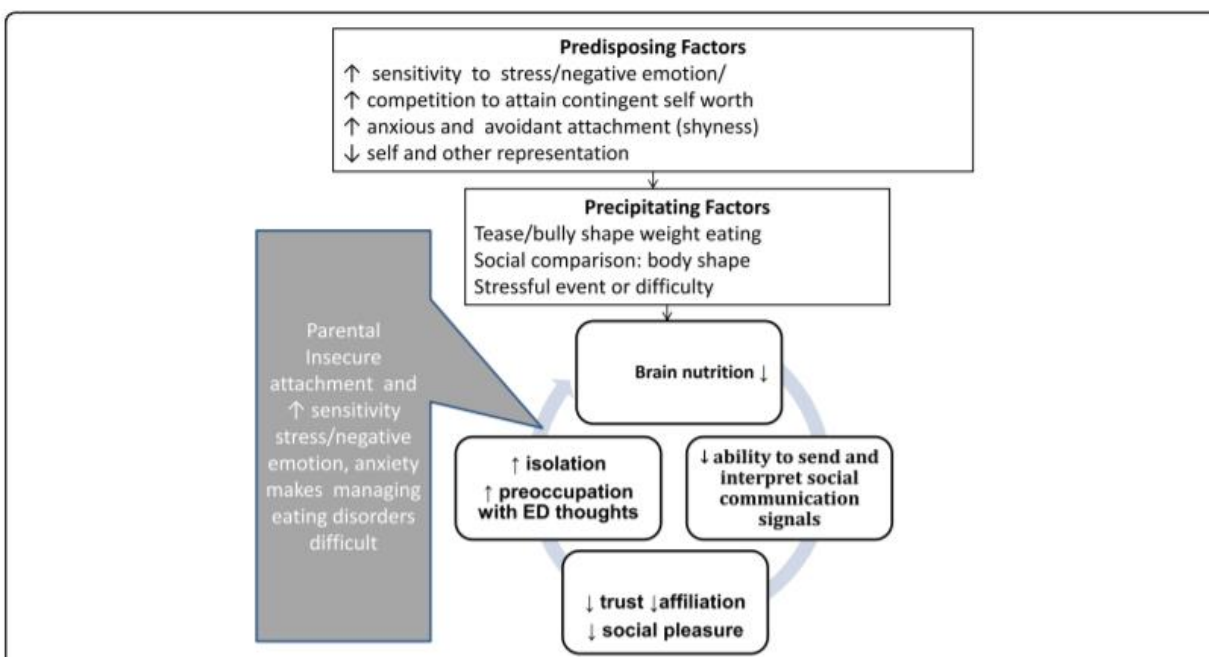
Impaired social communication and experiential avoidance may also cause or perpetuate AN. According to Treasure and Schmidt (2013), people with AN are more sensitive to negative expressions (i.e., dominance, criticism, anger) and less sensitive to positive expressions (i.e., happiness, compassion). People with AN display attentional bias towards negative expressions. They also exhibit impairments in social communication, such as interpreting social signals inaccurately and expressing little facial emotions during conversations (Treasure & Schmidt, 2013).

To prevent any intense negative emotions, people with AN tend to isolate themselves and avoid intimate interpersonal relationships. For instance, people with AN distance themselves

from others who try to exhort them because they are intolerant of criticisms and negative emotions. Additionally, evidence revealed that people with AN are aware of the effects of self-starvation, becoming emotionally numb by preoccupying their thoughts with eating and food, which could facilitate their capacity for avoiding intense emotions and intimate relationships (Schmidt & Treasure, 2006).

**Figure 2**

*A Diagrammatic Formulation of Social Processing Traits.*



*Note.* This figure was produced by Treasure and Schmidt in 2013. This open-access article is distributed under the terms of the creative commons CC BY license, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

### **Pro-anorectic Beliefs**

People with AN may experience a temporary improvement in mood and well-being in the early stage (Schmidt & Treasure, 2006). In this stage, they usually do not believe that they have any problem because they feel physically fine with the diet restriction. Besides, dieting provides them the opportunity to follow their rules and pay close attention to details. Upon successful

dieting and weight loss, they gain a sense of mastery and control over their lives, leading to the formation of pro-Anorectic beliefs. People with AN may initially receive compliments from close others about their weight loss and restrictive intake efforts, leading to unhealthy beliefs about being more attractive due to disordered eating. However, close others often become concerned and worried later when they recognize those weight loss and restrictive intake efforts as abnormal behaviors. Many of them become accommodative around the needs of people with AN. Unfortunately, extra attention and care elicited from disordered eating would further strengthen pro-anorectic beliefs (Schmidt & Treasure, 2006).

In a long-term starved state, food intake may arouse physical discomforts because of hormonal changes and further promote pro-anorectic beliefs (Schmidt & Treasure, 2006). Additionally, pro-anorectic beliefs are reinforced when people with AN associate the emotional numbing effect with starvation. They feel a sense of control over their emotions to mitigate intense negative feelings through starvation (Schmidt & Treasure, 2006). Therefore, they tend to utilize eating disorder behaviors to cope with their negative feelings.

### **The Response of Close Others**

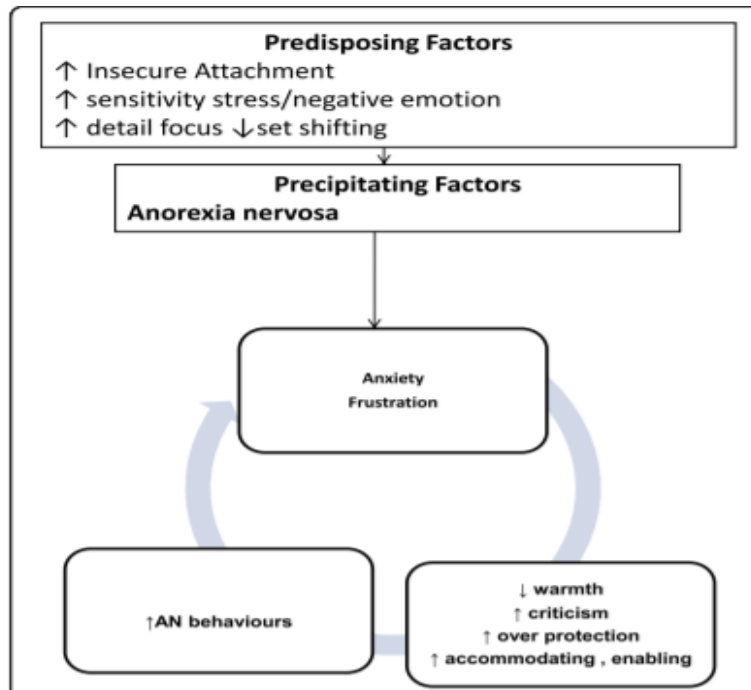
Although close others may organize and accommodate the needs of people with AN to avoid conflicts at all costs, close others may also develop strong negative emotions due to an increased level of caregiving burden and frustration. As a result, close others could respond to symptoms of AN with unhelpful, illness maintaining behaviors (Schmidt & Treasure 2006). According to Treasure and Schmidt (2013), these illness maintaining behaviors include a high level of expressed emotions (i.e., criticizing eating disorder behaviors, overprotecting the sufferers from assuming responsibilities or making decisions, and engaging in unhelpful communication with sufferers) and accommodating behaviors (i.e., facilitating eating rituals,

enabling unhealthy exercise regimes). For instance, close others may argue with people with AN in an attempt to have them eat. However, people with AN would often become more defensive with such confrontation. People with AN feel empowered when they reject their close others' arguments and remain firm with their disordered eating patterns. Thus, unhelpful confrontations would only strengthen pro-anorectic beliefs and behaviors.

Additionally, close others could demonstrate a high level of expressed emotions through offering people with AN excessive reassurance and comfort without challenging their anorectic behaviors (Schmidt & Treasure, 2006). People with AN often feel special and dominating when excessive reassurance and comfort are offered to them. Not only do excessive reassurance and comfort reinforce pro-anorectic beliefs, but they may also make other family members feel neglected. Consequently, other family members may develop resentment and hostility toward the person who has AN.

**Figure 3**

*A Diagrammatic Formulation of Carers Involvement with the Maintenance of an E.D.*



*Note.* This figure was produced by Treasure and Schmidt in 2013. This open-access article is distributed under the terms of the creative commons CC BY license, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

### **The Implication of the Cognitive Interpersonal Maintenance Model**

Research investigating the CIMM has demonstrated support for this model, suggesting that interventions targeting caregiver illness maintaining behaviors may promise to reduce caregiver burden and patient eating disorder symptoms (Goddard et al., 2013; Schmidt & Treasure, 2006; Treasure & Schmidt, 2013).

Given the support for the CIMM of eating disorders, the Experienced Carers Helping Others (ECHO) intervention was developed to directly address caregiver behaviors hypothesized to maintain eating disorder pathology (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). Broadly, ECHO is an intervention that combines psychoeducation with skills training (Goddard, Macdonald, Sepulveda, et al., 2011). The ECHO intervention includes educating caregivers on



moderating their expressed emotions such as criticizing eating disorder behaviors, overprotecting the sufferers from assuming responsibilities or making decisions, and engaging in unhelpful communication with sufferers. Appendix H describes the intervention techniques used to address factors hypothesized to maintain eating disorder symptoms (Rhind et al., 2014).

Based on the CIMM, the ECHO intervention was initially delivered in a workshop format (Sepulveda, Lopez, et al., 2008; Sepulveda et al., 2010). The initial delivery format consisted of six 2-hour workshops over three months; such a delivery format required a considerable amount of time commitment from the caregivers and a significant amount of resources from the healthcare team (McEvoy et al., 2019). McEvoy and his colleagues (2019) delivered the intervention in two 2.5-hour workshops over two weeks to reduce the time and resources required to deliver the intervention. The shorter workshop delivery strategy was able to increase caregiving knowledge, skills, and self-efficacy. However, expressed emotions (i.e., emotional overinvolvement) and accommodating behaviors were not significantly reduced in the study from pre-intervention to post-intervention.

Although the intervention was initially delivered in a workshop format, the developers subsequently created widely available self-help training materials to increase intervention dissemination. Specifically, Treasure and colleagues (2017) published *The Skilled-based Caring for a Loved One with an Eating Disorder: The New Maudsley Method* self-help manual and created a set of DVDs to help illustrate essential skills and support caregiver understanding (Langley, J., n.d.). The content of the DVDs developed by Treasure and her colleagues was outlined in a previous study (Sepulveda, Carolina, et al., 2008). According to Sepulveda, Carolina, and colleagues (2008), these DVDs covered the following topics: interpersonal impact

of eating disorders, supported eating, communication skills and the cycle of change, problematic behaviors, and analyzing behaviors.

Broadly, empirical studies testing the ECHO intervention across various formats indicate that this approach effectively decreases caregiving burden and illness maintaining behaviors (Treasure, Schmidt, & Crane, 2017). Self-help interventions may be an efficient and cost-effective way of disseminating proven techniques and therapies. To examine the efficacy of self-help ECHO interventions, Hodsoll and colleagues (2017) compared treatment as usual (TAU) to TAU plus ECHO self-help (i.e., *New Maudsley Method* self-help manual and DVDs) with and without telephone guidance (i.e., 10 30–60-minute phone coaching from experienced caregivers trained in ECHO and motivational interviewing techniques). Compared to caregivers in the TAU group, caregivers receiving the ECHO intervention (i.e., a combined group of caregivers who received ECHO with coaching and without coaching sessions) evidenced a slightly greater reduction in accommodating and enabling behaviors at 6-month follow-up (standardized E.S. = 0.19). At 12-month follow-up, caregivers receiving the ECHO intervention evidenced a greater increase in caregiving skills (standardized ES = 0.40,  $p = 0.036$ ), and time spent on caregiving (standardized ES = 0.40,  $p = 0.04$ ). Further, patients of caregivers in the ECHO intervention group demonstrated slightly greater increases in body mass index (E.S. = 0.17), decreases in peer problems (E.S. = -0.36), and more pro-social behaviors (E.S. = 0.51) at 12-month follow-up. Patients of caregivers in the ECHO intervention also had lower hospital admission rates than those in the TAU group at 6-month follow-up (19% versus 28%). When comparing ECHO groups with and without telephone guidance, caregivers in the two groups demonstrated no difference in skills (E.S. = 0.00) or time spent caring (E.S. = 0.02) at 12-month follow-up. ECHO without guidance produced somewhat greater improvement in patient E.D. pathology at 6-month

follow-up (E.S. = 0.28) and 12-month follow-up (E.S. = 0.10). ECHO with guidance produced a small benefit for peer problems (standardized E.S. = 0.13), but no benefit with patient distress (E.S. = 0.10) or impairment (E.S. = 0.08) over ECHO without guidance. The researchers concluded that the addition of telephone guidance to ECHO self-help materials produced unremarkable additional benefits. Similarly, Goddard, Macdonald, Sepulveda, and colleagues (2011) compared the impact of ECHO self-help (i.e., *New Maudsley Method* self-help manual and DVDs) with and without telephone guidance among a sample of E.D. caregivers recruited from a community setting. Telephone coaching did not provide additional benefit on the level of expressed emotion ( $p = 0.9$ ) and accommodating and enabling behaviors ( $p = 0.2$ ). In their study, Caregivers in the ECHO self-help group evidenced decreases in anxiety and depression (mean difference = -3.1,  $p < 0.001$ ) at the end of the intervention, as well as improvement in self-efficacy (mean difference = 9.0,  $p < 0.001$ ), expressed emotion (mean difference = -3.0,  $p = 0.002$ ), and use of accommodating and enabling behaviors (mean difference = -9.1,  $p < 0.001$ ). These improvements were comparable across intervention groups ( $p$ -values all  $> 0.05$ ), indicating no additional benefit of telephone guidance. Given this, the literature supports implementing a self-help ECHO intervention without phone coaching among caregivers of patients diagnosed with an E.D.

## **Summary**

In conclusion, the CIMM explained how intrapersonal and interpersonal factors could cause and maintain AN. People are more likely to develop AN when intrapersonal factors such as cognitive rigidity, perfectionistic mindset, avoidant personality, weak set-shifting, weak central coherence, and pro-anorectic beliefs. Furthermore, interpersonal factors such as close others responding to the eating disorder symptoms with a high level of expressed emotions and

accommodating behaviors may perpetuate disordered eating patterns in people with AN. Therefore, interventions that directly address these illness maintaining factors may decrease caregiving burden and illness maintaining behaviors.

## **CHAPTER THREE. METHOD**

### **Project Design**

This project was an evidence-based practice improvement project. The project utilized a case series design, in which participants were selected based on shared characteristics (i.e., caregivers of individuals with E.D.s). All enrolled caregivers received self-help training materials (i.e., *New Maudsley Method* self-help manual and streaming access to the video content from Dr. Treasure's DVDs), as well as weekly completion reminders from study staff. This project did not include a comparison group. The intervention effectiveness and acceptability were evaluated with pre-and-post-intervention questionnaires and a post-intervention interview.

### **Implementation Plan**

#### **Setting**

The EBP improvement project was implemented at an eating disorder treatment center in the Midwest (Sanford Eating Disorder and Weight Management Center; EDWMC). The EDWMC has a multidisciplinary team composed of clinical psychologists, licensed professional clinical counselors, social workers, nurse practitioners, registered dietitians, physician assistants, and primary care physicians. According to the co-director of the EDWMC, people from across the U.S. travel to this site to receive treatments for eating disorders (S. Wonderlich, personal communication, January 16, 2020). The EDWMC is located in Fargo, the largest city in North Dakota. In July 2018, around 124,844 residents lived in the city of Fargo. Out of the 124,844 residents, 49.4% were females, and 50.6% were males (United States Census Bureau, n.d.). While eating disorders are increasingly recognized in males, AN and BN diagnoses are more commonly identified among females (Hudson et al., 2007). At the time of implementation, it was estimated that 94% of the patients treated at the Sanford EDWMC were female (L. Schaefer,

personal communication, June 3, 2020). Therefore, it was expected that most caregivers enrolled in the current study were attending to a female patient.

## **Sample**

This EBP improvement project adopted a nonrandomized convenience sampling approach through a rolling admission. Referrals to this project were made directly by the clinical psychologists. The sample consisted of caregivers of patients diagnosed with AN, B.N., and OSFED receiving treatment from the outpatient eating disorders program at EDWMC. This study aimed to recruit caregivers for six separate patients, with a maximum of two caregivers per patient. Caregivers were defined as individuals providing unpaid help and support to a parent, child, partner, relative, friend, or neighbor (Treasure et al., 2015). For this project, the caregiver had to either be living with or directly involved in caring for a patient diagnosed with an E.D. (Sepulveda, Lopez, et al., 2008). Furthermore, caregivers need to also be at least 18 years of age, English-speaking, able to view online streaming videos, and able to participate in a video conference call for the exit interview to be included in the project.

## **Recruitment**

Recruitment for this EBP improvement project took place through the EDWMC staff and was intended to continue until caregivers for six patients had completed the intervention. Caregivers that expressed interest in participating in this EBP improvement project would be evaluated for eligibility by the co-investigator (S.C.), who was the student investigator. Appendix I provides a list of eligibility screening questions for project participation.

## **Consent Process**

A consent form and baseline assessment questionnaires (i.e., BAS, AESED, FQ) were sent to the eligible caregivers via Qualtrics. Refer to Appendix J for the informed consent form.

## **Intervention**

According to Melnyk and Fineout-Overholt (2018), piloting an intervention is indispensable in the EBP process. This EBP improvement project was planned to start in September 2020 or after the IRB approval and would end after six families have completed their six-week intervention separately (Goddard, Macdonald, Sepulveda, et al., 2011). The intervention adopted a self-help approach, utilizing an educational book titled *Skills-based Caring for a Loved One with an Eating Disorder* and videos developed by Janet Treasure and her colleagues (Hodsoll et al., 2017). Topics covered by the videos are as follows: interpersonal impact of eating disorders, supported eating, communication skills and the cycle of change, problematic behaviors, and analyzing behaviors (Quadflieg et al., 2017). Over six weeks, caregivers reviewed the training materials at their own pace (Goddard, Macdonald, Sepulveda, et al., 2011). The co-investigator had also sent out weekly reminders to the caregivers to complete their training materials via emails.

## **Evaluation**

### **Measures**

The Burden Assessment Scale (BAS) contained 19 items that assessed families' perceived burden for taking care of patients diagnosed with severe mental illness (Reinhard et al., 1994). Refer to Appendix K for the permission to use BAS and the items listed in the scale. Items were related on a Likert-type scale from 1 (*not at all*) to 4 (*a lot*), and caregivers were asked to indicate the number that reflects the extent of particular problems they had experienced over the past Month (McEvoy et al., 2019). Higher scores on the BAS indicated a greater level of perceived burden. The internal reliability was good ( $\alpha = 0.91$ ) in past research (McEvoy et al., 2019; Reinhard et al., 1994).

The Accommodating and Enabling Scale for Eating Disorders (AESED) contained 33 items that assessed caregivers' accommodating and enabling behaviors (Sepulveda et al., 2009). Refer to Appendix L for the permission to use AESED and the items listed in the scale. Caregivers were asked to rate the extent of accommodating and enabling behaviors demonstrated in the past Month on a Likert-type scale from 0 (*never*) to 4 (*every day*). Higher scores on the AESED indicated a greater level of accommodating and enabling behaviors. Reliability for the AESED had ranged from adequate to good in prior research. For example, McEvoy and colleagues (2019) research had internal reliability of  $\alpha = 0.91$  for the AESED scale. In contrast, Sepulveda and colleagues (2009) research had a Cronbach's alpha ranging from 0.77 to 0.92 for the AESED scale.

The Family Questionnaire (FQ) contained 20 items that assessed expressed emotions such as criticism and emotional overinvolvement (Wiedemann et al., 2002). Refer to Appendix M for the permission to use FQ and the items listed in the questionnaire. Caregivers were asked to evaluate their expressed emotion on a scale from 1 (*never/very rarely*) to 4 (*very often*). Furthermore, the questionnaire consisted of two subscales: Critical Comments and Emotional Over Involvement. Higher scores on the scale corresponded with higher levels of expressed emotion. Prior research indicated that scores for the FQ and its subscales demonstrate good reliability. According to Sepulveda and colleagues (2019), the internal reliability had an  $\alpha = 0.92$  for Critical Comments and an  $\alpha = 0.80$  for Emotional Over Involvement. Meanwhile, McEvoy and colleagues (2019) research had total internal reliability of  $\alpha = 0.92$  for the FQ.

The project utilized a Likert-type scale (0 = none, 10 = all) to assess the proportion of training materials reviewed by the caregivers to evaluate the intervention's acceptability. Furthermore, a Likert-type scale (score 0 = not at all helpful, 10 = extremely helpful) was also



utilized to assess caregiver perceived level of helpfulness of the information, the difficulty of accessing online training information, the usefulness of the training material information, helpfulness for stress/self-care, helpfulness for communication, and level of expectation met (Goddard, Macdonald, Sepulveda, et al., 2011). Refer to Appendix N for the permission to use the Likert-type scale.

Furthermore, the co-investigator conducted an exit interview that lasted no longer than 30 minutes via interactive video with the caregivers. The exit interview's purpose was to assess the feasibility, strengths, and weaknesses of the EBP improvement project. Appendix O outlines the interviewing questions.

### **Clinical Evaluation/Outcomes**

The overall goals for this EBP improvement project were that participating caregivers would:

- 1) Experience a decrease in caregiving burden from before to after the intervention, evidenced by a decrease in the scores collected from BAS.
- 2) Participating caregivers would demonstrate a decrease in illness maintaining behaviors (accommodation, expressed emotion) from before to after the intervention, evidenced by a decrease in the scores collected from AESED and FQ Furthermore, feedback in interviews with the caregivers would evaluate the feasibility, strengths, and weaknesses of the EBP improvement project.

### **Assessment Schedule and Data Analysis**

Before the intervention, caregivers were given the BAS, AESED, and FQ via Qualtrics to obtain the baseline scores of caregiving burden, accommodating and enabling behaviors, and the level of expressed emotions. Immediately following completion of the intervention (i.e., six

weeks after participants received their self-help materials), the same questionnaires were administered to the caregivers via Qualtrics to evaluate the intervention's efficacy. Also, the co-investigator interviewed the caregivers to discuss the intervention's feasibility, strengths, and weaknesses. Appendix P contains the detailed timeline for the project assessments. Furthermore, Appendix P contains descriptive statistics, including mean and range at baseline and end of treatment, were utilized to evaluate the intervention's effectiveness for data analysis.

### **Data Management**

Electronic files of summarized results (i.e., de-identified information) of the questionnaires, interviews, and surveys were stored on the co-investigators personal password-protected laptop.

### **Resources Required**

**Personnel.** EDWMC staff was needed for the EBP improvement project referral. The co-investigator was involved in the recruitment/screening process and provided weekly reminders to the caregivers for completing the training materials. Weekly reminders were sent to the caregivers via emails. Furthermore, the co-investigator also conducted exit interviews with the caregivers via interactive video.

**Technology.** Technologies were essential to facilitate the implementation of the interventions. The required equipment for participants and co-investigator included internet access and a computer or a smartphone, which were necessary to send out weekly reminders, access to streaming self-help videos, and complete self-report measures. Data were collected using Qualtrics.

**Budget.** The budget for implementing the self-help ECHO intervention included the cost of educational materials and additional office supplies. Appendix Q 8 contains details about the estimated cost of implementation.

## **CHAPTER FOUR. RESULTS**

The primary goal of this practice improvement project was to implement an evidence-based, self-help intervention for caregivers of people diagnosed with eating disorders at the outpatient Sanford EDWMC in Fargo, North Dakota. The self-help intervention focused on decreasing the caregiving burden, accommodating and enabling behaviors, and high levels of expressed emotion through skills-based training and eating disorders education. The project adopted a rolling admission to recruit caregivers of people with eating disorders, allowing the participants to complete their interventions and evaluations on different timelines. Overall, the participants started their six weeks of interventions between January and July of 2021 and completed their evaluations between April and September of the same year. Data collection included quantitative and qualitative findings utilizing validated questionnaires and exit interviews with the participants.

### **Sample Demographics**

A total of five participants related to four separate patients with eating disorders enrolled in the project. Four participants were female (Participants I through IV), and one was male (Participant V). All the participants were parents of someone with an eating disorder. Specific demographic data were not obtained from each participant to maintain patient and caregiver anonymity. Participants were referred directly by the clinical psychologist from the EDWMC and screened for eligibility by the co-investigator through an initial telephone interview. Participants were either living with or directly involved in the care of someone with an eating disorder receiving treatment from the EDWMC. In addition, all the participants were English speaking, at least 18 years of age, able to view online streaming videos, and could participate in a video conference call for an exit interview.

## Objective One Results

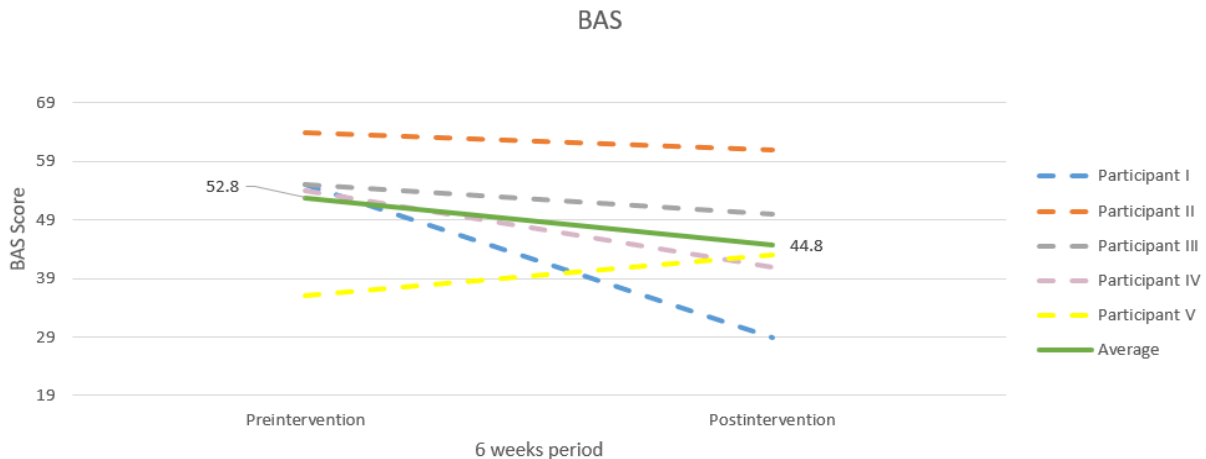
Objective one: Participating caregivers of patients with eating disorders would experience a decrease in caregiving burden from before to after the intervention, evidenced by a decrease in the scores collected from Burden Assessment Scales (BAS).

The BAS could range from 19 (the lowest possible score) to 76 (the highest possible score). At baseline, mothers (participants I through IV) of patients with eating disorders scored higher on BAS than the father (participant V). All the mothers scored lower on BAS after the intervention. The reduction in scores among the mothers ranged between three and twenty-six points. However, the father scored seven points higher than his baseline after the intervention. His postintervention score was lower than the preintervention scores of all the mothers, and it was also lower than the postintervention scores of two of the mothers. Overall, the average BAS score decreased from 52.8 before the intervention to 44.8 after the intervention. Refer to Figure 4 for the summarized BAS scores.

**Figure 4**

### *Burden Assessment Scale*

Burden Assessment Scale						
Participants/time	Participant I	Participant II	Participant III	Participant IV	Participant V	Average
<b>Preintervention</b>	55	64	55	54	36	52.8
<b>Postintervention</b>	29	61	50	41	43	44.8



## Objective Two Results

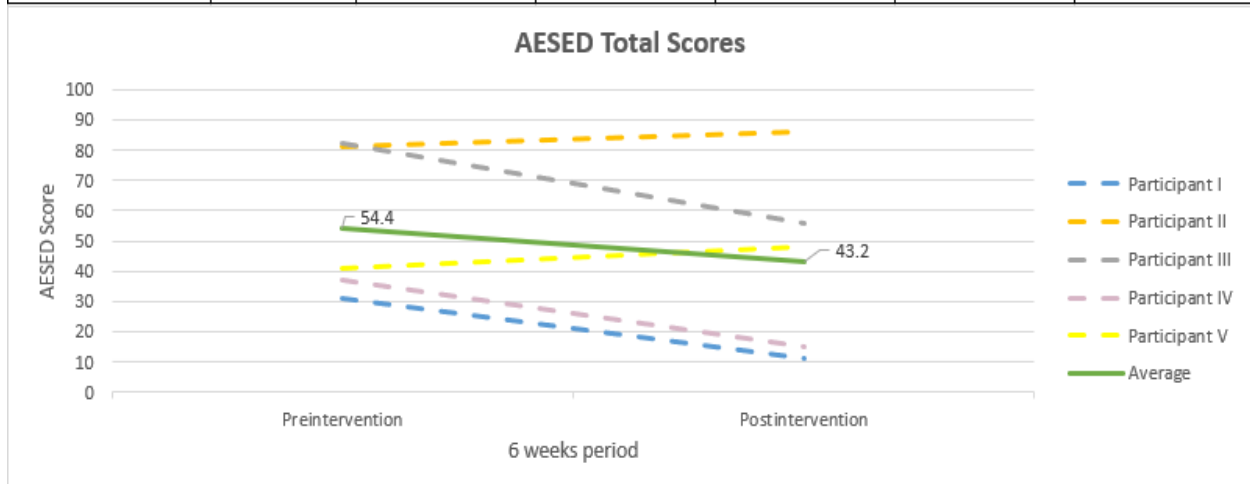
Objective two: Participating caregivers of patients with eating disorders would demonstrate a decrease in accommodating and enabling behaviors (e.g., repeatedly reassuring patients regarding their body image or accommodating ritualistic eating habits) from before to after the intervention, evidenced by a decrease in the scores collected from the Accommodating and Enabling Scale for Eating Disorders (AESED).

After six weeks of intervention, three out of five participants had lower total AESED scores. The total AESED score could range between zero and one hundred thirty-two. Overall, the average total AESED score was 54.4 before the intervention and 43.2 after the intervention. The participant who increased the total AESED score was a father of a patient with an eating disorder. His total AESED score increased from 41 before the intervention to 48 after the intervention. One mother (participant II) also had a five-point increase in her total AESED score. The total AESED scores from before to after the intervention are summarized in Figure 5.

**Figure 5**

*AESED Total Scores*

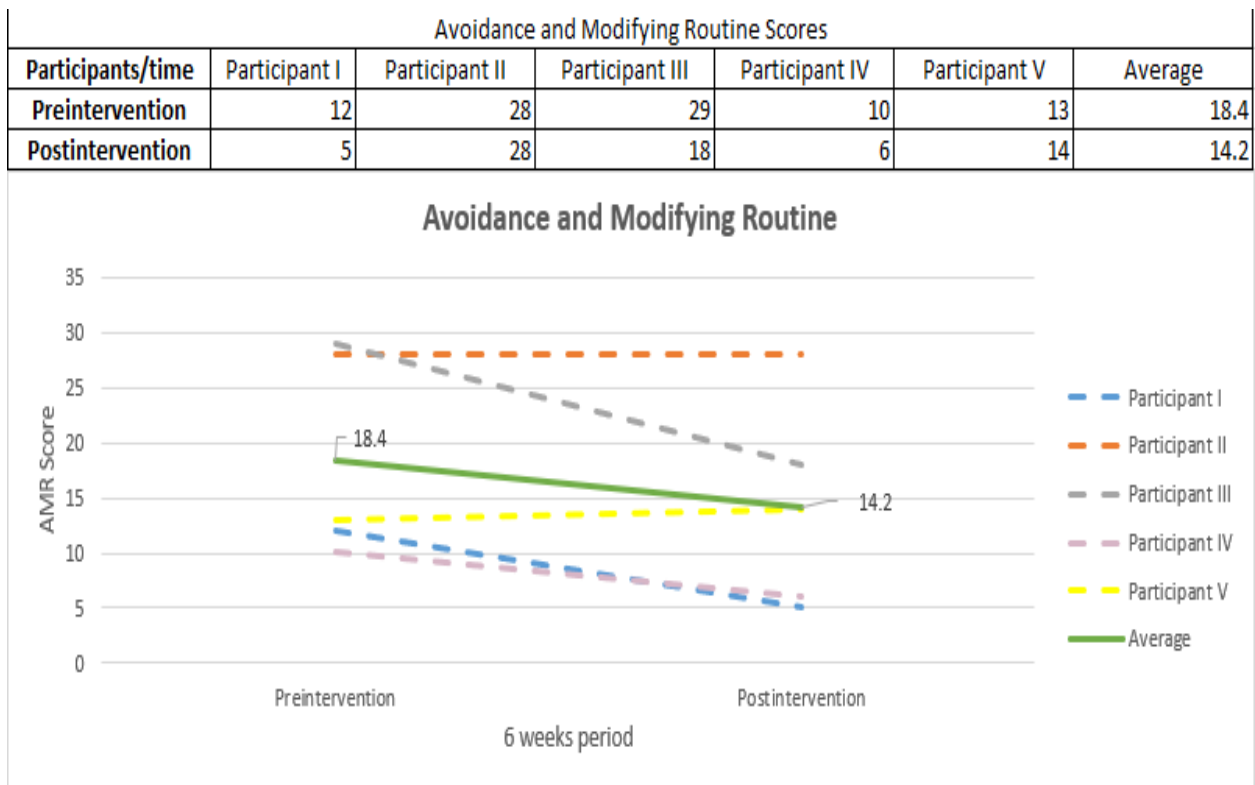
Total AESED Scores						
Participants/time	Participant I	Participant II	Participant III	Participant IV	Participant V	Average
Preintervention	31	81	82	37	41	54.4
Postintervention	11	86	56	15	48	43.2



Items 24 through 28 and 30 through 33 in AESED measured the scores for avoidance and modifying routine. The total score for avoidance and modifying routine could range between zero and thirty-six. After the intervention, three out of five participants had lower scores in this area compared to their prior scores, one mother (participant II) had no change in her score, and the father (participant V) increased his score. Overall, the average score for avoidance and modifying routine decreased from 18.4 before the intervention to 14.2 after the intervention. The father increased his score by one point after the intervention, whereas the other three mothers decreased their scores ranging from four to eleven points. The scores for avoidance and modifying routine are summarized below in Figure 6.

**Figure 6**

*AESED: Avoidance and Modifying Routine Scores*

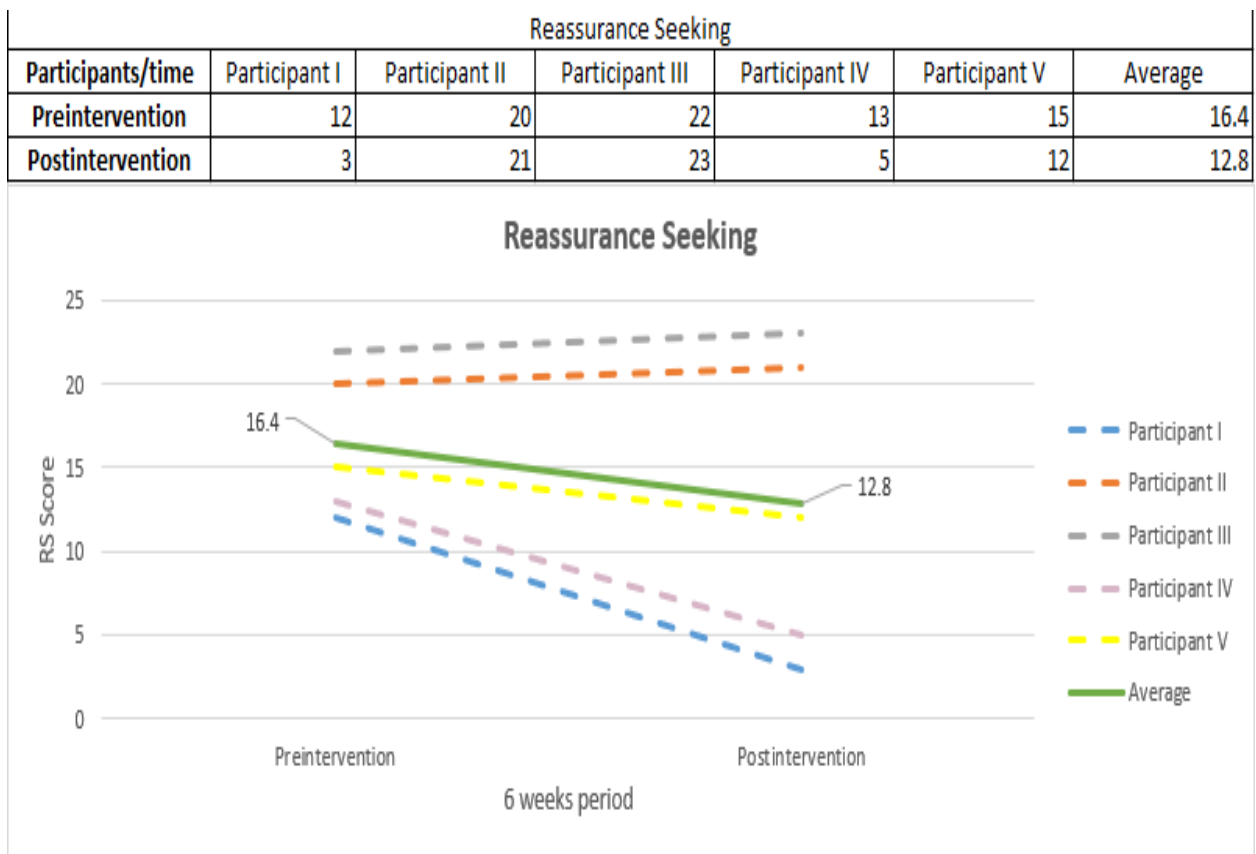


The reassurance-seeking scores are summarized in Figure 7. Items 5 through 10, 18, and 19 in AESED measured the reassurance-seeking scores. The total possible score for reassurance-

seeking was between zero and thirty-two. The average score for this area decreased from 16.4 before the intervention to 12.8 after the intervention. After the intervention, two mothers had higher scores, two mothers had lower scores, and the father had a lower score than the baseline. Those two mothers with increased reassurance-seeking scores after the intervention had scored one point higher than their scores from baseline. The other three participants decreased their scores by three to nine points after the intervention.

**Figure 7**

*AESED: Reassurance Seeking*



Meal ritual scores were measured with items 11 through 17 in AESED. The total score for the meal ritual section could range between zero and twenty-eight. Among the mothers, one had no change in her score, two had decreased their scores, and one had increased her score. The

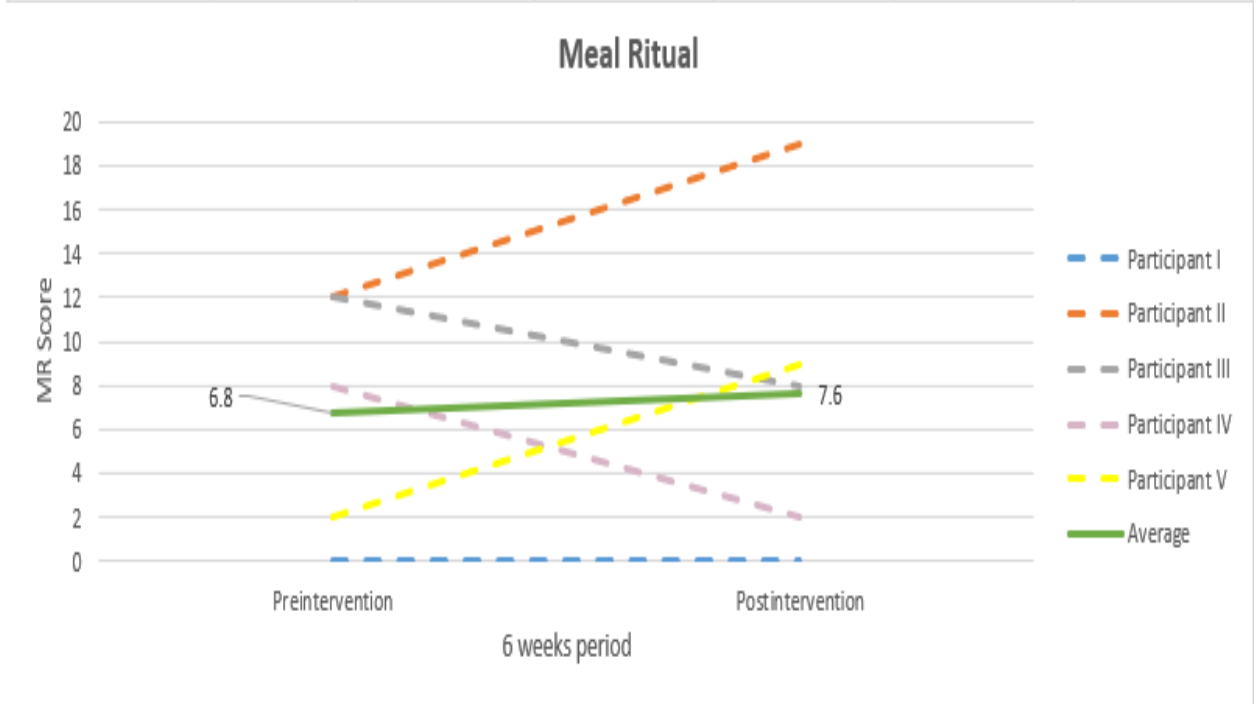


father scored higher than his score from the baseline. Overall, the average score increased from 6.8 to 7.6 after the intervention. Refer to Figure 8 below for the summarized meal ritual scores.

**Figure 8**

*AESED: Meal Ritual*

Meal Ritual						
Participants/time	Participant I	Participant II	Participant III	Participant IV	Participant V	Average
Preintervention	0	12	12	8	2	6.8
Postintervention	0	19	8	2	9	7.6

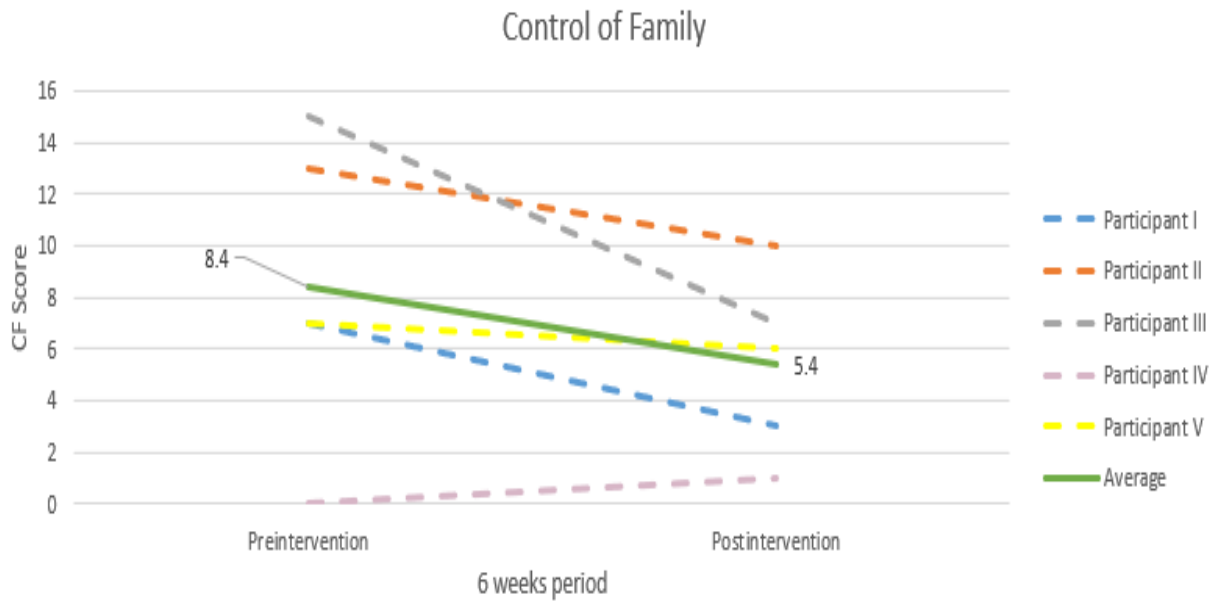


The scores for control of the family were measured with items one through four in AESED. The total score for control of the family could range between zero and sixteen. All participants had decreased their scores in this section after the intervention, except one mother scored one point higher than her baseline. The average score for this section was 8.4 before the intervention and 5.4 after the intervention. Refer to Figure 9 for the summarized scores on the control of the family.

**Figure 9**

*AESED: Control of Family*

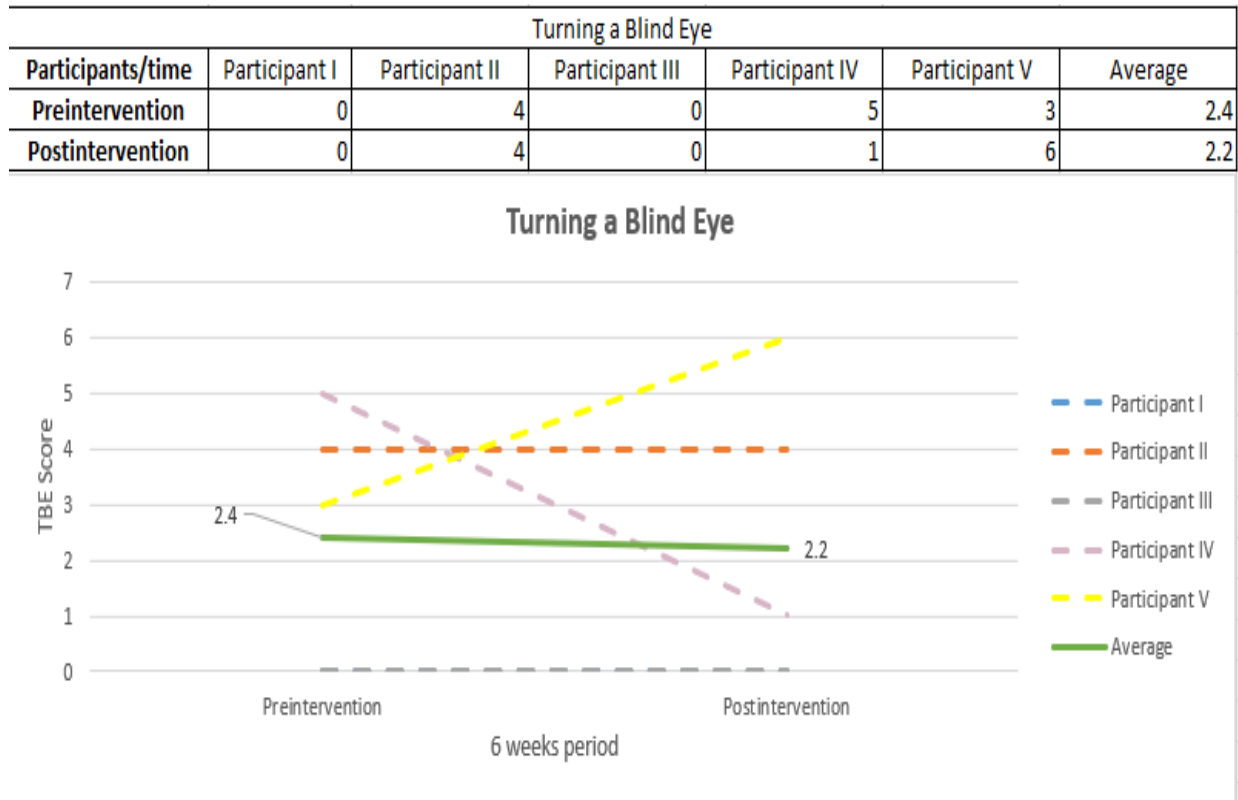
Control of Family						
Participants/time	Participant I	Participant II	Participant III	Participant IV	Participant V	Average
Preintervention	7	13	15	0	7	8.4
Postintervention	3	10	7	1	6	5.4



The scores for turning a blind eye were measured with items 20 to 23. The total score could range between zero and sixteen for this section. Among the mothers, two scored zero, and one scored four before and after the intervention. One of the mothers had a four-point reduction after the intervention. Different from the rest of the participants, the father scored three points higher after the intervention. The scores for turning a blind eye are summarized in Figure 10.

**Figure 10**

*AESED: Turning a Blind Eye*



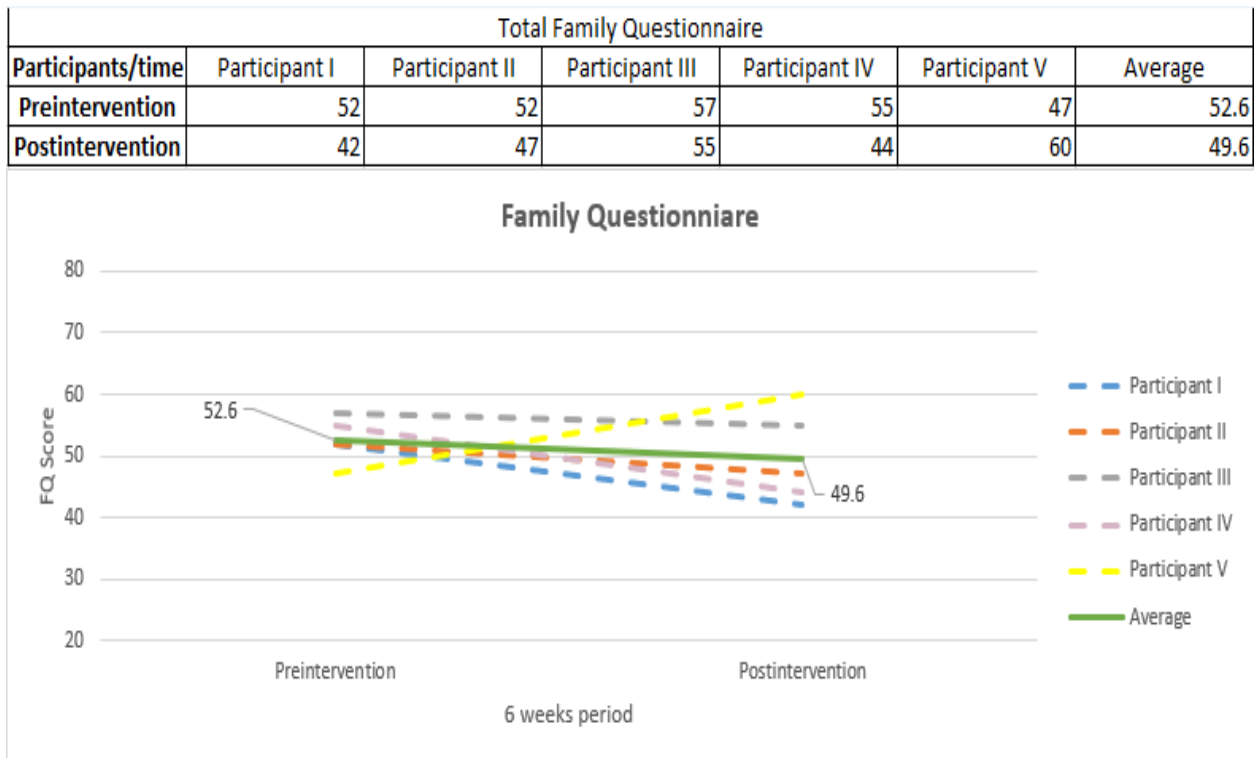
**Objective Three Results**

Objective three: Participating caregivers of patients with eating disorders demonstrated a decrease in expressed emotions from before to after the intervention, evidenced by a decrease in the scores collected from the Family Questionnaire (FQ).

The total FQ score could range between 20 (the lowest possible) and 80 (the highest possible score). All the mothers scored lower than their baseline after the intervention, whereas the father scored higher. The reduction of total FQ scores among the mothers ranged between 2 and 11 points. After the intervention, the father scored 13 points higher than his baseline. The total FQ scores are summarized below in Figure 11.

**Figure 11**

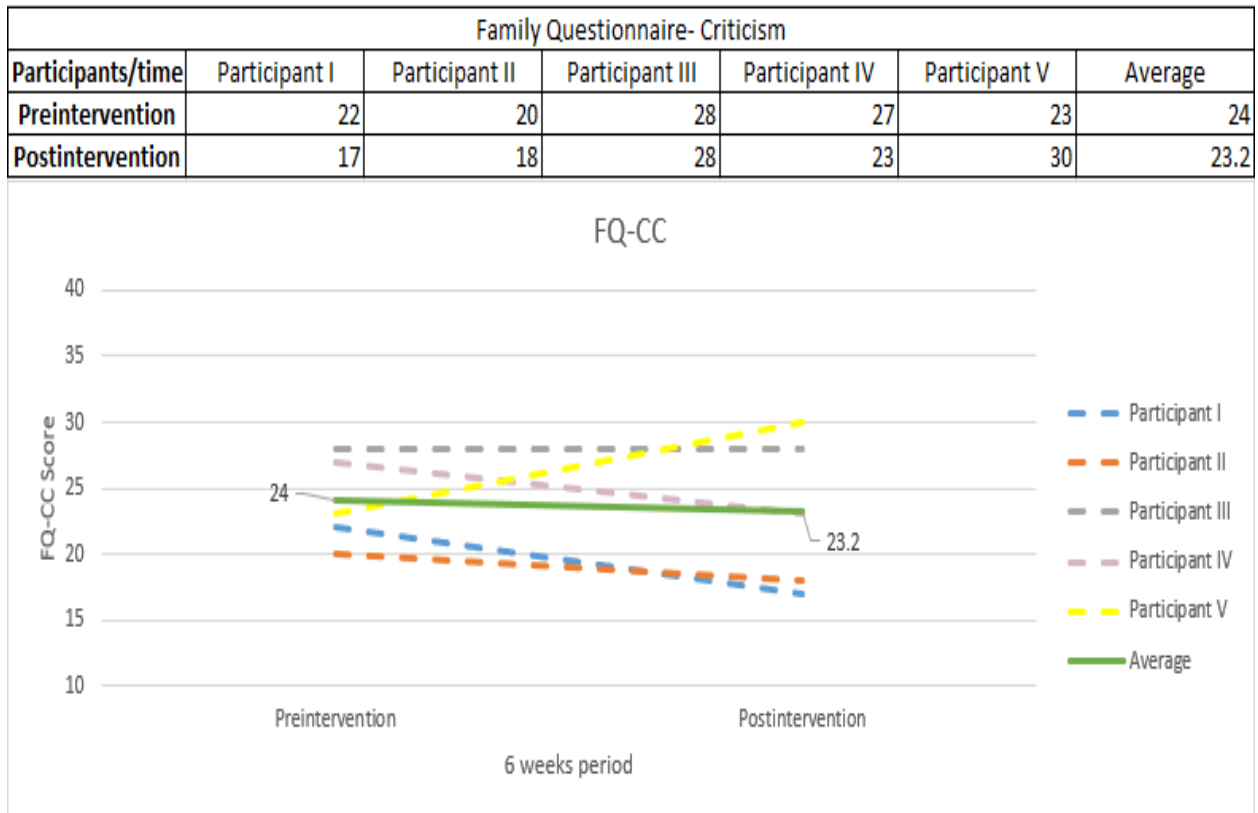
*Total Family Questionnaire*



Criticism is a subcategory of the FQ. Items with even numbers on the FQ measured the criticism scores. After the intervention, three mothers scored lower than their initial scores, one mother scored the same as her initial score, and the father scored higher than his initial score. The scores decreased between two and four points among the three mothers who scored lower on their postintervention score. However, the father increased seven points in his score after the intervention. Overall, the average score for this subcategory decreased by 0.8 after the intervention. Criticism scores are summarized below in Figure 12.

**Figure 12**

*Family Questionnaire: Criticism*

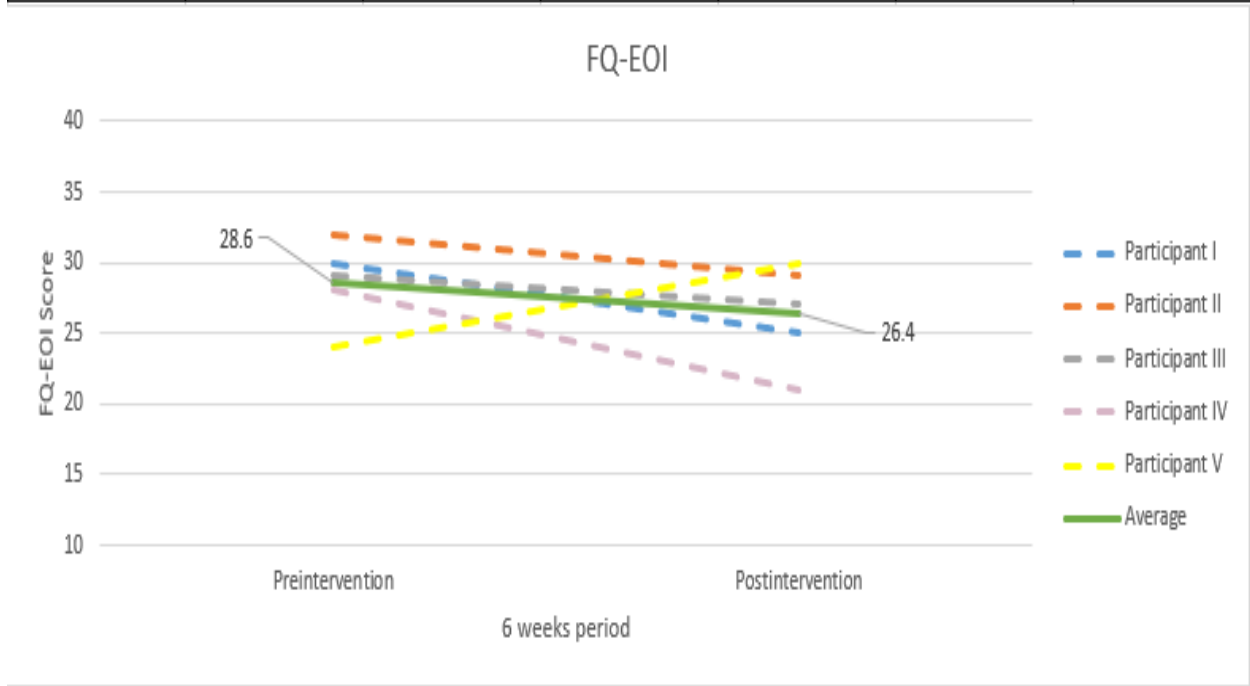


Emotional overinvolvement is another subcategory of FQ. Items with odd numbers on the FQ measured the emotional overinvolvement scores. All the participants scored lower on this subcategory after the intervention, ranging from two to seven points reduction, except the father, who scored six points higher than his initial score. Refer to Figure 13 for the summarized data on emotional overinvolvement scores.

**Figure 13**

*Family Questionnaire: Emotional Over-Involvement*

Family Questionnaire- Emotional Over-Involvement						
Participants/time	Participant I	Participant II	Participant III	Participant IV	Participant V	Average
Preintervention	30	32	29	28	24	28.6
Postintervention	25	29	27	21	30	26.4



**Acceptability of The Intervention**

At the end of the intervention, the participants completed a Likert-type scale survey to evaluate the acceptability of the intervention (EAI). The survey evaluated the portion of materials reviewed, the level of helpfulness, and the accessibility of the intervention (Figure 14).

**Figure 14***Evaluation of the Acceptability of the Intervention*

EAI Items	Time/Participants					
	Post-Intervention					
	I	II	III	IV	V	Average
Q1: What proportion of the materials did you watch/read?	9	8	8	5	4	6.8
Q2: How helpful did you find this information?	8	10	6	10	7	8.2
Q3: How difficult was it to access the online training information?	0	2	1	2	5	2
Q4: Was the intervention helpful for stress management and self-care?	7	10	7	5	8	7.4
Q5: How helpful was this intervention in improving communication with your loved one?	7	10	6	9	8	8
Q6: To what extent did the intervention materials meet your expectation?	8	8	8	9	9	8.4

**Q1: What proportion of the materials did you watch/read?**

All the participants responded to this question on a scale from zero to ten. Zero meant no portion of the material was covered, and ten meant all the materials were covered. Besides the father, every participant reviewed half or more of the training materials.

**Q2: How helpful did you find this information?**

The response to this question could range from zero (not at all helpful) to ten (extremely helpful). At the end of the intervention, the responses from the participants ranged from six to 10. Two participants responded 10. Overall, the average for this question was 8.2 out of 10.

**Q3: How difficult was it to access the online training information?**

The response to this question could range from zero (not at all difficult) to 10 (extremely difficult). All participants responded with a score of five or lower. The average score for this question was two out of 10.

**Q4: Was the intervention helpful for stress management and self-care?**

The response to this question could range from zero (not at all helpful) to 10 (extremely helpful). At the end of the intervention, all participants responded with a score of five or higher.

One participant responded with a score of 10 out of 10. The range to this question was from five to 10 out of 10. The average score for this question was 7.4 out of 10.

**Q5: How helpful was the intervention in improving communication with your loved one?**

The response to this question could range from zero (not at all helpful) to 10 (extremely helpful). All of the participants responded with a score of six or higher at the end of the intervention. The scores ranged from six to 10, and the average score was eight out of 10.

**Q6: To what extent did the intervention materials meet your expectation?**

The response to this question could range from zero (not at all met) to 10 (fully met). At the end of the intervention, all the scores were between eight and nine for this question. Three participants responded with an eight, and two responded with a nine. The average score for this question was 8.4 out of 10.

**Exit Interviews**

All participants completed an online exit interview with the co-investigator to provide qualitative feedback. Each interview lasted no longer than 30 minutes. Five questions were asked during the interview, and their responses were summarized and compiled in Table 2.



**Table 2**

*Responses from the Caregivers During the Exit Interviews*

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Q1: What do you find helpful from this intervention?

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- “Videos are helpful to see things in action.”
- “Identifying the different caring approaches.”
- “This material is more relatable and applicable.”
- “The most helpful information was how to talk to the individuals with eating disorders.”
- “The animal illustration.”
- “I think I learned to empathize with individuals with eating disorders through this experience.”
- “The intervention helps us to know how people with EDs think and how to communicate with them.”
- “Many things in the book pertain to what I was going through.”
- “I love that now I have a book that I can refer to whenever I have a question.”
- “I prefer reading over watching videos.”

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Q2: What did you find challenging and difficult about the intervention?

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- “Not second-guessing what I have done before the intervention.”
- “Staying consistent with what is helpful to the individual with an eating disorder is challenging.”
- “Switching from a default reaction to what was learned from the intervention.”
- “It was challenging to be coached about being patient from the intervention.”
- “We are habitual in the way we communicate, and we are not our best selves when emotions are high.”
- “Using new communication skills is challenging.”
- “The intervention is a bit overwhelming. I am not sure I am supposed to remember all the information.”

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Q3: If you can change something about the intervention, what would it be?

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- “A support group would be nice, but not sure how it would be feasible.”
- “Not sure what needs to be changed with the materials.”
- “Having a quick reference guide to help address eating disorder behaviors.”
- “Caregivers often want information quickly, so I would recommend categorizing the book a little bit.”
- “I would like to have more real-life scenarios.”

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Q4: Was six weeks enough time to cover the training materials?

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- “Six weeks would have been enough time if the patient were first diagnosed with ED.”
- “Many things could have been avoided if the intervention had been implemented earlier.”
- “Six weeks were enough to cover the information.”
- “I finished all the chapters at week four and spent other weeks reviewing the materials.”
- “No. I would read the chapters multiple times, and every time I learned something new.”
- “Yes.”

---

Q5: How easy was applying the information learned in the training material to a real-life scenario?

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- “Some were easy, and some were hard.”
- “Having to undo things that we have done for a long time is tricky.”
- “Very easy.”
- “The videos were very helpful, reinforced the reading, and brought the information to life.”
- “I would not say the information was easy to apply. It is difficult to break habits.”
- “Hard. I need to recognize the situation, keep my emotion in check, and then apply learned skills.”
- “Applying the information was difficult when my loved one constantly tried to argue with me.”
- “It was easy because the information was consistent with what I learned from the therapists.”

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## CHAPTER FIVE. DISCUSSION AND RECOMMENDATIONS

### Summary and Synthesis

Recent data revealed that in 2019 the United States had 759,000 new cases of eating disorders, and 1.2 million Americans struggled with eating disorders (Global Health Data Exchange, n.d.). The incidence rate and prevalence of eating disorders have increased over the years. More patients and families are affected negatively by the increase of eating disorders. In their literature review, Van Hoeken and Hoek (2020) stated that the annual healthcare costs were 48% higher for individuals with eating disorders than for the general population. Compared to the general population, the mortality risk was over five times higher for people who required inpatient treatment for anorexia nervosa. Furthermore, the mortality risk was around two times higher for people who required inpatient treatment for bulimia nervosa or outpatient treatment for anorexia nervosa (Hoeken & Hoek, 2020). Not only can eating disorders be life-threatening to the patients, but they can also be costly to both the patients and the family members.

In addition to the financial strain that eating disorders impose on the sufferers and family members, caregivers of people with eating disorders often experience increased levels of caregiving burden (Martin et al., 2015). Matthew and colleagues (2018) found that caregiver beliefs about eating disorders' negative consequences were associated with the caregiving burden. Increased tension in relationships, worrying about the sufferers, and the need to urge the sufferers to do things, could impede family-based therapy (Martin et al., 2015; Matthews et al., 2018). According to Treasure and colleagues (2017), caregivers would often react to eating disorder behaviors automatically due to increased levels of caregiving burden and the lack of training. However, those automatic reactions may not be the most helpful responses (Treasure et al., 2017). Most importantly, unhelpful responses may maintain eating disorder behaviors.

The purpose of this project was to decrease the caregiving burden and illness-maintaining behaviors by providing an evidence-based, self-help intervention to caregivers of individuals with eating disorders receiving treatment from Sanford Outpatient Eating Disorder and Weight Management Center (EDWMC). After nine months of recruitment and project implementation, five family members from four separate patients participated in this project. Out of the five participants, four were mothers, and one was a father. The father and one of the mothers were married. They participated in the project as a couple. For evaluation, validated questionnaires (i.e., BAS, AESED, FQ) were utilized at baseline and the end of the intervention to measure project outcomes. In addition, all five caregivers participated in the online interviews via Zoom with the co-investigator to provide their feedback on the project. The couple participated in a joint online interview with the co-investigator. However, the couple each completed their questionnaires before and after the intervention.

The Iowa Model of Evidence-Based Practice and the Cognitive Interpersonal Maintenance Model were utilized to structure the project's design, implementation, evaluation, and dissemination. According to Melnyk and Fineout-Overholt (2018), the Iowa Model was developed to provide a multi-step pathway with a series of feedback loops for healthcare providers to identify clinical problems, investigate solutions, and implement practice changes. While utilizing the revised Iowa Model, the co-investigator had to address the criteria of each step to move forward in the evidence-based practice process. In addition, the feedback loops in the Iowa Model helped the co-investigator assess changes required for project implementation.

Treasure and Schmidt (2013) utilized the Cognitive Interpersonal Maintenance Model (CIMM) to explain the interpersonal and intrapersonal causing and maintaining factors of anorexia nervosa. Although this model was comprehensive at explaining the psychopathology of

anorexia nervosa, the intervention was solely developed to address the interpersonal factors. The interpersonal causing and maintaining factors include high levels of expressed emotions (i.e., criticism, emotional-overinvolvement) and accommodating behaviors (i.e., facilitating eating rituals, enabling unhealthy exercise regimes, overlooking eating disorder behaviors). In this project, the participating caregivers received a self-help intervention based on the CIMM to address their caregiving burden and illness maintaining behaviors. The self-help intervention provided education on eating disorders, caregiving styles, and communication skills. In addition to the support from previous empirical evidence, the participants in this project also provided positive quantitative and qualitative feedback on this CIMM-based intervention.

Based on the positive feedback from the participating caregivers in this project and support from previous empirical evidence, the co-investigator recommends continuing to implement the CIMM-based self-help intervention at EDWMC and considering the addition of a support group for the future projects. Although this project focused on the outcomes of non-professional caregivers, the information in this intervention was utilized for staff training at a specialized eating disorder unit (Treasure et al., 2017). Treasure and colleagues (2017) suggested that this intervention applies to anyone in a caregiving relationship with someone who has an eating disorder. Future projects and research may consider implementing this intervention in a primary care setting targeting the healthcare providers. With additional knowledge of eating disorders and communication skills, primary care providers may facilitate early eating disorder recognition, referral, and treatment. Furthermore, the primary care providers may also offer helpful information from this intervention to the caregivers of someone with an eating disorder to increase their self-efficacy and knowledge (Spettigue et al., 2015).

## **Objective One**

The first objective was to decrease the caregiving burden experienced by the participants from before to after the intervention, evidenced by a decrease in the scores collected from the Burden Assessment Scale (BAS). Overall, this objective was met by four out of five participants. The average of all the collected BAS scores decreased after the intervention. All participants experienced a decrease in the caregiving burden, except one. This participant was a father of a patient with an eating disorder. His score actually increased by seven points at the end of the intervention. Ironically, Treasure and colleagues (2017) stated in their self-help book that “fathers in particular benefit from this approach (Maudsley method) by helping them to step into a more active role when they put the tips into practice” (p. viii). Compared with the rest of the participants, this participant covered the least amount of the training materials. This participant was able to cover 40% of the materials within six weeks. The lack of decrease in the caregiving burden could be related to not having enough time to cover all the training materials.

## **Objective Two**

The second objective was to decrease participants’ accommodating and enabling behaviors from before to after the intervention, evidenced by a decrease in the scores collected from the Accommodating and Enabling Scale for Eating Disorders (AESED). Overall, this objective was met by three out of five participants. Three out of five participants had lower AESED scores after the intervention. Furthermore, the average scores for four out of five subcategories were decreased as well. Most participants reported having less illness maintaining behaviors such as inappropriately avoiding conflicts, modifying routines, providing excessive reassurance, losing control in the family, and overlooking problems. The only subcategory with a slightly increased average score after the intervention was meal ritual. During the exit interviews,

some participants indicated that breaking habits was challenging. Thus, addressing meal rituals may take longer than the time allotted to the participants.

### **Objective Three**

The third objective was to decrease participants' high levels of expressed emotions from before to after the intervention, evidenced by a decrease in the scores collected from the Family Questionnaire (FQ). According to Treasure and Schmidt (2013), high levels of expressed emotions could cause and maintain eating disorders. Overall, the third objective was met by four out of five participants. After the intervention, most participants reported having less criticism and emotional overinvolvement in the FQ. All participants except one scored lower on the FQ after the intervention. This participant had consistently scored higher on all other questionnaires, which could result from insufficiently reviewing training materials. However, another possibility could be that he became more aware of his emotional responses and reactions to eating disorder behaviors after the intervention. Although ineffective intervention for this particular individual could be possible, he could also be overwhelmed by increased awareness of his emotional responses toward eating disorder behaviors.

### **Evaluation of the Intervention Acceptability**

At the end of the intervention, a Likert-type scale containing six questions was utilized to evaluate the portion of materials reviewed, the level of helpfulness, and the accessibility of the intervention. Although the caregivers had six weeks to complete their interventions, covering all the training materials may still be challenging. In a previous study by Hodsoll and colleagues (2017), only 36% of the caregivers completed more than half of the self-help manual, and 20% completed more than half of the training videos. Thankfully, four out of five (80%) participants in this project covered at least half of the training materials. The father (participant V) was the

only caregiver who covered less than half of the training materials. He covered 40% of the training materials in six weeks.

Regardless, the participants all thought that the self-help intervention was effective and met their expectations. On a scale of zero to ten, all participants scored six or higher for the levels of helpfulness on general information, stress management and self-care, and communication with their loved ones. Furthermore, the participants all scored eight or higher for the level of expectation met with the self-help intervention.

In general, the online portion of the intervention was considered easy to access. The average score was two out of ten for difficulty accessing the online training information. The father had the most difficulty in accessing the online training information. In this section, he scored five on a scale of zero to ten. Having difficulty accessing the training materials may explain why he covered less training materials than other participants. Thus, future projects may consider having an orientation meeting to provide technical instructions.

### **Responses from the Exit Interviews**

At the end of the self-help intervention, each participant had an exit interview with the co-investigator via Zoom separately, except the married couple. Due to limited time availability, the married couple decided to participate in a joint interview with the co-investigator. During the interviews, the co-investigator asked the participants what they found helpful and challenging about the intervention. Furthermore, the participants were asked if they had enough time to cover the training materials, what they would change about the intervention, and how they felt about applying the learned information to a real-life scenario.

Overall, the participants expressed that learning how to interact with their loved ones was most helpful. The participants described the intervention as “applicable, relatable, and pertinent.”

Through this self-help intervention, the participants reported that they could better understand “how people with eating disorders think.” One participant stated that she learned to have more empathy through this intervention. According to Treasure and colleagues (2017), caregivers may develop more empathy toward their loved ones after realizing the difficulty of changing their own reactions toward eating disorder behaviors. Furthermore, the responses from this project were similar to the feedback from a qualitative study by Annemarie and colleagues (2019). The participants in the qualitative study reported having a greater understanding of eating disorders and communication skills after the intervention (Annemarie et al., 2019).

Nonetheless, most of the participants in this project reported that changing their “habitual” reactions toward eating disorder behaviors was the most challenging part of the intervention. Consequently, three out of five participants reported having difficulty applying the learned information to real-life scenarios. The participants thought that “breaking” and “undoing” habits were difficult. Interestingly, participants in the previous study also reported that much practice was required to eliminate “habitual” reactions (Annemarie et al., 2019). Contrary to the rest, two participants in this project thought that the intervention was “easy” to apply and “consistent” with the information provided by the clinical psychologists.

Although the participants had six weeks to complete the intervention, many had busy schedules. Therefore, completing the intervention within six weeks could be challenging. According to the survey, three out of five participants thought six weeks was enough time to cover the training materials, while two participants thought differently. Regardless, four out of five participants completed at least half of the training materials.

Although the participants’ intervention engagement was higher in the study by Goddard and colleagues (2011) than the intervention engagement from this project, the participants in this



project were more engaged than the participants in the study by Hodsoll and colleagues (2017). The participants in the study by Goddard and colleagues (2011) completed an average of 80% of training materials. Meanwhile, only 36% of the participants completed more than half of the self-help manual, and 20% completed the training videos in a more recent study by Hodsoll and colleagues (2017).

However, the two participants were mothers who thought they needed more time to cover the training materials in this project. One of those two mothers stated that she learned new information each time she reviewed the materials. Thus, she did not think six weeks was enough time to learn all the information adequately. Similarly, the other mother thought she needed to change her unhelpful reactions to eating disorder behaviors within six weeks. Instead of asking the participants if they had enough time to cover the information within six weeks, asking them if six weeks was enough time to read all the chapters and watch all the videos may be more appropriate to avoid confusion.

Lastly, the participants provided various responses when asked what they would change about the intervention. Only one participant did not have any recommendation. Meanwhile, two of the participants wanted a “quick” reference guide to help them respond to eating disorder behaviors appropriately and timely. One of the participants “would like to have more real-life scenarios.” Although the participants would like to know how to always respond to their loved ones appropriately, making mistakes would provide valuable learning opportunities (Treasure et al., 2017). Consistent with the feedback from a previous study by Dimitropoulos and colleagues (2019), the participants in this project also desired to have a support group. Having a support group would allow them to have more opportunities to practice their caregiving skills and

connect with other caregivers. Future projects may consider incorporating a support group in addition to the current intervention in this project.

### **Recommendations**

The goal of implementing a self-help intervention for caregivers of people with eating disorders is to decrease their caregiving burden and illness maintaining behaviors. Although eating disorders affect the sufferers and the caregivers, the impacts on the caregivers have often been neglected. Increased caregiving burden predisposes the caregivers to cope ineffectively. According to the Cognitive Interpersonal Maintenance Model (CIMM), responding to the sufferers with maladaptive behaviors may prolong the illnesses and prevent recovery (Treasure & Schmidt, 2013). Over the years, various effective interventions were developed to address caregivers' burdens and maladaptive behaviors (Hibbs et al., 2015).

According to Philipp and colleagues (2021), providing caregivers with the CIMM-based intervention might increase the chance of recovery for patients who suffer from eating disorders. Although up to 60% of patients with eating disorders might recover with standard treatments, Philip and colleagues (2021) noted higher recovery rates from their study participants at one-year follow-up. In their study, 87% of the participants made a partial or complete recovery when the caregivers received the online intervention. Meanwhile, 72% of the participants made a partial or complete recovery when the caregivers received the workshop intervention. Although the study included two different delivery formats, the materials and intervention were based on the CIMM. Therefore, addressing the needs of the caregivers can not only decrease the caregiving burden but also improve the patients' outcomes (Hibbs et al., 2018; Philipp et al., 2021).

Based on the design from a previous study by Goddard and colleagues (2011), this project adopted the six-week self-help intervention to address caregiving burden and illness

maintaining behaviors. According to Goddard and colleagues (2011), their participants' caregiving burden, accommodating and enabling behaviors, and expressed emotions were significantly reduced after six weeks of intervention. In a recent study, participants' caregiving burden decreased significantly after eight weeks of intervention (Truttmann et al., 2020). In addition, according to Truttmann and colleagues (2020), their participants' caregiving skills improved significantly after the intervention. Although the length of the intervention varied between these two studies, both were based on the Cognitive Interpersonal Maintenance Model.

Consistent with previous studies, the results from this project indicate that the caregivers experienced decreased caregiving burden and demonstrated less illness maintaining behaviors after the intervention. Participants appreciated the videos on real-life scenarios and the communication skills in the self-help manual. Based on these findings, the co-investigator recommends that the EDWMC continue implementing the self-help intervention. While the self-help intervention is helpful for both the caregivers and the sufferers, this intervention is not meant to replace any clinical treatment.

The co-investigator would also suggest changes to future projects to provide more opportunities for the caregivers to connect with others and practice the skills they learned from the intervention. The project participants' feedback is similar to those in a previous study (Dimitropoulos et al., 2019). According to their feedback, caregivers enjoy learning skills at their own pace through online training and books, but they also desire a support group to practice what they learned from the intervention. Future projects may consider having a support group to allow caregivers to connect with others and practice their skills learned from the materials.

## **Dissemination**

Dissemination is an essential step of the evidence-based practice (EBP) improvement project. The dissemination of results may facilitate the adaptation of evidence-based practices (Melnyk & Fineout-Overholt, 2018). According to Serrat (2017), knowledge dissemination is as crucial as knowledge production. He argues that knowledge is wasted when it is not shared with the audience. Therefore, the preliminary findings from this project were presented to fellow graduate nursing students and nurse practitioners at the North Dakota Nurse Practitioner Association (NDNPA) 2021 pharmacology conference. In addition, an executive summary of this project will be provided to the EDWMC, and the dissertation will be published.

The NDNPA pharmacology conference is a regional conference, peer-reviewed, and available virtually via Zoom and in person at Bismarck, North Dakota. In May of 2022, another poster session will be held at North Dakota State University. During the NDNPA 2021 pharmacology conference, the co-investigator discussed this project with a few nurse practitioner students. They were impressed with the idea of improving patient and caregiver outcomes via a caregiver-oriented intervention. They thought that this holistic approach aligns with the biopsychosocial nursing model of care. At the end of the conference, the poster for this project was awarded first place.

Future dissemination includes providing an executive summary to the EDWMC, hosting a poster session, and publishing this EBP improvement project. The co-investigator plans to seek journals interested in publishing information about a self-help intervention for caregivers of people with eating disorders. The target audience includes primary care providers and mental health providers. The Journal of the American Association of Nurse Practitioners or the Journal of Psychiatric and Mental Health Nursing may be most fitting for this type of publication.

## **Strengths and Limitations**

### **Strengths**

With the advancement of technology, participants can easily access the training materials online. After obtaining permission from the DVD copyright owner, the co-investigator converted the training DVD for the participants into online streaming videos with the help of technical support from the University. The participants also had the option to choose between a hard copy or a virtual self-help manual. Moreover, the self-help intervention and delivery format were chosen based on an in-depth literature review and discussion with clinical experts.

Besides easily accessible training materials, this project had a similar withdrawal rate to a previous study by Dimitropoulos and colleagues (2019). Four out of twenty-seven participants withdrew from the web-based intervention in that study. In comparison, one out of six participants withdrew from this project. All the remaining participating caregivers completed their preintervention and postintervention questionnaires in this project. Also, they all participated in the exit interviews and provided their feedback. The high retention rate could be related to the active involvement of the clinical psychologist in the recruitment process. Without the support or buy-in from the clinical staff, the project would not have progressed.

Not only were the clinical staff invested in the project, but the participants were also dedicated to covering the training materials within six weeks. Only one covered less than half of the training materials out of the five participants. Three out of five participants covered 80% or more. Although the participants covered various amounts of training material, all the participants expressed that the intervention was beneficial. Furthermore, their average scores on all the questionnaires were lower after the intervention.

## **Limitations**

This intervention was based on the Cognitive Interpersonal Maintenance Model (CIMM), designed to explain interpersonal and intrapersonal causing and maintaining factors of anorexia nervosa. Although the intervention was proven effective in other types of eating disorders (Dimitropoulos et al., 2019; Hibbs et al., 2015), most studies focused on caregivers of patients with anorexia nervosa and anorexic patients of adolescent age (Philipp et al., 2021). Therefore, more research is recommended to support the intervention's efficacy in different patient ages and types of eating disorders. Furthermore, this project limited the intervention to caregivers of patients from an outpatient setting due to the lack of studies targeting caregivers of hospitalized patients with eating disorders. Nevertheless, Hibbs and colleagues (2015) found that hospitalized patients with severe anorexia reported an increase in quality of life and reduction in hospital stay after their caregivers received the intervention. According to Hibbs and colleagues (2015), not only did the patients have positive clinical outcomes after the intervention, but the caregivers also reported a decrease in caregiving burden, expressed emotions, and time spent providing care. However, additional studies are needed to examine the benefits and drawbacks of providing the CIMM-based intervention to caregivers of patients in an inpatient setting.

Although the online training videos and hard copies of the self-help manual helped decrease the caregiving burden and illness maintaining behaviors, one of the participants thought the online training videos were somewhat challenging to access. On a scale of zero to ten, he rated a five for the level of difficulty in accessing online training videos. Out of all the participants, he was only able to complete 40% of the training materials within six weeks, while the rest of the participants completed at least 50% of the training materials. Completing less than half of the intervention could be related to technical difficulties or insufficient time to cover the

materials. Regardless, an orientation meeting to provide instructions and allow questions should be considered for future projects.

Furthermore, many participants expressed their desire to have a support group. However, the project could not provide a support group due to limited meeting space, available time, and clinical staff. The participants may consider hosting a support group in a community setting. They could seek approval from the EDWMC to advertise their support group. Dimitropoulos and colleagues (2019) found that the participants “appreciated the benefits associated with gaining a peer group, which persisted beyond the intervention” (p. 647). Having a support group would allow caregivers to connect with others and practice the skills learned from their intervention.

After several months of recruitment, the number of participants did not meet the initial goal. The recruitment ended on October 1, 2021, to allow sufficient time for data analysis and documentation. Initially, the project aimed to recruit caregivers from six separate patients. Eight caregivers from seven separate patients were approached. However, this project ended with five caregivers from four separate patients. In the future, investigators may consider creative advertising strategies such as social media and several scheduled meetings with the recruiter to improve the number of participating caregivers. In addition, future investigators may consider offering alternative content delivery formats, including online modules or workshops either in person or virtually. Having optional delivery formats and length of interventions may also increase the number of participants and their intervention engagement.

### **Application to the Advanced Practice Nurse Role**

Treating eating disorders requires specialized training and a multidisciplinary approach. Eating disorders affect patients in different ways. Not only do eating disorders affect patients’ physical and mental health, but also their relationships with others. Through the Cognitive

Interpersonal Maintenance Model, Treasure and colleagues (2013) explained how eating disorders affecting patients physically, mentally, and socially could further perpetuate their illnesses. Therefore, they developed an intervention to address these biopsychosocial concerns. Their holistic theoretical model and intervention are aligned with the nurse practitioners' practice model. According to the American Association of Nurse Practitioners (AANP, n.d.), the "nurse practitioner's practice model emphasizes patient-centered holistic care."

Nurse practitioners are trained and expected to care for their patients under the biopsychosocial model. According to the AANP (n.d.), nurse practitioners focus on the health and well-being of the whole person. Such a unique approach sets the nurse practitioners apart from other healthcare providers. A recent literature review states that the biopsychosocial model is instrumental in addressing chronic illnesses in primary care (Kusnanto et al., 2018). This project exemplifies how healthcare providers may holistically approach illnesses by involving and empowering caregivers. By disseminating this intervention to other healthcare providers, they will have the tools to support caregivers of people with eating disorders. In addition to psychology referrals and pharmacological interventions, healthcare providers may provide the caregivers with resources to support their loved ones who suffer from disordered eating. Furthermore, healthcare providers may decrease the caregiving burden and illness maintaining behaviors of the caregivers and improve patient outcomes by addressing the need of the caregivers (Hibbs et al., 2018).



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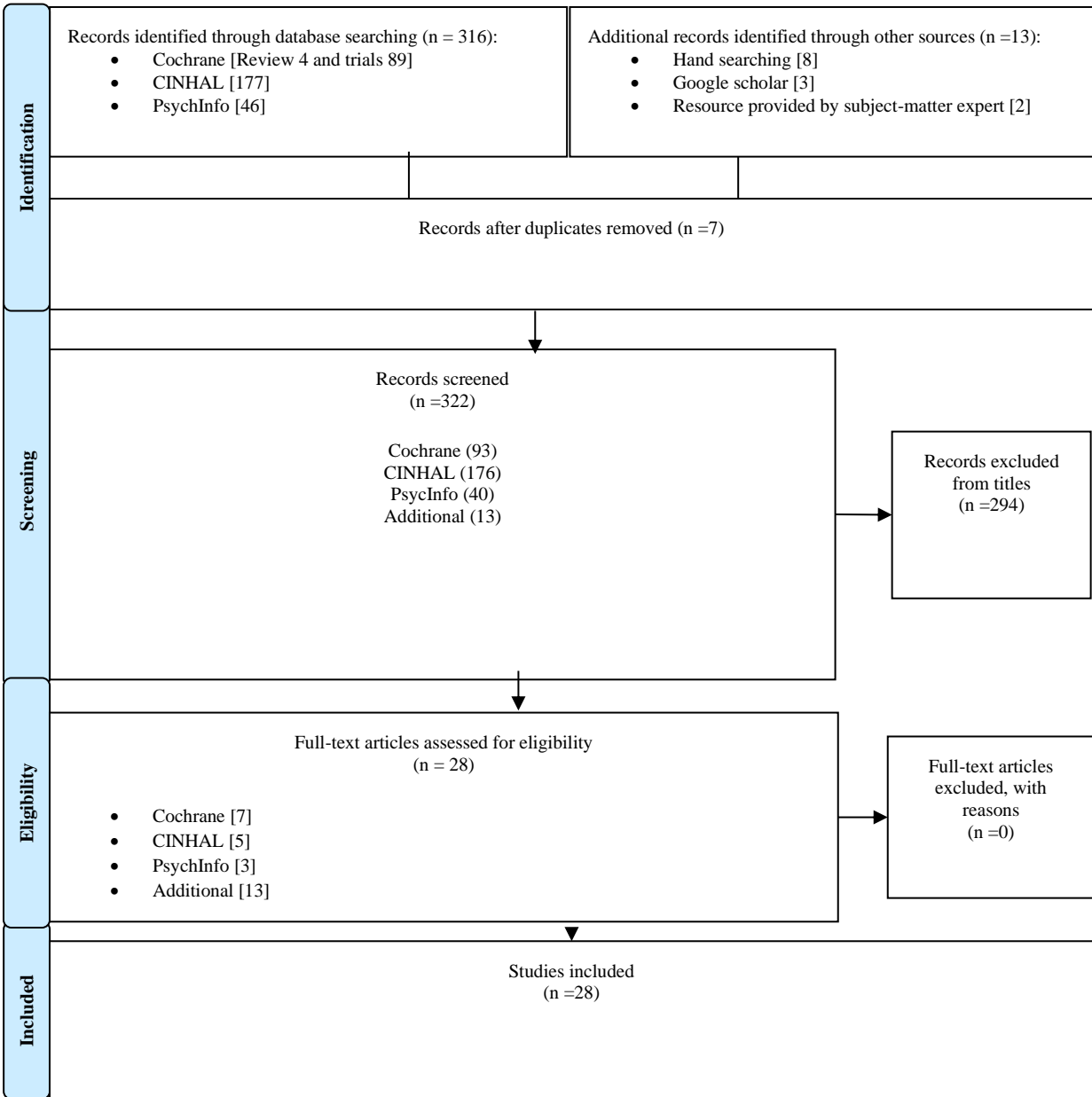
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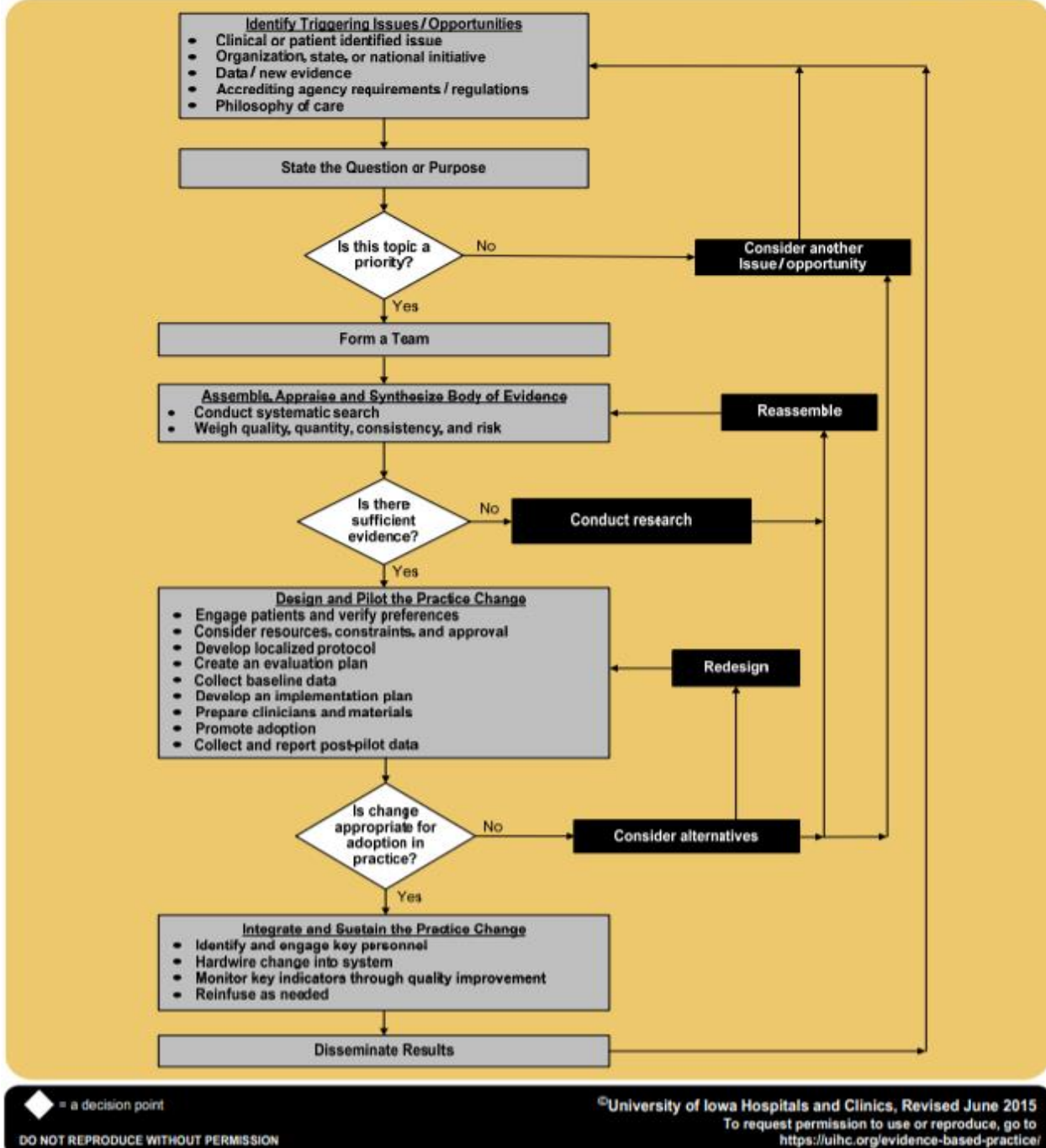
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## APPENDIX A. PRISMA FLOW DIAGRAM



## APPENDIX B. IOWA MODEL

# The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care



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**APPENDIX C. EVIDENCE-BASED PRACTICE PROJECT FOLLOWING THE IOWA**

**MODEL**

**Identify Triggering Issues/Opportunities:**

- Caregivers of people diagnosed with eating disorders demonstrate illness maintaining behaviors as a result of an increased level of caregiving burden (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013).
- Research revealed a decrease in illness maintaining behaviors and caregiving burden with the implementation of interventions based on the Cognitive Interpersonal Maintenance Model for caregivers of people diagnosed with an eating disorder (Hodsoll et al., 2017; McEvoy et al., 2019).

**State the Question or Purpose**

- The purpose of this evidence-based practice (EBP) improvement project was to support caregivers of patients diagnosed with anorexia nervosa (AN), bulimia nervosa (BN), and other specified feeding or eating disorder (OSFED) by delivering an empirically-supported intervention designed to decrease caregiving burden and illness maintaining behaviors.

Is this topic a priority?

**YES**

According to the director of outpatient ED clinic, she was able to list multiple caregivers of different patients that could benefit from this EBP improvement project (T. Meyer, personal communication, August 14, 2020). The directors expressed their desire to implement the interventions that could alleviate caregiving burden and mitigate illness maintaining behaviors.

**Form a Team.**

Name	Role
Dean Gross	Chair
Stephen Wonderlich	Committee Member
Lauren Schaefer	Committee Member
Heidi Saarinen	Committee Member
Kristi Steffen	Graduate Appointee

**Assembling and Analyzing Relevant Research**

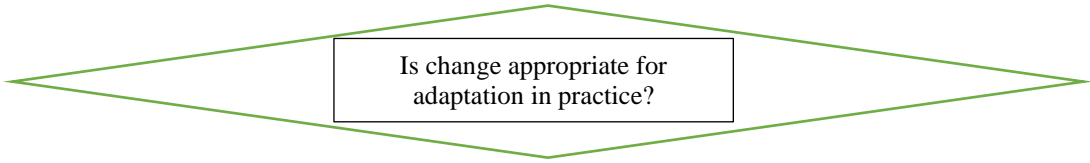
A literature review and synthesis were completed with the research indicating that there was an adequate base of information to continue with the next step of piloting the change in practice. empirical studies testing the ECHO intervention across various formats indicated that this approach was effective at decreasing caregiving burden and illness maintaining behaviors (Treasure, Schmidt, & Crane, 2017).

There is sufficient evidence.

**Design and Pilot the Practice Change**

- Project outcomes were determined, and baseline data was collected. After supervisory committee and EDWMC approval, the project was submitted to IRB. Upon IRB approval, the project was able to start. Implementation of the intervention was planned to start in September 2020 and would end when caregivers of 6 patients or more had completed their 6 weeks of intervention.

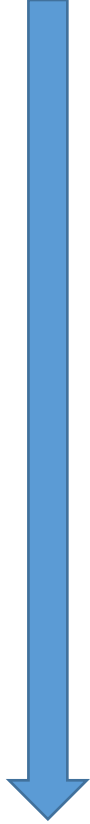




**YES**  
The results from this EBP improvement project revealed positive outcomes (i.e., decreased caregiving burden and illness maintaining behaviors) from the participating caregivers.

**Integrate and Sustain the Practice Change**  
Minimal resources are required to sustain the practice change. Training materials were provided to Sanford EDWMC, at no cost, to integrate and to sustain the practice change. Directors from both inpatient and outpatient units expressed their support in sustaining this practice change. Staff from EDWMC will receive handoff from the co-investigator.

**Dissemination**  
After caregivers of 4 patients had completed the self-help intervention, results collected from the project were disseminated at North Dakota State University and Sanford EDWMC through PowerPoints and poster board presentations.



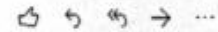
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## APPENDIX E. IRB APPROVAL (SANFORD HEALTH)



### NOT HUMAN RESEARCH

September 23, 2020

Dear Dean Gross:

The IRB reviewed the following submission:

Type of Review:	Initial Study via Non-Committee Review
Title of Study:	A self-help intervention for caregivers of people diagnosed with an eating disorder: A self-help intervention for caregivers of people diagnosed with an eating disorder
Investigator:	Dean Gross
IRB ID:	STUDY00002170
Special Determinations:	none

The IRB determined, on 9/23/2020, that the proposed activity is not human research. Sanford IRB review and approval is not required.

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are being considered and there are questions about whether IRB review is needed, please submit a study modification to the IRB for a determination. You can create a modification by clicking **Create Modification / CR** within the study.

For questions, please contact the IRB Office: [eIRB@sanfordhealth.org](mailto:eIRB@sanfordhealth.org).

## APPENDIX F. IRB APPROVAL (NDSU)



October 9, 2020

Dr. Dean Gross  
Nursing

Re: IRB Determination of Exempt Human Subjects Research:  
Protocol #PH21055, "A Self-Help Intervention for Caregivers of People Diagnosed with an Eating Disorder"

NDSU Co-investigator(s) and research team: Steven Condon

Date of Exempt Determination: 10/9/2020 Expiration Date: 10/7/2023

Study site(s): Sanford Eating Disorder and Weight Management Clinic Funding Agency: n/a

The above referenced human subjects research project has been determined exempt (category 1) in accordance with federal regulations (Code of Federal Regulations, Title 45, Part 46, Protection of Human Subjects). This determination is based on the revised protocol received and consent 10/7/2020.

Please also note the following:

- If you wish to continue the research after the expiration, submit a request for recertification several weeks prior to the expiration.
- The study must be conducted as described in the approved protocol. Changes to this protocol must be approved prior to initiating, unless the changes are necessary to eliminate an immediate hazard to subjects.
- Notify the IRB promptly of any adverse events, complaints, or unanticipated problems involving risks to subjects or others related to this project.
- Report any significant new findings that may affect the risks and benefits to the participants and the IRB.

Research records may be subject to a random or directed audit at any time to verify compliance with IRB standard operating procedures.

Thank you for your cooperation with NDSU IRB procedures. Best wishes for a successful study.  
Sincerely,

A handwritten signature in purple ink that reads "Kristy Shirley".

Kristy Shirley, CIP, Research Compliance Administrator

For more information regarding IRB Office submissions and guidelines, please consult [https://www.ndsu.edu/research/for\\_researchers/research\\_integrity\\_and\\_compliance/institutional\\_review\\_board\\_irb/](https://www.ndsu.edu/research/for_researchers/research_integrity_and_compliance/institutional_review_board_irb/). This Institution has an approved FederalWide Assurance with the Department of Health and Human Services: FWA00002439.

### INSTITUTIONAL REVIEW BOARD

NDSU Dept 4000 | PO Box 6050 | Fargo ND 58108-6050 | 701.231.8995 | Fax 701.231.8098 | [ndsu.edu/irb](https://www.ndsu.edu/irb)

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# APPENDIX G. PERMISSION FOR COGNITIVE INTERPERSONAL MAINTENANCE

## MODEL



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Help



Email Support

### The cognitive-interpersonal maintenance model of anorexia nervosa revisited: a summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors

**Author:** Janet Treasure et al

**SPRINGER NATURE**

**Publication:** Journal of Eating Disorders

**Publisher:** Springer Nature

**Date:** Apr 15, 2013

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**APPENDIX H. MAINTAINING FACTORS TARGETED BY THE INTERVENTION**

Maintaining factors	Skills Intervention
Anxiety, depression	Pleasant activity scheduling, social support. Emotion-focused therapy, compassion-focused therapy, self-care, self-nurturing
Guilt and shame	Education about illness Contact with other carers, self-reflection regarding getting support for self, medication, counseling
Rigidity, compulsivity, preoccupation with detail, eating	Education and feedback. Remediation to ameliorate extreme traits
Misconception and misunderstanding of eating disorder	Education about illness
Enabling and accommodating to the illness	Functional analysis. Training in communication and problem-solving
Expressed emotion (criticism, hostility, and overprotection)	Education about ‘transference’ issues. Education about expressed emotion animal models
Unhelpful communication	Motivational interviewing

*Note.* From Rhind et al., 2014

**APPENDIX I. ELIGIBILITY SCREENING QUESTIONS FOR PROJECT  
PARTICIPATION**

You are a caregiver who is currently living with or directly involved in the care of a patient diagnosed with an eating disorder	Yes	No
You are at least 18 years of age	Yes	No
You speak English	Yes	No
You are able to view online streaming videos	Yes	No
You are able to participate in a video conference call for an exit interview	Yes	No
The patient is receiving treatment from Sanford Eating Disorder and Weight Management Center	Yes	No

*Note.* For the purpose of this project, any No selected in this questionnaire will result in an exclusion from this project.

## APPENDIX J. INFORMED CONSENT

### A Self-Help Intervention for Caregivers of People Diagnosed with an Eating Disorder Informed Consent

Dear Caregivers,

I would like your help in an evidence-based practice (EBP) improvement project for caregivers of people diagnosed with an eating disorder.

#### **Introduction:**

My name is Steven Condon; I have been working as a registered nurse for 3 years and am currently in a doctoral program at NDSU. As part of my doctoral degree requirements, I need to complete a project that improves healthcare for patients and families. During my years of practice, I have noticed that caregivers of patients diagnosed with an eating disorder (E.D.) often feel overwhelmed by the many challenges of caring for a loved one with an E.D. Unfortunately, the needs of the caregivers are often neglected. Therefore, this project seeks to provide support to these caregivers.

#### **Purpose of the project:**

The current project seeks to provide resources to caregivers of individuals with E.D.s, which have been shown to improve caregivers' sense of self-efficacy and interaction with their loved ones and patient outcomes.

#### **Procedures:**

If you decide to participate in this EBP improvement project, you will receive the training materials (i.e., the *New Maudsley Method* self-help manual and streaming access to the video content from Dr. Treasure's DVDs) at no cost. You will receive a weekly reminder via email to cover these training materials, even though this is a self-paced intervention, over 6 weeks. Regardless, baseline questionnaires and surveys will be required of you via Qualtrics before receiving the training materials. At the end of 6 weeks, after receiving the training materials, you will complete an exit interview via a secured video conference call with the co-investigator (S.C.; myself) and post-intervention questionnaires via Qualtrics.

The maximum amount of time expected for this project: 6 – 7 hours.

- Total length of the videos/audios: 2 hours and 55 minutes
- Total time to complete questionnaires (before and after 6 weeks): 30 minutes.
- Total time for exit interview: 30 minutes
- Total time to read the self-help manual (276 pages): Estimated 2 - 3 hours.

#### **Benefits:**

This intervention was shown in previous research to improve caregivers' sense of self-efficacy, interaction with their loved ones, and patient outcomes.

### Risks:

The risk of participation in the project is thought to be limited. You may find some of the questions from the clinical interviews, questionnaires, or surveys upsetting. Additionally, you may experience some distress while reviewing the interventional material provided in this project. You are free not to answer any questions, and you can choose to discontinue your participation at any time.

Other possible risks include the remote possibility that private information would be released outside the research setting. However, strong measures are taken to ensure confidentiality. (See CONFIDENTIALITY below).

### Confidentiality:

All questionnaires and verbal responses will be kept confidential. The questionnaires and verbal responses are anonymous and contain no personal identifying information. The questionnaires should take less than 15 minutes to complete. Additionally, the exit interview should take less than 30 minutes to complete. Participant responses will educate healthcare professionals on the efficacy of caregiver-oriented intervention for caregivers of people diagnosed with an eating disorder. In addition, the de-identified questionnaire results and verbal responses may be used in a future publication in a healthcare journal.

All your contact information will be stored on the co-investigator's personal strong password-protected laptop. In addition, all contact information will be assigned to a pseudonym (i.e., participant A, B, C...) that cannot be linked to your name or other personal identifiers except by the co-investigator. While we cannot guarantee absolute confidentiality, we will use all available security measures to minimize the risk of giving this information to someone outside the project. In any report about this project that might be published, you will not be identified.

### **Training materials for the project:**

Training materials include a hard copy of the *New Maudsley Method* Self-help Manual and streaming access to the video content from Dr. Treasure's DVDs. These training materials will be provided to you at no cost once you have finished the baseline questionnaires and surveys.

### **Explanation of the Consent:**

- You understand that you must respond to the baseline questionnaires and surveys to participate in this EBP improvement project.
- You understand that your consent is completely voluntary and can be withdrawn at any time.
- You may withdraw your consent at any time, either verbally or in writing.
- You understand that patient care at the EDWMC is not affected by your decision whether to participate in the EBP improvement project or not.
- You understand that any information gathered before, during, and after the intervention will be confidential.

- You understand that the project facilitators will use electronic means (including but not limited to email, Qualtrics, Polycom/Webex, etc.) to communicate and gather information for research purposes.

**Permission to use Non-Identifying Information for Research:**

- You understand that information collected will be used for research purposes.
- You understand that any information will be presented as means, ranges, or other forms that make it impossible to identify the participating caregivers.
- You understand that the collected information will be used to improve future projects and healthcare practices.

**Consent for Research:**

- Your consent is given freely and without coercion.
- You have been able to discuss any questions or concerns about this informed consent with the co-investigator (S.C.) for this EBP improvement project. This person answered any and all questions you may have had.
- You understand that you may contact the co-investigator (S.C.) via email (steven.l.condon@ndsu.edu) or the principal investigator (D.G) via email (dean.gross@ndsu.edu). You may also call 701-231-8355 at any time to withdraw this consent or ask any questions you may have about the project or consent. You understand that you may withdraw consent at any time without penalty. You may withdraw consent either verbally or in writing.
- You understand that in order to receive the training materials, you need to consent to the conditions in this form. If you do not agree to this form, you will not be eligible for the project.
- You grant the research team the consent to communicate with you via your personal email address/cellular devices.
- You have rights as a research participant. If you have questions about your rights or complaints about this research, you may talk to the researcher or contact the NDSU Human Research Protection Program at 701.231.8995, toll-free at 1-855-800-6717, by email at ndsu.irb@ndsu.edu, or by mail at: NDSU HRPP Office, NDSU Dept. 4000, P.O. Box 6050, Fargo, ND 58108-6050.

**Verbal Consent:**

The co-investigator (S.C.) has provided you with the information letter and invitation to participate in this evidence-based practice project. You understand the terms and conditions mentioned above. You hereby provide your verbal consent to the co-investigator (S.C.) to participate in this EBP improvement project. Furthermore, completing the questionnaires and surveys will also constitute your consent to participate in this evidence-based practice project.

## APPENDIX K. BURDEN ASSESSMENT SCALE

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## BURDEN ASSESSMENT SCALE

The following is a list of things that other people have found to happen to them because of their loved one's illness. Please rate to what extent you have had any of the following experiences in the past six months.

Because of your loved one's illness, to what extent have you:      Not at all    A little    Some    A lot

1. Had financial problems	1	2	3	4
2. Missed days at work (or school)	1	2	3	4
3. Found it difficult to concentrate on your own activities	1	2	3	4
4. Had to change your personal plans like taking a new job, or going on vacation	1	2	3	4
5. Cut down on leisure time	1	2	3	4
6. Found the household routine was upset	1	2	3	4
7. Had less time to spend with friends	1	2	3	4
8. Neglected other family members' needs	1	2	3	4
9. Experienced family frictions and arguments	1	2	3	4
10. Experienced friction with neighbors, friends, or relatives outside the home	1	2	3	4
11. Become embarrassed because of your loved one's behavior	1	2	3	4
12. Felt guilty because you were not doing enough to help	1	2	3	4
13. Felt guilty because you felt responsible for causing your loved one's problem	1	2	3	4
14. Resented your loved one because she/he made too many demands on you	1	2	3	4
15. Felt trapped by your caring role	1	2	3	4
16. Were upset about how much your loved one had changed from his or her former self	1	2	3	4
17. Worried about how your behavior with your loved one might make the illness worse	1	2	3	4
18. Worried about what the future holds for your loved one	1	2	3	4
19. Found the stigma of the illness upsetting	1	2	3	4

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# APPENDIX L. ACCOMMODATION AND ENABLING SCALE FOR EATING DISORDERS

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?  
Help

✉  
Email Support

## Development and validation of the Accommodation and Enabling Scale for Eating Disorders (AESED) for caregivers in eating disorders

**SPRINGER NATURE**

**Author:** Ana R Sepulveda et al

**Publication:** BMC Health Services Research

**Publisher:** Springer Nature

**Date:** Sep 23, 2009

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Accommodation and Enabling Scale for Eating Disorders

The following items contain a number of statements that commonly apply to the family members or loved ones who live with a relative or friend with an eating disorder. Please read each one and decide how often it has applied to your family members or loved ones over the **past one month**. It is important to note that there are no right or wrong answers. Your first reaction will usually provide the best answer. Please use the following scale to describe how often each item occurs.

- 0 = never over the past month
- 1 = rarely over the past month
- 2 = sometimes over the past month
- 3 = often over the past month
- 4 = every day over the past month

---

<b>A. Does your loved one with an eating disorder control:</b>	PLEASE CIRCLE				
<hr/>					
1. The choices of food that you buy?	0	1	2	3	4
2. What other family members or others do, and for how long, in the kitchen?	0	1	2	3	4
3. Cooking practices and ingredients you use?	0	1	2	3	4
4. What other family members and others eat?	0	1	2	3	4
<hr/>					
<b>B. Does your loved one engage others in repeated conversations:</b>					
<hr/>					
5. Asking for reassurance about whether she/he will get fat?	0	1	2	3	4
6. About whether it is safe or acceptable to eat certain food?	0	1	2	3	4
7. Asking for reassurance about whether she/he looks fat in certain clothes?	0	1	2	3	4
8. About ingredients and amounts and possible substitutes for ingredients?	0	1	2	3	4
9. About negative thoughts and feelings?	0	1	2	3	4
10. About self-harm?	0	1	2	3	4
<hr/>					
<b>C. Does anyone have to change his/her behavior in any of the following ways to accommodate the requests of your loved one who has an eating disorder?</b>					
<hr/>					
11. What dishes are used?	0	1	2	3	4
12. How are dishes cleaned?	0	1	2	3	4

13.	What time is food eaten?	0	1	2	3	4
14.	Where is food eaten?	0	1	2	3	4
15.	How is the kitchen cleaned?	0	1	2	3	4
16.	How is food stored?	0	1	2	3	4
17.	How is the house cleaned and tidied?	0	1	2	3	4
18.	Adjust their schedule to accommodate the exercise routine of the loved one with an eating disorder?	0	1	2	3	4
19.	Accommodate your loved one's checking his/her body shape or weight?	0	1	2	3	4

---

**D. Do you choose to ignore aspects of your loved one's eating disorder that impinge on your, or someone else's, life in an effort to reconcile or make it tolerable for others, such as if**

20.	Food disappears?	0	1	2	3	4
21.	Money is taken?	0	1	2	3	4
22.	The kitchen is left a mess?	0	1	2	3	4
23.	The bathroom is left a mess?	0	1	2	3	4

---

**E.**

24. In general, to what extent would you say that the loved one with an eating disorder controls others' lives and activities?

Not at All			About Half of the Time					Completely		
0	1	2	3	4	5	6	7	8	9	10

---

**F.** On the 0 – 4 scale below, please choose a score that best describes how often an item applies to you over the past month.

- 0 = never over the past month
- 1 = 1-3 times over the past month
- 2 = 1-2 times every week over the past month
- 3 = 3-6 times every week over the past month
- 4 = daily over the past month

25.	How often did you participate in behaviors related to your loved one's compulsions (e.g., repeatedly telling your	0	1	2	3	4
-----	---	---	---	---	---	---

loved one that he/she is thin enough; preparing lower calorie meals to avoid confrontation or distress)?

- |     |   |   |   |   |   |   |
|-----|---|---|---|---|---|---|
| 26. | How often did you assist your loved one in avoiding things that might make her/him more anxious?                  | 0 | 1 | 2 | 3 | 4 |
| 27. | How often have you avoided doing things, going places, or being with people because of your loved one's disorder? | 0 | 1 | 2 | 3 | 4 |
| 28. | How often have you modified your and others' routine because of your loved one's symptoms?                        | 0 | 1 | 2 | 3 | 4 |
| 29. | How often have you modified your work schedule because of your loved one's needs?                                 | 0 | 1 | 2 | 3 | 4 |
| 30. | How often have you modified your leisure activities because of your loved one's needs?                            | 0 | 1 | 2 | 3 | 4 |
| 31. | How often has helping your loved one, in the ways described above, caused you distress?                           | 0 | 1 | 2 | 3 | 4 |
| 32. | How often has your loved one become distressed/anxious when you have not provided assistance?                     | 0 | 1 | 2 | 3 | 4 |
| 33. | How often has your loved one become angry/abusive when you have not provided assistance?                          | 0 | 1 | 2 | 3 | 4 |
-

## APPENDIX M. FAMILY QUESTIONNAIRE

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## FAMILY QUESTIONNAIRES

This questionnaire lists different ways in which people try to cope with everyday problems. For each item, please indicate how often you have reacted to your loved one with an eating disorder in this way. There are no right or wrong responses. It is best to note the first response that comes to mind. Please respond to each question, and mark only one response per question.

	Never/very rarely	Rarely	Often	Very often
1. I tend to neglect myself because of him/her	1	2	3	4
2. I have to keep asking him/her to do things	1	2	3	4
3. I think about what is to become of him/her	1	2	3	4
4. He/she irritates me	1	2	3	4
5. I think about the reasons for his/her illness	1	2	3	4
6. I have to try not to criticize him/her	1	2	3	4
7. I cannot sleep because of him/her	1	2	3	4
8. It is hard for us to agree on things	1	2	3	4
9. When something about him/her bothers me, I keep it to myself	1	2	3	4
10. I think he/she does not appreciate what I do for him/her	1	2	3	4
11. I regard my own needs as less important	1	2	3	4
12. I think he/she gets on my nerves	1	2	3	4
13. I am very worried about him/her	1	2	3	4
14. I think he/she does some things out of spite	1	2	3	4
15. I think about becoming sick myself	1	2	3	4
16. When he/she constantly wants something from me, it annoys me	1	2	3	4
17. I think he/she is an important part of my life	1	2	3	4
18. I have to insist that he/she behaves differently	1	2	3	4
19. I give up important things in order to be able to help him/her	1	2	3	4
20. I am angry with him/her	1	2	3	4

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A Likert-type Scale to Evaluate the Acceptability of the Intervention (EAI)

1. What proportion of the materials did you watch/read?  
(0 = NONE to 10 = ALL)

0      1      2      3      4      5      6      7      8      9      10

2. How helpful did you find this information?  
(0 = NOT AT ALL HELPFUL to 10 = EXTREMELY HELPFUL)

0      1      2      3      4      5      6      7      8      9      10

3. How difficult was it to access the online training information?  
(0 = NOT AT ALL DIFFICULT to 10 = EXTREMELY DIFFICULT)

0      1      2      3      4      5      6      7      8      9      10

4. Was the intervention helpful for stress management and self-care?  
(0 = NOT AT ALL HELPFUL to 10 = EXTREMELY HELPFUL)

0      1      2      3      4      5      6      7      8      9      10

5. How helpful was this intervention in improving communication with your loved one?  
(0 = NOT AT ALL HELPFUL to 10 = EXTREMELY HELPFUL)

0      1      2      3      4      5      6      7      8      9      10

6. To what extent did the intervention materials meet your expectation?  
(0 = WORSE THAN EXPECTED, 5 = SAME AS EXPECTED, 10 = BETTER THAN EXPECTED)

0      1      2      3      4      5      6      7      8      9      10

Note. From Goddard, Macdonald, Sepulveda, et al., 2011



## **APPENDIX O. INTERVIEW QUESTIONS**

1. What did you find helpful from this intervention?
2. What did you find challenging or difficult about the intervention?
3. If you could change something about the intervention, what would it be? Why?
4. Was six weeks enough time to cover the training materials?
5. How easy was it to apply the information learned in the training materials to real-life scenarios?

**APPENDIX P. TIMELINE AND STATISTICS FOR THE PROJECT ASSESSMENTS**

Weeks/ Interventions	Week I	Week II	Week III	Week IV	Week V	Week VI
AESED	X					X
BAS	X					X
FQ	X					X
EAI						X
Caregiver Interview						X

*Note.* AESED = Accommodating and Enabling Scale for Eating Disorders; BAS = Burden Assessment Scale; FQ = The Family Questionnaire; EAI: A Likert-type Scale to Evaluate the Acceptability of the Intervention.

The questionnaires (AESED, BAS, FQ) will be administered before the self-help ECHO intervention at the beginning of week I. They will be administered again at the end of week VI after the self-help ECHO intervention.

Interviews will be conducted at the end of week VI after the self-help ECHO intervention.

Time	Pre-intervention		Post-intervention	
	Mean	Range	Mean	Range
AESED	54.4	31 – 82	43.2	11 – 86
BAS	52.8	36 – 64	44.8	29 – 61
FQ	52.6	47 – 57	49.6	42 – 60
EAI Item 1			6.8	4 – 9
EAI Item 2			8.2	6 – 10
EAI Item 3			2	0 – 5
EAI Item 4			7.4	5 – 10
EAI Item 5			8	6 – 10
EAI Item 6			8.4	8 – 9

*Note.* AESED = Accommodating and Enabling Scale for Eating Disorders; BAS = Burden Assessment Scale; FQ = The Family Questionnaire; EAI: A Likert-type Scale to Evaluate the Acceptability of the Intervention.

**APPENDIX Q. ESTIMATED COST OF IMPLEMENTATION**

Educational Materials	Book/DVD		Total: \$279.2 USD
	The New Maudsley Method Manual	\$33 per book x 8 \$9 per shipment fee x 4	
	Streaming access to online DVD content	\$6.1 per DVD x 2	

*Note.* The cost of the New Maudsley Manual was obtained from Walmart.

The cost of the DVD is 5 pounds (Google was utilized to convert pounds to U.S. dollars) and was obtained from the following website:

<http://thenewmaudsleyapproach.co.uk/wp-content/uploads/2020/01/SUCCEED-DVD.pdf>

# EXECUTIVE SUMMARY

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## A Self-Help Intervention For Caregivers of People Diagnosed with an Eating Disorder

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### Introduction

Eating disorders profoundly affect caregivers and sufferers. However, the needs of the caregivers are often neglected. Caregivers may demonstrate maladaptive behaviors in response to high levels of caregiving burden. Those maladaptive behaviors such as emotional overinvolvement, criticism, avoidance, and accommodation may perpetuate disordered eating. Treasure and colleagues developed an empirically supported self-help intervention designed to decrease caregiving burden and illness maintaining behaviors. This project implemented the evidence-based self-help intervention to support caregivers of patients with eating disorders at Sanford eating disorder and weight management center (EDWMC).

### Purpose

The purpose of this evidence-based practice improvement project was to support caregivers of patients with eating disorders by delivering an empirically-supported intervention designed to decrease caregiving burden and illness maintaining behaviors.

### Project Design

This project adopted a rolling admission to recruit caregivers from EDWMC. The caregivers would complete the intervention (i.e., self-help manual, online training video) at their own pace over six weeks. In addition to completing validated questionnaires at baseline and post-intervention, caregivers would also virtually participate in an exit interview for evaluation.

### Results and Conclusion

- Caregivers reported having decreased caregiving burden and illness maintaining behaviors, as shown in the decreased average scores of the validated questionnaires.
- Caregivers provided positive feedback regarding the intervention and desired to have a support group in the future for emotional support and skill practice.

### Recommendations

- Continue implementing the self-help intervention at EDWMC.
- Provide an orientation meeting for the intervention.
- Consider a peer-led support group in the future.