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LOYOLA UNIVERSITY CHICAGO

EATING DISORDERS AND HEALTH RELATED QUALITY OF LIFE:
WHAT RESIDENTIAL TREATMENT CAN DO

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

PROGRAM IN SOCIAL WORK

BY

ROBYN M. WELK-RICHARDS

CHICAGO, ILLINOIS

DECEMBER 2012

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The driving force behind my desire to be a “doctor” is rooted in my honored friendship with my grandfather, Maynard E. Welk. I vividly remember having dinner at the Village Inn with my Grandfather on a Monday evening during my undergraduate work at the University of Iowa. This was a weekly tradition that my grandfather and I had through my years at the University. He couldn’t drive and I had no money, so every Monday evening I would pick him up for dinner and he would buy. These memories are etched in my mind.

So, one particular Monday evening I was telling my grandfather all about one of my *riveting* required general education classes. In the middle of my long-winded narrative my grandfather reached across the table, grabbed both of my hands in his and said, “Robby, I have no idea what you just said, but you’re real smart, and your gonna’ be a doctor someday, I just know it!” I hold onto that memory tightly- close to my heart, and I know that today my grandfather is watching over me and saying, “See Robby, I told you that you could do it.” Grandpa, thank you for being the spark that ignited my passion for academia and my drive to be a Doctor. Rest in Peace.

Above all else, I want to thank and acknowledge my husband, Daniel Wayne Richards. I LOVE YOU! Dan has never known me to NOT be a student. From the summer of 2006, when we began dating until the defense date of this manuscript, I have been enthralled in the world of academia. His patience, guidance, and genuine faith in

my passion for learning and my Overdrive Mind have been my Northern Star through this entire process. I can honestly say that without Dan's steady comfort and belief, I would not have made it through this process. Thank you for loving me, and all of my quirky nuances; you balance me, which is something that I never had before I had you. I love you so much more, Dan!

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To Annabelle Grace and Danny
I love you more.

Life isn't about finding yourself. Life is about CREATING yourself.

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LIST OF ABBREVIATIONS

| | |
|-----------|---|
| EDQLS | Eating Disorder Quality of Life Scale |
| HRQOL | Health-Related Quality of Life |
| BDI-II | Beck Depression Inventory, 2 nd edition |
| EDI-3 | Eating Disorder Inventory, 3 rd edition |
| AN | Anorexia Nervosa |
| BN | Bulimia Nervosa |
| EDNOS | Eating Disorder, Not Otherwise Specified |
| DSM-IV-TR | Diagnostic and Statistical Manual of Mental Disorders, fourth edition |
| LOS | Length of Stay |
| ADC | Average Daily Census |
| MCO | Managed Care Organization |
| CBT | Cognitive Behavioral Therapy |
| IPT | Interpersonal Therapy |
| DBT | Dialectical Behavior Therapy |

ABSTRACT

Objective: This study was designed to investigate the Health-Related Quality of Life (HRQOL) in individuals being treated for eating disorder at the residential level of care. The objective of this study was to inform collectively the multiple paradigms that have power in the treatment decisions for individual's seeking clinical care for an eating disorder, i.e. clinicians, payers, policy-makers, friends and family, and the afflicted person. Residential treatment is often overlooked or dismissed as a primary level of care, due to a lack of insurance and other third-party payment. The intension of this research study is to build support for a 360-degree assessment including physical, behavioral, mental, emotional, and existential transformation with this population.

Method: Data collection began in August 2011 and concluded August 2012. There were three unique test-times, (1) admission, (2) discharge, and (3) three-month post-discharge follow-up. The researcher analyzed the change in HRQOL between these three test times as well as correlational relationships between the change in HRQOL and change in depressive and eating disorder symptomatology, utilizing the Beck Depression Inventory, second edition and the Eating Disorder Inventory, third edition. Finally, the research investigated the relationship between duration of illness and HRQOL.

Results: Preliminary data support the researcher's hypotheses that residential treatment is an effective model for treating individuals with severe eating disorders as evidenced by HRQOL at discharge and three month follow-up. Furthermore, there were

negative correlational relationships between the change in HRQOL and change in symptoms from admission to discharge, ultimately supporting the researcher's hypothesis that during the course of residential treatment subjects' HRQOL improves and symptoms decrease. Contrary to the researcher's hypothesis, duration of illness did not have any relationship with the subjects' change in quality of life from admission to discharge.

Discussion: This research study reaped important results specific to health-related quality of life and residential treatment for individuals afflicted with severe eating disorders. A 360-degree approach is warranted in assessment and evaluation of treatment and discharge readiness. This study, though preliminary, provides significant data that can be used to inform multidisciplinary clinicians, policy-makers, third-party payers, and friends and family seeking counsel.

CHAPTER ONE

INTRODUCTION TO THE PROBLEM

What lies within these pages is complicated. Mental health treatment, remarkably treatment for Anorexia Nervosa (AN), Bulimia Nervosa (BN), and Eating Disorders, Not Otherwise Specified (EDNOS) is compromised due to limited financial resources, comprehensive outcomes data, and specialized facilities expert in the area of treating eating disorders. Riddled with co-morbidity, ego-syntonicity, and significant physical, emotional, and cognitive compromise, eating disorders are recognized as one of the most challenging mental illnesses to treat. There is a dynamic breakdown in collaboration between treatment facilities and third party paying sources, resulting in a high probability of recidivism and chronicity. The stigma that surrounds the financial burdens of these behavioral health anomalies will be investigated as an overarching problematic framework identified herein to further highlight the importance of collaboration between multiple societal constructs holding power over patients' destiny and outcome.

The ego-syntonic nature of anorexia nervosa (AN) has dismayed professionals for centuries, even prior to assignment of diagnostic labels that now flavor the medical and psychiatry field. According to Golden, Katzman, Kreipe, Stevens, Sawyer, Rees, Nicholls and Rome (2003), due to the complexity in biopsychosocial issues that eating disorders possess, ideally an interdisciplinary team of medical, nutritional, mental health and nursing professionals will be in place for the extended treatment. Although

emaciation and significant weight loss is typically a hallmark warning signal of Anorexia Nervosa, Golden and colleagues (2003) reiterate that physiological evidence of medical compromise can be found even in the absence of significant weight loss, particularly in adolescents. This reality highlights the importance of early diagnosis and treatment by a multidisciplinary team of experts in the field. Adolescents with eating disorders may be losing critical tissue components including muscle mass, body fat, and bone minerals due to the impact that the disease has on growth and development. These physical complications ultimately are reversing the natural course of development during a phase when such elements of loss should rather be multiplying. Furthermore, the implication of an eating disorder on social and interpersonal development is devastating. “Social isolation and family conflict arise at a time when families and peers are needed to support development” (Golden et al, 2003, pp. 497-498). Self-esteem, a sense of self-concept, capacity for intimacy, and autonomy are all retarded in the throes of an eating disorder.

“Anorexia nervosa affects .5%-1% of young adult women and... due to medical causes and suicide, the mortality rate for this illness is among the highest of any psychiatric illness” (Crow and Nyman, 2004, pp. 155-156). Golden and colleagues (2003) further expand on these statistics: “Eating disorders rank the third most common chronic illness in adolescent females, with an incidence of up to 5%” (p. 496). Frisch, Herzog and Franko (2006) state that, “the incidence rates of anorexia are highest among females 15-19 years and rates of bulimia are highest among females 20-24 years” (p. 440). Ultimately, the more progressive and severe an eating disorder, the poorer a

persons' health related quality of life (HRQOL) becomes and the more complex the treatment intervention need be. Golden and colleagues (2003) state that:

Optimal duration of hospitalization has not been established, although there are studies that have shown a decreased risk of relapse in patients who are discharged closer to their ideal body weight (IBW) compared to patients discharged at a low body weight. The overall goals of treatment are the same in a medical or psychiatric inpatient unit, a day program, or outpatient setting: to help the adolescent achieve and maintain both physical and psychological health. (p. 498)

Anorexia nervosa is considered one of the most challenging mental illnesses to treat due to its complexity and severity in medical as well as mental complications (Vitousek and Gray, 2005). There is no proven evidence-based practice model for treatment of eating disorders; current research continues to grow. The American Psychiatric Association (2006) currently supports Cognitive Behavioral Therapies (CBT) and Interpersonal Therapies (IPT) as premier therapy interventions (American Psychiatric Association, 2006); and creativity, flexibility, eclecticism and longitudinal intervention are all necessary when embarking upon a therapeutic journey with an individual battling an eating disorder.

Physical stability and proper nutrition are significant parts of treating eating disorders, and it is imperative to move beyond the physical stabilization and maladaptive behaviors. The process of psychotherapy must lead the afflicted individual to self-awareness of the burden they are carrying and an acceptance to change. Traditionally, treatments were based on change in behaviors and symptoms (Adair, et al, 2007) resulting in treatment frequently terminating prematurely. Furthermore, outcome data also has been focused on maladaptive behavior and symptom reduction, which has

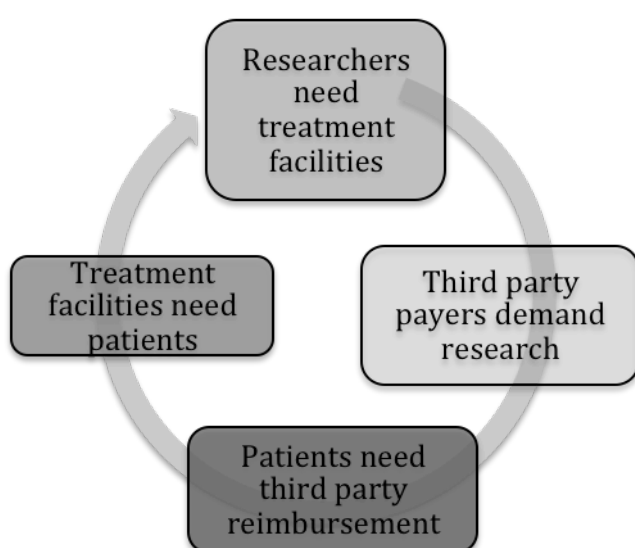
proven to limit researchers' scope of evaluation. Rather, Adair and colleagues (2007) suggest that treatment outcome measurement must additionally include, "broader areas such as role functioning or quality of life" (p. 2). Without repairing the deficits highlighted in health-related quality of life literature treatment outcomes are often diminished (Engle et al, 2009; Adair et al, 2007); thus the symptomatology and existential demise of an eating disorder continues to burden such individuals.

There is a limited but keen body of research that highlights the standard tiered-levels of care for treatment of eating disorders; including from most intensive to least intensive- inpatient, residential, partial hospital programming (or day treatment), intensive outpatient, and outpatient (defined in section 1.2). The vast majority of research data focuses on treatment outcomes rooted in cognitive and behavioral symptom reduction, weight restoration, and medical stabilization. There has been some use of generic health-related quality of life scales (i.e. the Nottingham Health Profile and Short Form-36), however due to the generic nature they do not account for specific hallmark characteristics of an eating disorder, i.e. ego syntonicity in anorexia nervosa (Engle et al, 2009; Engle et al, 2006; Adair et al, 2007, Abraham et al, 2006; Vitousek et al, 2005).

Through discussion of the proposed problem the researcher will present a quandary: among the paradigmatic constructs of mental health care providers and treatment centers, researchers, third party payers, and patients and their families there are discrepancies within recovery goals, foci, and values. The push-pull relationship between these societal constructs demands that collaboration and a common working vocabulary are established in order for one another to survive. Cooperation and further outcome

research is needed to replace discrepancies between these interconnected paradigms with a concerted initiative in the best interest of the patients. The creation of a successful and evidence-based practice model for the treatment of eating disorders requires a collaborative, two-way relationship between all parties. Health insurance and managed care companies need evidence of unique treatment options' worth. These companies and organizations need data to support their potential investment. Not only in the short-term but also longitudinally. This worth can and should be measured by concrete and objective data, symptom-reduction results, and outcomes of perceived improvement of total quality of life, short-term and long-term.

Figure 1. The Collaborative Paradigmatic Relationship



Focusing on “medical necessity” fails to grasp an individual’s ability to enjoy and appreciate life, which is suggested to be a significant indicator of treatment-gain maintenance (Engle, 2009). Pragmatically, if an individual solely restores physical and

medical stability however continues to be distracted by misery, it can be presumed that a willingness to embrace and maintain one's journey of recovery will be diminished.

Disease-specific quality of life scales can be used as a self-report indicator of necessary intensity of treatment, readiness for change, and preparedness for step-down treatment interventions. According to Engle and colleagues (2009) it is hypothesized that health related quality of life information may, at some point, "be required by third party payers as a means of demonstrating that the treatments organizations provide are effective" (pg. 182). This being stated, it is imperative that eating disorder-specific treatment centers begin to consistently utilize these effective tools in order to craft individualized therapeutic care for their patients, as well as also provide third-party payers with this valuable data.

Treatment facilities such as Rogers Memorial Hospital need the opportunity to provide uninterrupted expert-level care by a highly skilled multidisciplinary team, during which they can focus on medical stability, symptom reduction and personal and emotional growth and development. This opportunity needs to be funded, which is a role and responsibility of third-party paying sources. When such facilities have the flexibility to treat the mentally, physically, and interpersonally debilitating characteristics of Anorexia Nervosa (AN), Bulimia Nervosa (BN), and Eating Disorders, not otherwise specified (EDNOS) without interruption, it is the researcher's hypothesis and personal clinical experience that we, as a society, will see a higher rate of recovery and significantly improved health related quality of life, longitudinally.

Within the past decade, there has been an increased awareness and interest in the health-related quality of life of individuals who are afflicted by eating disorders and those who are in recovery. This body of literature is small and growing and will potentially be utilized to inform third-party paying sources of the worth of residential treatment centers. This proposed research project is intended to evaluate individuals' health-related quality of life and examine the impact that an eating disorder-specific residential treatment facility can have on this factor. The goal is to provide worthwhile and useful data to the public at large and to inform third party payers, researchers in the field, treatment centers, and multidisciplinary team members of the importance of residential care within a transtheoretical system of treatment intensity.

Definitions

Diagnostic Categories

There are three primary eating disorder diagnoses defined in the Diagnostic Statistical Manual of Mental Illness, Fourth Edition, text revised (DSM-IV): Anorexia Nervosa- Restrictive subtype and Binge-Purge subtype (AN-R and AN- BP), Bulimia Nervosa (BN), and Eating Disorder, Not Otherwise Specified (EDNOS) (American Psychiatric Association, 1994).

Anorexia Nervosa (Diagnostic Code 307.1)

Anorexia Nervosa is characterized by an intense fear of gaining weight, even when underweight and refusal to maintain weight at or above what is considered an ideal weight for height and stature. The Diagnostic Statistical Manual of Mental Disorders,

fourth edition, Text Revised (1994) identifies specific diagnostic criteria for Anorexia

Nervosa. These include:

- A. Refusal to maintain body weight at or above a minimally normal body weight for age and height (e.g. weight loss leading to a maintenance of body weight less than 85% of the expected; or failure to make expected weight gain during period of growth, leading to body weight less than 85% of the expected.
- B. Intense fear of gaining weight or becoming fat, even when under weight.
- C. Disturbance in a way in which one's body weight or shape is experienced, undue influence of body or shape on self-evaluation, or denial of seriousness of the current low body weight.
- D. In postmenarcheal females, amenorrhea, i.e. absence of at least three consecutive menstrual cycles. (p. 589)

There are two subtypes of AN including: (a) Anorexia Nervosa- Restricting subtype (AN-R) and (b) Anorexia Nervosa- Binge Purge subtype (AN- BP) (American Psychiatric Association, 1994). Restricting subtype is specifically related to behaviors not in line with binge eating or compensatory in nature, but rather fasting or severely restricting caloric intake. Binge-Eating/Purging subtype is identified as engaging in binge-eating or purging behaviors regularly, during an episode of Anorexia Nervosa (American Psychiatric Association, 1994).

Bulimia Nervosa (Diagnostic Code 307.51)

Bulimia Nervosa is characterized by repeated episodes of eating far more than what is considered normal in one setting followed by compensatory behavior- including but not limited to self-induced vomiting, laxative abuse, use of ipecac, and/or excessive exercise. Typically there is a distorted perception of one's body and dissatisfaction with body image (American Psychiatric Association, 1994). The Diagnostic Statistical

Manual of Mental Disorders, fourth edition, Text Revised (1994) identifies specific diagnostic criteria for Bulimia Nervosa. These include:

- A. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following:
 - 1. Eating, in a discrete period of time an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances
 - 2. A sense of lack of control over eating during the episode
- B. Recurrent inappropriate compensatory behavior in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, enemas, or other medications; fasting; or excessive exercise.
- C. The binge eating and inappropriate compensatory behaviors both occur, on average, at least twice a week for 3 months.
- D. Self-evaluation is unduly influenced by body shape and weight.
- E. The disturbance does not occur exclusively during episodes of Anorexia Nervosa. (p. 594)

Purge-type BN, is designated by the person having regularly engaged in self-induced vomiting or misuse of laxatives, diuretics or enemas during a current episode of Bulimia Nervosa. Nonpurging-type BN is designated by the person having used other inappropriate compensatory behaviors, i.e. excessive exercise or fasting during a current bulimic episode however this individual has not engaged in self-induced vomiting or other behaviors identified as purge-type BN (American Psychiatric Association, 1994).

Eating Disorder, Not Otherwise Specified

When an individual has features of Bulimia Nervosa and/or Anorexia Nervosa, however, s/he does not fulfill criteria to diagnostically justify one or the other. Specific examples identified in the DSM-IV are:

- 1. All criteria for Anorexia Nervosa are met except that the individual has a regular menses.
- 2. All the criteria for Anorexia Nervosa are met except that, despite significant weight loss, the individual's current weight is within normal range.

3. All of the criteria for Bulimia Nervosa are met except that the binge eating and inappropriate compensatory mechanisms occur at a frequency of less than twice a week or for a duration of less than 3 months.
4. The regular use of inappropriate compensatory behavior by an individual of normal body weight after eating small amounts of food.
5. Repeatedly chewing and spitting out, but not swallowing, large amounts of food.
6. Binge-eating disorder: recurrent episodes of binge eating in the absence of the regular use of inappropriate compensator behaviors characteristic of Bulimia Nervosa. (pp. 594-595)

Level Of Care

The researcher conceptualizes level of care through a transtheoretical lens, which provides patients various treatment intensity options. Determination of necessity is dependent upon severity of symptoms, cognitive impairment, behavioral maladaptation, and physical compromise. Ideally, perceived quality of life would also be considered in assessment. The unique levels of care defined herein, and discussed throughout the literature review are: (a) inpatient, (b) residential, (c) partial hospital programming (PHP)/day treatment, (d) intensive outpatient (IOP), and (e) outpatient. The determination of necessary levels of care should be a concerted effort among treatment providers, family and the patient him/herself. Furthermore, within a transtheoretical model an individual would have the availability to move between levels of care, increasing and decreasing in intensity, based on his/her psychological and physiological needs.

Inpatient Treatment

Specifically in relationship with eating disorder treatment, inpatient is the highest (most intensive) level of care (LOC) available and is reserved for the most acute needs

(Wiseman, et al, 2001). This would be utilized when an individual is mentally and medically compromised and needs 24-hour nursing supervision. It is important at the inpatient LOC that an individual who is using compensatory behaviors, such as purging, has stable laboratory values as assessed by frequent blood draws and is medically stabilized prior to discharge. For an individual with AN, the focus is to promote weight gain, which may be done with a naso-gastric tube feed if necessary, and to do this re-feeding slowly in order to prevent any physiological compromise. For individuals hospitalized at this level of care, for a diagnosis of BN, a primary focus of treatment is to decrease or eliminate self-destructive behaviors (i.e. bingeing, purging, and other compensatory behaviors).

Residential Treatment

This level of care offers an individual a milieu-based therapeutic environment (<http://www.rogershospital.org>). Individuals receive a variety of therapeutic interventions including, but not limited to, group, family, individual, art, experiential (program specific), yoga, relaxation, weight training, equine therapy (program specific), nutritional counseling, and exposure therapy. Residential treatment is a step-down intensity-wise from inpatient treatment. It offers residents' opportunities to physically become active, once medically stable, and to practice recovery skills interactively with peers as well as with a community environment. Residents are typically allowed off-ground passes into the community to practice skills learned in treatment. Goals may include but are not limited to: obtain and maintain a healthy body weight, forego use of

unhealthy behaviors, gain control of their negative cognitions, and improve one's perceived QOL. These goals are in preparation for the reintegration into home life.

Partial Hospital Programming (PHP) /Day Treatment

PHP typically offers group and family therapy, nutritional counseling, educational counseling, and program-specific experiential therapies. On average, a PHP program provides six to 10 hours of treatment per day, five to seven days per week and includes some if not all meals and snacks. Individuals being treated at PHP will attend programming during the day and possibly in the evening and they return home at night and on the weekends.

Intensive Outpatient (IOP) and Outpatient

Outpatient and intensive outpatient treatment are reserved for patients that have the ability to maintain activities of daily living, are physically stable and are able to manage their lives in between sessions. IOP is an outpatient level of care that utilizes group therapy as a primary mode of intervention. Typically in IOP, the dose of treatment is 9-12 hours per week of group therapy with adjunct family and individual work as needed. This may be a "step down" treatment option, once an individual has completed a higher level of care, or may be a first step intervention when the result of basic outpatient psychotherapy has been ineffective. Basic outpatient can be offered in the form of individual psychotherapy, psychiatric medication management, dietary counseling, and psychotherapeutic and skills groups. It can be a combination of any of these identified counseling services. Frequency of outpatient appointments is individualized.

Additional Definitions

The researcher has identified terms and phrases not commonly used, of which the understanding are imperative to this research project and reviewed literature representation.

Quality of Life (QOL)

“WHO defines Quality of life (QOL) is defined as individuals’ perception of their position in life in the context of the cultural and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (WHOQOL, 1997, p. 1). This is the primary accepted definition highlighted in research articles referring to Quality of Life (Bamford & Sly, 2010, Adair et al, 2007, Mond et al, 2005), and therefore will be accepted as standard for this research project. Furthermore, Adair et al, (2007) expands on this definition and describe QOL as,

- Subjective
- Multi-dimensional
- Having positive and negative aspects
- Minimally including physical, psychological and social dimensions.

Managed Care & Manage Care Organizations (MCO)

“Any kind of health care services which are paid for, all or in part, by a third party, and for which the locus of any part of clinical decision-making is other than between the practitioner and the client or patient” (Shapiro, 1995, p. 441). Neuman and Ptak (2003) define managed care as a “collective term used to describe a variety of strategies implemented by insurers to control health and mental health care costs” (p.

384). According to the *Dictionary of Health Insurance and Managed Care* (2006), managed care is defined as,

An integrated system of health insurance, financing, and service delivery functions involving risk sharing for the delivery of health services and defined as networks of providers... Any system of health payment or delivery arrangements where the health plan attempts to control or coordinate use of health services by its enrolled members to contain health expenditures, improve quality, or both (Marcinko & Hetico, 2006, p.174).

Medical Necessity

Medical necessity is defined as the need for professional intervention regarding a physical ailment. This may include physical consequences of a mental illness (such as malnutrition), however, once physical “stability” is achieved medical necessity is eliminated. This cross-point is where the definition of medical necessity ambiguously detaches mental from medical (Berghold, 1995). “The term medical necessity has been mainly a placeholder in insurance plans for over 30 years. However, it is rarely defined, largely unexamined, generally misunderstood and idiosyncratically applied in medical and insurance policies,” (Berghold, 1995, pp. 180-181). Managed Care Organizations (MCO) consult with the American Psychiatric Association (2006), and the editors of the Diagnostic Statistical Manual of Mental Illness-IV-TR (American Psychiatric Association, 1994) to determine if mental health treatment is “medically” necessary (Berghold, 1995).

Purpose of this Study

This study is aimed at examining the outcome of residential treatment for individuals battling eating disorders through a well-rounded investigation of health-

related quality of life, eating disorder symptomology, depressive symptoms, and demographic descriptors. The researcher is committed to investigating the effect residential treatment has on individuals' recovery process and the ability to maintain gains, post treatment. The project will specifically utilize outcome measures from admission and discharge, as well as a short-term three-month follow-up.

Evaluation of the change in eating disorder symptomatology, will be evidenced by the global Eating Disorder Risk Composite (EDRC) score, which is a composite score on the Eating Disorder Inventory (3rd Edition); this score will be correlated with the subjects' perceived change in quality of life. Change in depressive symptoms as evidenced by a total score on the Beck Depression Inventory (2nd Edition), will also be correlated with the subjects' perceived change in quality of life from admission to discharge. Analysis at 3-month post-treatment follow-up will be performed solely with the disease-specific quality of life measure. Remarkably this study will investigate QOL data utilizing the Eating Disorder Quality of Life Scale (EDQLS), a disease specific health related quality of life instrument, developed by a collaborative team of eating disorder experts in Calgary Canada (Adair, et al, 2007, Adair, et al, 2008) (See Appendix B). Finally, the researcher will examine the relationship between perceived quality of life and duration of illness.

The purpose of using a disease-specific quality of life scale is discussed further in Chapter 2. The review of the literature will reflect that a generic quality of life scale does not provide an accurate estimation of quality of life, due to the ego-syntonic nature of an eating disorder, which is accounted for in the EDQLS.

The researcher is passionate about the treatment of eating disorders, across all diagnostic specification, and is purposeful in her research. She desires to share outcomes with professional colleagues within the medical, psychiatric, psychological, dietetic, and social work fields. Of particular note, the researcher is particularly interested in educating third party paying sources including managed care companies, private health insurance companies, and governmental agencies of the benefit and value of residential care, for the treatment of eating disorders as evidenced by a well-rounded evaluation of progress and prognosis.

Data was collected at Rogers Memorial Hospital (RMH), a mental health facility in Oconomowoc, Wisconsin, which specializes in treating eating disorders and other behavioral health diagnoses (<http://www.rogershospital.org>). The program specifically identified for this research project was the Eating Disorder Center (EDC), a residential treatment facility that treats men and women 12 years of age and older. Four unique units were included in this project. Units are identified by age and gender. The populations under investigation included individuals with a reading and comprehension level equivalent to 14¹ years of age and older, males and females alike. All participants had an eating disorder diagnosis. This project was intended to explore the importance of utilizing health-related quality of life in conjunction with measures that track symptom reduction, weight restoration and physical rehabilitation when determining appropriate level of care, treatment plan and discharge preparedness.

¹ The EDQLS instrument in use has been designed to be developmentally appropriate for adolescents, ages 14 and up.

Significance of the Study for Social Workers

Matthew McHugh (2007) suggests that given the severity and expansive etiology of eating disorders, a well-trained interdisciplinary team is necessary in order to provide a patient with the tools needed for recovery. This is a long-term process that could take years, at best. An improved understanding of the relationship between health-related quality of life, symptom severity, and preparedness for discharge will assist clinical social workers in their interactive, clinical work with this population regardless if employed by a care-giving organization, research facility, or a third party payer. Clinical social workers are estimated to provide 65% of all psychotherapy and mental health services in the United States (Cohen, 2003). This statistic in conjunction with the estimated 11 million individuals battling eating disorders in the United States-10 million female and one million males (<http://www.nationaleatingdisorders.org>) would suggest an obvious crossover at some point in one's career. As the prevalence of eating disorders has failed to decrease over the years but rather the severity, co-morbidity and complexity of the illness increase, clinical social workers must be prepared to advocate for their customers in any capacity.

Research Questions, Hypotheses and Null-Hypotheses

Research Questions

Question 1

Do individuals that receive eating disorder-specific residential treatment gain a statistically significant improvement in their health-related quality of life from admission to discharge?

Question 2

Do individuals who receive residential treatment maintain their treatment gains and /or continue to improve upon their quality of life at 3-month follow-up, post-discharge?

Question 3a

What is the relationship between the change in subjects' quality of life and the change in depressive symptoms from admission to discharge?

Question 3b

What is the relationship between the change in subjects' quality of life and the change in eating disorder symptomatology from admission to discharge?

Question 4

What impact does duration of illness have on health-related quality of life over the course of eating disorder-specific residential treatment?

Hypotheses and Null-Hypotheses**Hypothesis 1**

Residential eating disorder treatment will result in statistically significant improvements in the subjects' health-related quality of life from admission to discharge.

Null-Hypothesis 1

Residential treatment has no impact on the subjects' health-related quality of life.

Hypothesis 2

Residential eating disorder treatment will result in continued quality of life improvement, post-treatment.

Null-Hypothesis 2

There will be no continued progress at three-month follow-up, specific to health-related quality of life.

Hypothesis 3a

There will be a negative correlation between the change in health-related quality of life and depressive symptoms at discharge for individuals receiving residential eating disorder treatment.

Null-Hypothesis 3a

There will be no relationship between change in quality of life and change in depressive symptoms for individuals receiving residential treatment for eating disorders.

Hypothesis 3b

There will be a negative correlation between the change in health-related quality of life and eating disorder symptomatology at discharge for individuals receiving residential eating disorder treatment.

Null-Hypothesis 3b

There will be no relationship between change in quality of life and change in eating disorder symptomatology for individuals receiving residential treatment for eating disorders.

Hypothesis 4

The longer the duration of the illness, the less progressive change a subject will make in their health-related quality of life over the course of residential eating disorder treatment.

Null-Hypothesis 4

The duration of illness has no impact on the subjects' response to treatment, specific to their health-related quality of life.

CHAPTER TWO

REVIEW OF RELEVANT LITERATURE

Disease-Specific Health-Related Quality of Life

Engle, Adair, las Hayas, and Abraham (2009) suggest a myriad of uses for health-related quality of life research: (a) clinicians are able to enhance the assessment of their client's progress, identify the focal treatment goals, and personalize care; (b) program evaluation committees can demonstrate efficacy, which is a particularly important use, as evidence-based treatment for eating disorders has not been identified and a wide variety of treatment models, interventions, and levels of care are utilized; (c) third-party paying organizations have multiple uses for this type of data, in making determinations regarding reimbursement and coverage; (d) research opportunities are endless in utilizing these instruments adjunct to alternative self-report questionnaires and interviews that focus on symptomatology. The evolution of disease-specific quality of life instruments is early in development and there is a limited amount of outcome data utilizing these designs to date, leaving an open-ended arena for future growth and maturity (Engle, 2006, Padierna, et al, 2000).

The health-related quality of life of individuals affected by mental health has been a research area of interest since the 1980s (Bamford & Sly, 2010). Assessment of quality of life has emerged in many forms. Particularly quality of life assessments have begun to appear in therapeutic trials, clinical intake and assessment, and have become a focus for

treatment interventions, specifically psychosocial treatments (Bamford et al, 2010).

Although this has been of interest to the mental health field globally, the emergence of health-related quality of life assessment specifically with eating disordered patients has been remarkably slight. Until recently, eating disordered patients were assessed for QOL by use of a generic quality of life scale that yielded mediocre data. Within the past several years, eating disorder-specific quality of life measures have been developed, resulting in a more accurate description of quality of life in this unique population (Bamford and Sly, 2010, Adair, et al, 2007).

Utilization of generic quality of life surveys, such as the Short Form 36 (SF-36) and the Nottingham Health Profile (NHP) with individuals afflicted by eating disorders have only been helpful somewhat in providing insight to individuals' perceived quality of life as they have several limitations. These generic forms should no longer be considered as an assessment tool, as disease-specific instruments have been developed (de la Rie et al, 2007; Adair et al, 2007; Engle et al, 2006). The SF-36 and NHP are insensitive to the emotional distress and ego-syntonicity of eating disorders. These characteristics might include rigid control of dietary intake and the consequence of weight loss ironically resulting in a feeling of happiness, power, or superiority despite the fact that the patient is dramatically declining emotionally, psychologically and medically, potentially resulting in death (Mond et al, 2005; Engle et al, 2006). Engle and colleagues (2006) further dedicate this phenomenon, most often occurring in individuals with the subtype of

restricting Anorexia Nervosa, as a severe lack of insight and possible delusion to which the more generic QOL surveys are insensitive.

According to Engle and Colleagues (2009), between 1994 and 2005, only fifteen research papers focusing on the impact of health-related quality of life were written. At the end of this era, Hay and Mond (2005) concluded that, “the impact upon peoples’ ‘quality of life’ secondary to the eating disorder is a relatively neglected area of research” (Engle, 2009, p. 181). Organizations and researchers have begun to look seriously at the health-related quality of life through a lens developed specifically for individuals battling eating disorders across the spectrum (Engle et al, 2009, Hay and Mond, 2005). Mond, Hay, Rodgers, Owens, and Beumont (2005) summarize the historical presentation of quality of life assessment and delineated that:

Assessment of quality of life may provide a useful adjunct to the use of disease-specific measures in outcome studies of eating disorder patients. However, QOL measures have rarely been included in eating disorders research and are typically not considered in reviews of outcome assessment (p. 172).

Prior to attention being given to health-related quality of life outcomes of recent past, the most common research measures for the eating disordered population fell into three primary categories,

- Symptom-focused self-report questionnaires;
- Semi-structured interviews;
- Clinical interviews;

Of the self-report questionnaires there are seven that have been most commonly used (a) Eating Disorder Inventory (EDI-3); (b) Body Shape Questionnaire (BSQ); (c) Three-

factor Eating Questionnaire (TFEQ); (d) Mizes Anorectic Cognitions Questionnaire (MAC); (e) Bulimia Test Revised (BULIT-R); (f) Questionnaire on Eating and Weight Patterns revised (QEWP-R); (g) Eating Disorder Examination Questionnaire (EDE-Q). Semi-structured interviews include: (a) Structured Clinical Interview for DSM-IV (SCID-I) and (b) Eating Disorder Examination (EDE). Clinical interviews both unstructured and observer-based have also been typical in assessing eating disorders (Engle et al, 2009).

The challenge with utilizing these instruments by themselves is that they focus solely on the reduction of symptoms and potentially dismiss deep-rooted psychological and interpersonal factors common in individuals struggling with eating disorders. There is also danger in third-party payers solely basing treatment necessity and reimbursement on these factors or objective data such as weight restoration or medical and physical stability. Such misguided analysis can have grave impact on the outcome of patients' long-term recovery, recurrent symptoms, and quality of life (Engle et al, 2006; Engle et al, 2009; Frisch et al, 2006). McHugh (2007) provides a research-based perspective on important consideration when evaluating treatment outcomes, admission assessment, and readiness for clinical discharge for individuals diagnosed with Anorexia Nervosa:

At minimum, anorexia nervosa outcomes research should include weight gain, core eating disorder symptomatology, comorbid psychiatric illness, and quality of life (QOL) measures. The American Psychiatric Association has also encouraged broadening the clinical scope of recovery stating that patients who are medically stabilized still require inpatient treatment if they do not meet biopsychosocial criteria for discharge (p. 603).

In the early 21st century Padierna, Quintana, Arostequi, Gonzalez, and Horcajo (2001) began to shed light upon this gap in outcomes research. There was an identified need for more pointed attention on the interpersonal, social and emotional wellbeing of individuals affected by a diagnosed eating disorder. They suggested that in comparison to the general female population, aged 18-34, there is a global deterioration in the perception of health-related quality of life for those individuals diagnosed with an eating disorder and receiving outpatient treatment. The psychosocial deterioration was most evident in areas of vitality, emotional role, social functioning, and mental health. Specific domains related to one's physical wellbeing and general health also suggested levels of psychosocial deterioration. According to Padierna, et al (2001), "Eating disorders' impact on the psychological, physical, and social aspects of life has an important tendency to evolve, become chronic or to recover only partially, or to be a relapsing/recurring condition and have high mortality rate" (p. 667).

Abraham, Brown, Boyd, Luscombe, and Russell (2006) determined that quality of life assessment tools are designed to emphasize the person, not the disease. These instruments "have the ability to unearth issues that are important to the patient, thus facilitating optimal treatment and outcomes and enhanced patient-health professional interactions" (Abraham et al, 2006, p. 153). This article suggests that a quality of life survey should indicate "the amount of distress perceived by the person at a given time, and not as assessed by the clinician on the basis of objective measures" (p. 155). Furthermore, true to the character of eating disorders, "wellness is both an objective as

well as subjective term and is determined through physical, psychological and behavioral criteria” (Abraham et al, 2006, p. 151).

According to De la Rie and colleagues (2007) in a disease specified instrument such as a health-related quality of life scale, fixed domains are determined based on the specific criteria, which are affected by the disease. Engle and colleagues (2009) collaborated their efforts to analyze and compare four unique eating disorder specific quality of life surveys developed in the early 21st Century. The primary composition of these instruments include the following sub-groups:

- General health;
- Physical functioning;
- Physical symptoms and toxicity;
- Emotional functioning;
- Role functioning;
- Social wellbeing and functioning;
- Sexual functioning;
- Existential functioning.

Furthermore, Engle and colleagues (2009) state:

Findings show that lives of patients with eating disorders are impacted in ways that are much farther reaching than their eating symptomatology: suggesting that patients with eating disorders are impaired in other important domains of their lives such as social, psychological and physical. (p. 183)

All four disease-specific quality of life instruments went through a rigorous process of consulting with experts in the field, recovered patients, and pilot testing with current

patients. Engle, et al (2009) summarize six general themes that surfaced through investigating disease-specific HRQOL surveys:

- Patients with eating disorders report lower QOL than normal controls;
- HRQOL impairment occurs in patients with full DSM IV-TR diagnosis as well as those who have sub-threshold eating disorder symptoms;
- Family caregivers of patients with eating disorders experience HRQOL impairment;
- HRQOL impairment in patients with eating disorders is considerable;
- Patients with eating disorders receiving treatment report improvements in their HRQOL;
- There are gender differences in HRQOL in patients with eating disorders.

Recent research published by Bamford and Sly (2010) utilized the EDQOL survey, developed by Scott Engle, to investigate three potential contributing factors to a patients' quality of life: (a) duration of illness/chronicity, (b) Body Mass Index (BMI), and (c) self-report symptomology. Interestingly, a longer duration of illness / chronicity was not indicative of a lower health-related quality of life or diminished treatment response. According to Bamford and Sly (2010) these findings were surprising yet appear to be in line with the opinion of other researchers' that global functioning is not affected with the progressive symptomology of an eating disorder over time.

Furthermore, Bamford and Sly (2010) hypothesize that such outcomes support the philosophy that motivation and readiness for change are more accurate predictors of

improved quality of life versus chronicity. Theoretically, patients can adapt to decreased functioning by altering values and / or expectations. As an eating disorder becomes a more chronic concern, patients ultimately redefine and adapt core values and learn to function in a way that does not impact quality of life, even though their illness is routinely present (Bamford & Sly, 2010). This research is useful to identify and individualize treatment modalities in addition to theoretical interventions. It effectively portrays the crossover between physical deterioration, behavioral symptomatology, and quality of life while also collaborating with research supporting readiness for change as an indicator of prognosis.

Health-Related Quality of Life and Readiness for Change

Adair and colleagues (2007) imply a positive association between the EDQLS and stages of change models. This suggests that health-related quality of life improves with readiness for change. Furthermore, a connection can link stages of change theory and quality of life that suggests higher readiness to change will result in more significant response to treatment as evidenced by improved quality of life scores. Bamford and Sly (2010) produced health-related quality of life research that also emphasized the importance of incorporating readiness for change and motivational enhancement evaluation into clinical assessment and intervention with the chronically affected patients. According to Bamford and Sly (2010) motivation and readiness for change can have a direct impact on a patient's willingness to embrace the recovery process, which then has a direct correlation with his / her improved quality of life.

Adair and colleagues (2007) suggest that individuals who are able to remain in treatment longer, beyond the initial stages of change and into later stages of change (i.e. action or maintenance) result in an overall higher quality of life. Both tools, readiness for change (RFC) and disease-specific quality of life measures, are useful as predictors to outcome but also potentially useful for assessing and determining level of care and length of stay. This information may be useful informing and educating third party payers of psychological necessity.

McHugh (2007) compared short-term outcomes of individuals being treated at a residential treatment facility based on their admitting readiness for change (RFC) score, utilizing the Anorexia Nervosa Stages of Change Questionnaire (ANSCQ). He investigated the correlations between readiness for change (RFC) at admission, length of stay in residential treatment, and short-term outcomes including weight gain, drive for thinness, depression, anxiety, and health-related quality of life. As hypothesized, those patients admitting with a high level of RFC discharged with a shorter length of stay and having achieved a clinically more favorable short-term outcome. Those admitting with lower readiness for change required a longer length of stay (McHugh, 2007). Discharging and transitioning prematurely to a lower level of care or to the home environment “can set [the patient] up for failure while positive early treatment outcomes are critical in promoting a longer lasting treatment effect” (McHugh, 2007, p. 609).

According to De la Rie, Noordenbos, Donker and Furth (2006), if treatment interventions are matched with progressive readiness for change stages the goals for

treatment and experience of treatment might also evolve and change. Furthermore, it is suggested that allowing the patients' to have some autonomy in negotiating goals throughout treatment ultimately gives them a voice or a sense of control and empowerment, which was positively correlated with their RFC and movement in treatment. This concept directly attends to the common characteristic of "needing control" found in individuals afflicted by eating disorders and allows them to channel this need in a healthy manner. Furthermore, this would address two of the sub-domains suggested to be important in the HRQOL survey: existential functioning and emotional functioning (Engle et al, 2009). Control is a common characteristic that presents in individuals diagnosed with Anorexia Nervosa, Bulimia Nervosa or Eating Disorder, Not Otherwise Specified; comprehensive assessment and deliberation must take this feature into account. Recommendations about treatment facilities and appropriate levels of care need account for one's need of control, readiness and motivation for change, physical compromise, and quality of life. It is imperative for the individual to take back control of his or her mind and environment.

Residential Treatment

Weltzin, Weisensel, Cornella-Carlson and Bean (2007) state that the "primary goal [of residential treatment] is the recovery of a fully functioning individual and re-integration back into the community" (p. 55). Residential treatment offers daily living activities, individual and family psychotherapy, group/milieu therapy, nutritional therapy, and maintenance counseling. Milieu treatment is a forum for individuals fighting eating

disorders to discover a different reality (Weltzin, et al, 2007). Necessary in-vivo and educational therapeutic experiences are primary initiatives in residential treatment centers (RTCs). Skill development occurs over the course of treatment and assists in a patient's opportunity to progress in life and re-construct their identity socially, clinically and physically (Weltzin, et al, 2007, Brunette, Drake, Woods and Harnett, 2001). "The residential eating disorder center [at Rogers Memorial Hospital] provides long-term treatment in a home-like environment in a manner that promotes self-discovery, enhances self-esteem, fosters a sense of autonomy, and assists in developing a healthy balanced lifestyle" (Weltzin et al, 2007, p. 55).

An uninterrupted, lengthy stay in residential treatment typically will favor the weight and existential changes that need occur with individuals seeking recovery from an eating disorder (Weltzin, et al, 2007). However, achievement of these goals is often not feasible due to the trajectory of treatment being diminished. According to Matthew McHugh (2007),

Length of stay has been correlated with insurance status suggesting that a person's ability to pay for treatment influences how long they will be treated at a higher level of care. This raises issues concerning fairness and the constraints on health-care providers' ability to carry out evidence-based clinical decisions regarding the appropriate setting and duration of care. Because recovery is a process that requires time, patient status at discharge is, at least in part, dependent upon the length of stay. (p. 604)

As part of his platform, McHugh (2007) highlights that longer lengths of stay in mental health treatment, remarkably residential eating disorder treatment, have been associated with favorable outcomes in the recovery process. Correlations are drawn

between the length of stay and discharge factors of lower weight, inadequate Body Mass Index (BMI), low health-related quality of life scores, and Readiness for Change (RFC) scores. Such outcomes suggest that deficiency in these factors set the patient up for a higher risk of relapse and readmission (Weltzin et al, 2007; McHugh, 2007; Striegel-Moore, 2005), which ultimately result in additional financial burden to the paying source.

According to Brewerton and Costin (2011b) there is a lack of long-term follow-up studies for individuals with diagnosed eating disorders following intensive residential treatment. Overall data on the effectiveness of residential treatment for eating disorder is limited (Brewerton and Costin, 2011a, Frisch, et al 2006). Although research is sparse it is suggested that residential treatment offers an effective treatment model and provides for a foundation of cognitive and behavioral restructure that need occur in the recovery process (Weltzin, et al, 2007, Bean, Welk, Hallinan, Cornella-Carlson, Weisensel and Weltzin, 2008). Although not every person afflicted with an eating disorder needs the level of care, it is supported as a necessary and warranted option for those who do.

Bean and Weltzin (2001) published a report that studied 47 females with Bulimia Nervosa (BN) and 53 females with Anorexia Nervosa (AN) post- residential treatment from Rogers Memorial Hospital; there was significant symptom improvement on eight subscales of the Eating Disorder Inventory, 2nd edition (EDI), suggesting that residential treatment is effective. Additionally, achievements of weight restoration and maintenance are two important factors that indicate positive, short-term sustainable results and can be accomplished in a controlled, residential level of care. Weight restoration and

maintenance is identified as a significant part of the recovery process, which in itself is time-dependent. Individuals who are able attain and maintain an ideal body weight and appropriate BMI (≥ 18) are likely to have better treatment outcomes and post-treatment sustainability (Bean, et al 2001, Weltzin, et al 2007, McHugh, 2007, Brewerton and Costin, 2011a, Brewerton and Costin, 2011b). According to Weltzin and colleagues (2007) regarding males receiving treatment at an eating disorder-specific residential treatment facility, it is indicated that most weight restoration occurs after the first 30 days of residential treatment, once behaviors have decreased. Individuals who gain weight too quickly, in an attempt to maximize benefits can run the risk of re-feeding syndrome, which can lead to problematic medical conditions. Furthermore, individuals restoring weight at too slow of a pace, as a result of their pre-contemplative stage of change, also proves to be problematic and an indicator of readmission (McHugh, 2007).

Treatment considerations for an individual afflicted with a severe eating disorder may warrant admission to an intensive level of care, including inpatient hospitalization or a residential treatment program. Inpatient hospitalization is the most intensive level of care and is reserved for the most acute, life-threatening cases (Frisch et al, 2006; Wiseman et al, 2001). Residential treatment is an intermediate level of care that has emerged as a common long-term substitute for inpatient treatment providing a unique milieu philosophy for treating individuals fighting eating disorders. Each individual is at a unique point in his/her personal journey and quality of life, therefore individualized recommendations and care is imperative. According to Brewerton and Costin (2011b),

“RTC [residential treatment centers] offer the advantage of a long-term, structured and intensive treatment setting outside a hospital environment generally at lower cost” (p. 133). Frisch, Herzog and Franko (2006) support residential treatment as a cost-effective option for long-term intervention that warrants financial support. Outcome data stemming from different levels of care, remarkably community based residential facilities (CBRF) in the United States are sparse however available outcomes are remarkable. More research is needed to evidence that an investment in residential treatment is worthwhile (Frisch, 2006).

Frisch and colleagues (2006) published a systematic review of residential treatment facilities across the nation, which was the first investigation of its kind. It uncovered that as eating disorder specific residential treatment facilities have become increasingly more common, the standards between these programs vary dramatically. Over the past decade, the number of residential treatment centers has tripled; between 2000 and 2004 alone the number of programs increased by 44%. Only a percentage of the facilities are operating under federal and/or State accreditation and effectiveness measures are currently non-standardized. This leaves the door open for scrutiny (Frisch, et al, 2006).

With the limited research and diversity among treatment models, therapeutic interventions, costs of treatment, and lengths of stay third-party payers have a viable platform upon which to challenge residential treatment effectiveness. Third-party payers question the potential investment in their members’ mental health recovery at a

residential level of care as evidenced by limited coverage (Frisch et al, 2006). An evolving trend in managed care and other third party payer policies is not recognizing residential treatment as a coverable level of care. The result of this political and economic determination is that patients will be prematurely discharged to a less intensive and insufficient level of care or the family's financial burden becomes monumental.

Third-Party Coverage

Extrinsic barriers to adequate care might include: lack of coverage, coverage with inadequate scope of benefits, low reimbursement rates, and limited access to health care specialists and appropriate interdisciplinary teams with expertise in eating disorders. This could be due to insurance limitations or geography (American Psychiatric Association, 2006, Golden, et al, 2003). Although external barriers are obvious, there are significant internal barriers that impact the accessibility of treatment for eating disorders as well. Intrinsic barriers to accessing treatment may be an individual's denial, ambivalence, resistance, or pre-contemplation to change. Any and all of these characteristics can be indicative of the family system as well (Golden et al, 2003). Furthermore, the importance of assessing health-related quality of life is useful in order to make recommendations based on such barriers.

There are significant intrinsic and extrinsic barriers to be addressed and if we, as a society, pigeon hole individuals into a "cost effective" or "time limited" treatment model, the result will inevitably have little to no departure from ambivalence. Secured comprehensive insurance coverage for adults and adolescents suffering from Anorexia

Nervosa (AN), Bulimia Nervosa (BN), and Eating Disorder, Not Otherwise Specified (EDNOS) is important. Additionally, financial and therapeutic support for individuals battling experimental disordered eating is a necessity. To provide counsel as a preventative intervention may ultimately prevent the need for higher levels of care later. Treatment and counsel need be dictated by generally accepted guidelines and should be based on psychological severity as well as medical severity of the condition (Striegel-Moore, 2005).

“Mental health benefits can differ substantially between [insurance] plans” (McHugh, 2007, p. 609). Policy surrounding mental health coverage and parity is ambiguous; the current Mental Health Parity Act (MHPA) provides us with a broad baseline of guidelines and expectations however, it leaves state-by-state implementation open for interpretation. Furthermore, loopholes and differences between companies and organizations have marked an era of disparity among necessary medical versus mental health care (Barry 2006, Cohen, 2003). This disparity creates a dilemma in accessing essential mental health benefits for important therapeutic services. This conflict results in shortened lengths of stay, premature discharges, or a less-intensive levels of care than is recommended by multidisciplinary team members (McHugh, 2007).

Trends in eating disorder treatment facilities prove that there is a progressive decrease in inpatient average length of stay (LOS). Weisman et al (2001) presented that the average inpatient LOS in 1984 was 149.5 days and 14 years later, in 1998, this had diminished to 23.7 days (Wiseman et al, 2001; Frisch et al, 2006). Presently, inpatient

treatment centers are primarily utilized for acute care and medical stabilization rather than psychotherapeutic stabilization. This decrease in inpatient LOS has a negative correlation with the development and growth of residential treatment facilities. The evolution of residential treatment options in the United States also correlates with changes in the health insurance arena in which social workers and other clinical professionals operate (Schwartz & Weiner, 2003; Cohen, 2003; Wiseman, 2001; Frisch, 2006). A steady increase in recidivism rates can be highlighted during this same era (Halimi et al, 2001).

Change in the US health care industry is unavoidable with unique political transformations. The industry continues to move further away from a “fee for service” medicine model and toward a “managed care” model, which has resulted a profound change in the treatment of eating disorders (Striegel-Moore, 2005; Lock, 2003). Furthermore, the practice of cost-containment and “carving-out” mental health services results in individuals’ access to care being restricted, length of treatment decreasing, use of medication for the treatment of mental disorders increasing, and an overall limitation to necessary treatment options (Striegel-Moore, 2005, p. 532; Lock, 2003).

According to Crow and Nyman (2004), it is estimated that the cost of treatment for eating disorders is approximately \$119,200 per year. This figure takes into account the longevity of treatment to be approximately two years. Compared to other severe mental illnesses (SMI), such as Schizophrenia and compared to other medical interventions this figure is extremely cost effective (Crow and Nyman, 2004; Striegel-

Moore, 2005). Crow and Nyman (2004) analyzed the cost of usual care versus the cost of an adequate care package recommended by expert medical professionals and discovered that in using assumptions for mortality rate, age at mortality, treatment response, and life expectancy, “the incremental cost-effectiveness ratio (ICER) of adequate care is only \$30,180 per year of life saved” (p. 158). These statistics combined with analysis of amalgamated objective and subjective outcome measures lead the researcher to surmise that evaluation of multiple outcome markers (i.e. quality of life, readiness for change, symptom reduction, cognitive functioning) is imperative in determining treatment effectiveness. Such comprehensive analysis is a reasonable and justifiable and should be considered by treatment providers and payers.

Fox, McManus, and Reichman (2003) examined the nature and extent of private health insurance, available for six hypothetical adolescent mental health case scenarios. In this journal article the authors estimate that even using best-case scenario, which would be the utilization of private health insurance, only 3% of these health insurance plans would fully cover the recommended course of treatment for a hypothetical adolescent seeking treatment for Anorexia Nervosa (Fox, et al, 2003, Striegel-Moore, 2005). Furthermore, in *Eating Disorders in Adolescents: Position Paper for the Society for Adolescent Medicine*, prepared by Golden, et al (2003) it is reported that, “in most insurance plans the scope of benefits for treatment of eating disorders is currently insufficient” (p. 499). Cost containment, daily limitation of yearly behavioral health visits and admissions, and preclusion of specialized practitioners are third party payers’

attempts at cutting cost, which has a paradoxical approach of driving up recidivism, co-morbidity, and chronicity.

Taking into account internal and external barriers to care and holistically accepting the considerable “worth” of various levels of care is a priority in providing comprehensive support for individuals battling eating disorders. Residential treatment facilities have an important place in treating individuals fighting eating disorders, holistically. Flexibility to individualize a patient’s treatment not only once they arrive in treatment but also by identifying and providing appropriate and necessary levels of care (as evidenced by physiology, psychology, symptomology, RFC and health-related quality of life), multi-disciplinary teams can enhance the individuals’ experiences and outcomes, during and post-treatment. It is this researcher’s hypothesis that with respect, support and collaboration between all decision-making paradigms the financial burden, eating disorder chronicity, and recidivism rates will decrease.

CHAPTER THREE

METHODOLOGY AND DESIGN

Design Description

This study is geared toward evaluating the change in individuals' health-related quality of life (HRQOL) from admission to discharge, and again at three-months post-discharge from a specialized eating disorder residential treatment facility. Utilization of specialized community based residential facilities (CBRFs) is considered a premiere treatment option for individuals, allowing them to reconstruct their personal identity-separate from the illness that haunts them (Weltzin, 2007). The specific populations under investigation are adolescent and adult sufferers of eating disorders. Individuals with a primary diagnosis of Anorexia Nervosa (AN), Bulimia Nervosa (BN), and Eating Disorder, Not Otherwise Specified (EDNOS) were considered for this research project. Although challenges continue to arise with the process of securing third-party payment for coverage of this level of care, the use of a specialized CBRF for treatment of this complex, sub-population of the diagnosed mentally ill continues to be recognized as a valuable level of intervention (Frisch, et al, 2006). Rogers Memorial Hospital (RMH)-Eating Disorder Center (EDC) in Oconomowoc, WI was the research site for this project (www.rogershospital.org).

Utilization of data focusing solely on symptom reduction and objective data targeting physical and medical stability does not provide a comprehensive picture of

progress and readiness for recovery (Engle, 2009). This research project integrated an eating disorder-specific health-related quality of life (HRQOL) measure, the Eating Disorder Quality of Life Scale (EDQLS), into a standard battery of instruments. Additionally, the researcher collected and analyzed data from the Beck Depression Inventory (BDI) and the Eating Disorder Inventory, third edition (EDI-3). The BDI and EDI-3 scores specifically target depressive and eating disorder symptom reduction respectively, from admission to discharge. The EDQLS targets subjects' perceived changes in quality of life. Investigating the change in symptomatology and perceived quality of life in combination with objective data of medical and physical stabilization provides a 360-degree analysis of an individual's treatment effectiveness and potential for recovery.

This quantitative research study utilized the Eating Disorder Quality of Life Scale (EDQLS) (Adair and Marcoux, 2008) as the primary instrument. The investigator focused on the subjects' change in quality of life from admission to discharge and then again at a 3-month, post-treatment follow-up. Correlations between the change in quality of life from admission to discharge and the change in eating disorder symptomatology, as represented via the EDI-3 instrument, was investigated. In addition, the relationship between the change in QOL and change in depressive symptoms was evaluated using the Beck Depression Inventory, Second Edition. Of note is that there was a hospital-wide change approximately two-thirds of the way through the researcher's data collection, in which the hospital changed their primary depression inventory scale from the BDI-II to a public domain depression inventory, the Quick Inventory of Depressive Symptomatology

(QIDS). Upon contemplation, it was determined by the researcher to not utilize the data post-change in instruments, so as to not complicate the results and to remain focused on the primary analysis of quality of life change. Therefore, the data specific to correlation between change in quality of life and change in depressive symptoms is limited to 36 paired subjects ($n = 36$). This is identified as a limitation in the study's generalizability and further analysis of this correlation is warranted.

This study included three collection times: (1) Admission (pre-), (2) Discharge (post-) and, (3) Three-month follow-up (post-post). The three-month follow-up solely targeted results of the EDQLS.

The researcher will answer the following questions in Chapter Four:

- (1) Do individuals that receive eating disorder specific residential treatment gain a statistically significant improvement in their health related quality of life from admission to discharge?
- (2) Do individuals who receive eating disorder specific residential treatment maintain and/or continue to improve in their HRQOL at three-month follow-up, post-discharge?
- (3a) What is the relationship between the change in a subject's HRQOL and their level of depression from admission to discharge?
- (3b) What is the relationship between the change in a subject's HRQOL and eating disorder symptomatology from admission to discharge?
- (4) What impact does duration of illness have on the change in HRQOL from admission to discharge at an eating disorder-specific residential treatment?

Sampling and Limitations

Recruitment of the Sample

All research participants were voluntary. Eligible subjects considered for this project included adolescents and adults, males and females alike. It was a requirement that the subjects be active patients who had been admitted to the Eating Disorder Center (EDC) at Rogers Memorial Hospital during the 12-month, data collection time frame. The eligibility criteria for this project included: (1) all potential participants must have an eating disorder diagnosis, including Anorexia Nervosa (AN), Bulimia Nervosa (BN), or Eating Disorder, Not Otherwise Specified (EDNOS) as defined in Chapter 1; (2) all potential participants are able to read, write and speak at the level of a fourteen-year-old.

Limitations

The sample is one of convenience. It is non-random in nature. The external validity may be compromised through the use of a convenient sample and such limitation is recognized. The sample determined for this project is recognized to be representative of the greater eating disordered population presenting at a severity level that warrants intensive residential care, which typically includes physical, emotional and cognitive compromise. Rogers Memorial Hospital- Eating Disorder Center treats people with eating disorders of all ages, socioeconomic status, gender, ethnicity and race. The residential programs at Rogers Memorial Hospital welcome third-party payment sources and self-pay alike. At this level of care, the treatment methods address eating disorder diagnostic features of AN, BN and EDNOS as well as co-morbid diagnostic features, remarkably depressive and mood disorders, anxiety disorders, and Obsessive Compulsive

Disorder (OCD). This is comparable to other residential treatment facilities, nation-wide. The EDC does not treat individuals who subscribe to a vegan culture, due to the theoretical compromise and assumption that this may be a behavioral and/or symptomatic subset of the disease under scrutiny.

Data collected specific to question number (3a) had a premature end date, due to the hospital ceasing to use the Beck Depression Inventory, second edition (BDI-II) instrument. The *n*-value is limited, which is recognized as a limitation to the generalization of results.

Measure and Instrumentation

Eating Disorder Quality of Life Scale (EDQLS)

This is a disease-specific quality of life survey, developed to account for the egosyntonic nature of eating disorders, remarkably Anorexia Nervosa (Engle et al, 2009; Engle et al, 2006; Adair et al, 2007, Abraham et al, 2006; Vitousek et al, 2005). The EDQLS is written at a 14-year old reading level. It was designed to measure the health-related quality of life in adolescents and adults, struggling specifically with eating disorders.

A 5-point Likert scale ranging from “Strongly Agree” to “Strongly Disagree” is used for rating purposes. The scales are divided into 12 domains, including (a) school/work, (b) family and close relationships, (c) physical health, (d) psychological health, (e) eating, (f) relationships with others, (g) future, (h) feelings, (i) appearance, (j) leisure, (k) values and beliefs, and (l) cognitive. For the purpose of this research project

the researcher is specifically investigating the global score of the EDQLS. The internal consistency reliability is .96 (Cronbach's alpha) (Adair, et al, 2007).

Eating Disorder Inventory- 3rd Edition

The Eating Disorder Inventory, 3rd Edition (EDI-3) assesses and measures eating disorder symptomatology in individuals 12-years of age and older. For the purpose of this project, the researcher utilized the Eating Disorder Risk Composite (EDRC) score for evaluation. This composite includes the three eating disorder-specific scales within the EDI-3: Drive for Thinness, Bulimia, and Body Image dissatisfaction. Alternative composites include Ineffectiveness Composite, Interpersonal Problems Composite, Affective Problems Composite, Overcontrol Composite, and General Psychological Maladjustment Composite. The Psychological Scales that are utilized in these five composites include Low Self Esteem, Personal Alienation, Interpersonal Insecurity, Interpersonal Alienation, Interoceptive Deficits, Emotional Dysregulation, Perfectionism, Asceticism, and Maturity Fears (Garner, et al, 2004).

The Eating Disorder Inventory (EDI) has 64-item that are 6-point forced-choice inventory that assesses behavioral and psychological traits common in eating disorders. It is a self-report measure and has a variety of uses; it can be used as a screening device, an outcome measure for treatment effectiveness, or as a research tool (<http://cps.nova.edu/~cphelp/EDI.html>, retrieved on January 23, 2010, 18:00).

The Eating Disorder Risk Composite (EDRC) reliability ranges from .90 to .97 with a median of .94 (Garner, D, 2004). The four identified eating disorder diagnoses are Anorexia Nervosa-Restricting type (ANR), Anorexia Nervosa-Binge-Eating/Purging type

(ANBP), Bulimia Nervosa (BN), and Eating Disorder Not Otherwise Specified (EDNOS) (Garner, 2004).

Beck Depression Inventory (BDI- II)

The BDI-II was most recently revised in 1996. It is a self-report tool to assess an individual for their severity of depression and is utilized interactively with the DSM-IV-TR (1994). The BDI-II has a Cronbach's Alpha coefficient score equal to .92, showing high internal consistency (<http://www.pearsonassessments.com>). Data collection of the Beck Depression Inventory was discontinued approximately two-thirds of the way through this project due to Rogers Memorial Hospital choosing an alternative depression scale that was offered through a public domain. The *n*-value for question number 3a, specific to depressive symptoms, is 36.

Ethical Considerations, Informed Consent and Confidentiality

The researcher obtained approval from the Institutional Review Boards at Loyola University Chicago and Rogers Memorial Hospital. Ethical considerations were scrutinized and controlled for the physical, mental and emotional safety and security of all subjects under investigation. All subjects had been informed that their participation was voluntary and, if at any time they chose to discontinue their involvement they would be allowed to do so with no penalty. All subjects were provided the description of the outcome studies packet, which emphasized the voluntary nature of the project, the purpose of the studies, and instruction of involvement, participants' rights, and confidentiality and anonymity of participants.

Informed consent and parental consent and assent (when under the age of consent) were obtained from all subjects admitting to the program and participating in this research project. All potential subjects were given the opportunity to decline participation if so desired. It was explained to the potential subjects, prior to completing the outcomes and research packet, that the information obtained through the pre-treatment outcome packet would be used in order to individualize the subject's treatment stay at the EDC. Furthermore, the pre- and post-tests combined would be analyzed for treatment effectiveness and are used to help the staff at Rogers Memorial Hospital improve programming overall. Participants were informed that the information obtained would be used for research purposes. An additional consent and assent form was signed at discharge, which requested the subjects' permission to be contacted at a later date for a follow-up questionnaire. The follow-up was voluntary. Under no circumstances did participation or lack therein impact subjects' treatment at the Eating Disorder Center.

Due to the nature of residential treatment, often times adolescents subjects were not accompanied at admission by their parents/guardians. Rogers Memorial Hospital treats individuals from across the nation as well as internationally. In these cases, verbal consent was obtained from the parents/guardian over the phone during an initial phone conference with their Masters-prepared therapist and a copy of the consent form was faxed to the parents/guardians for signature. In-person signature was obtained when the parents/guardians were onsite for a therapeutic visit. A similar process occurred at discharge- if parents/guardians were not onsite upon discharge, the minor subject signed their assent and the parents were asked to provide verbal consent. The signature at

discharge gave permission for the subject to be contacted within three to 14 months for follow-up questionnaires via phone or email.

There were no names attached to the data. All data was entered into SPSS version 19 with a medical record number assigned to each subject in order to preserve confidentiality. All collected data for the purpose of this research project was saved and copied onto the researcher's password protected computer in aggregate form so that anonymity and confidentiality was maintained. All stored data will be destroyed immediately following the completion of this researcher's dissertation project. Participants and their parents were advised, in writing, that there is minimal to no risk associated with this project.

Data Collection and Management Process

Collection Protocol

Data collection began in August 2011 and was completed August 22, 2012. This research project had a lifespan of 12-months, which was longer than originally anticipated due to extraneous circumstances. The Eating Disorder Center (EDC) had an unexpected decrease in its average daily census (ADC) at the onset of the data collection process. This low census extended for approximately 5 months of data collection. During this time, the EDC was operating between 50 and 60 percent capacity. Census normalized in January 2012 and an *n*-value of 81 was achieved within that 12-months of data collection. Of the subjects that participated, 52 subjects provided an email address at which to be contacted for follow-up. Of these 52 subjects, 18 completed the post-post

survey ($n=18$), yielding a 34.6 percent completion rate. This value is recognized as a limitation to generalizability and further follow-up research is warranted.

Rogers Memorial Hospital and Rogers Center for Research and Training (RCRT) have been collecting data and producing outcomes for decades. The facility already had an effective data collection process. This project followed all standard procedures, in place at Rogers Memorial Hospital, Eating Disorder Center.

Following obtained consent and assent, a sealed envelope with an extensive battery of instruments was provided by a Masters or PhD-prepared therapist who had gone through specific training of the research project and distribution protocol. The distribution of this outcome studies packet occurred at two unique test times during the subjects' treatment- admission and discharge. As well, there were four measures (YBOCS, ASI, QIDS and SAS) within the packet that were distributed every two weeks during the treatment stay, in order to track progress specific to anxiety. These results were not analyzed in this specific research project.

The initial pre-test was provided within the first 48 hours of admission, the post-test was provided within 72-hours of discharge. The completion of the battery of tests occurred in a quiet room, away from staff and other residents in order to provide privacy and an undisturbed space. Once completed, the subject returned the packet to the administering therapist. At that time the therapist clarified any questions of the subject. Both of these testing times included all measures. The Eating Disorder Quality of Life Scale (EDQLS) was included in the standard Outcome Studies packet for the duration of

the research project and was removed from the packets upon the researcher's completion of the follow-up surveys.

Although for the purpose of this research project, the researcher was solely looking at the results from the EDQLS, the BDI-II and the EDI-3, a summary of the complete outcome studies packet is referenced here for the purpose of future data analysis: (a) Eating Disorder Inventory- 3 (EDI-3), (b) Quick Inventory of Depressive Symptomatology (QIDS) (replaced the BDI), (c) Eating Disorder Examination Questionnaire (EDE-Q), (d) Liebowitz Social Anxiety Scale (SAS), (e) State-Trait Anxiety Inventory (STAI), (f) Maudsley Obsessive Compulsive Inventory (MOC), (g) Compulsive Activity Checklist (CAC), (h) Anxiety Sensitivity Index (ASI) and (i) Yale-Brown Obsessive Compulsive Scale (Y-BOCS). As mentioned previously the Eating Disorder Quality of Life Scale (EDQLS) was included only for the duration of this project and has since been extracted.

The researcher was specifically interested in exploring the sustainability of health-related quality of life, post-residential treatment. It was decided by the researcher to track outcomes at three-months, post-treatment discharge in order to limit the external factors that may have an impact on quality of life changes once discharged from residential treatment. Presumably, this smaller window of time allowed for the outcomes to remain focused on the relationship between residential treatment and HRQOL.

A staff member of Rogers Center for Research and Training managed the data collection and three-month follow-up procedures, in order to maintain confidentiality. Survey Monkey (<http://www.surveymonkey.com>) was used to collect the post-post

follow-up survey results. Three-months after discharge an email was sent from Rogers Memorial Hospital requesting the subjects' participation in this project. If the subject did not respond following 10 business days, a second attempt was made via email. If at that point no response was obtained, the subject was considered non-participatory and no further attempts were made. These results were entered into SPSS version 19.

Data Storage and Confidentiality

The Eating Disorder Center is one of five residential programs on the Oconomowoc Campus, and is not physically attached to the Main Hospital. Once an outcomes packet was completed a member of the Rogers Memorial Hospital research team transported it to the RCRT. The data was then entered directly into the SPSS version 19 databases. The data collection and entry occurred at a frequency of two times per week for the duration of this research project. All packets were stored in a locked file cabinet, to which only research analysts and members of the RCRT had access.

A medical record number identified each subject in order to protect his/her confidentiality as well as protect from bias. If subject were a returning patient, his/her identification number is the medical record number plus a dash and then the number of visit (i.e. 12345-2). No identifying information or medical record numbers will be used in the analysis or publication of this research project. Once data was entered into SPSS the original paper copies were stored by identifying medical record number in a locked filing cabinet in the RCRT office in Oconomowoc, Wisconsin. Admission and discharge packets were stored together, along with data from repeat admissions.

Data Analysis Procedures and Strategies for Interpretation

This research project was quantitative in nature and evaluated how a specialized residential treatment facility for eating disorders impacted subjects' health-related quality of life from admission to discharge and, the sustainability of this progress from discharge to post-post treatment follow-up at three-months. In Chapter 4, the researcher will use a paired t-test to evaluate these variables. There were opportunities to control for unique variables within the data, including, but not limited to gender, diagnosis, and duration of illness. An analysis of variance (ANOVA) was used to compare change in HRQOL between primary diagnoses as well as gender. These results will also be discussed in Chapter 4.

Additional investigation included results from the EDI-3 and the BDI-II. A Pearson's R correlation analysis was computed to investigate the relationship between the change in HRQOL and change in depressive symptoms from admission to discharge. This same test analysis was computed to investigate the relationship between change in HRQOL and eating disorder symptomatology, as evidenced by the Eating Disorder Risk Composite score of the EDI-3. Furthermore, the researcher used a Pearson's R correlation analysis to evaluate the relationship between the change in health-related quality of life and duration of illness.

CHAPTER FOUR

ANALYSIS OF DATA

Introduction

Chapter Four will provide a summary of the data that was collected at Rogers Memorial Hospital- Eating Disorder Center (RMH-EDC). Data collection began August 2011 and was complete on August 22, 2012. There were three subject test times for data collection: Pre-treatment (admission), Post-treatment (discharge) and Post-post treatment (three-month follow-up). Pre-treatment was completed within the initial 48 hours of admitting to the EDC, a residential treatment facility specializing in the care of eating disordered individuals. The post-treatment was administered within 72-hours of discharge. Post-post treatment data collection was administered three-months after discharge from EDC and was collected via email utilizing Survey Monkey, a web-based survey company (<http://www.surveymonkey.com>).

This study was aimed at evaluating health-related quality of life outcomes of specialized residential treatment for individuals battling a primary diagnosis of Anorexia Nervosa-Restrict type (AN-R), Anorexia Nervosa- Binge-Purge type (AN-BP), Bulimia Nervosa (BN), or Eating Disorder, Not Otherwise Specified (EDNOS). There has been limited research to date that explores the change in an individuals' health-related quality of life (HRQOL) while participating in eating disorder-specific residential treatment. Within the past 10 years, disease-specific HRQOL surveys have been evolving. The

purpose of utilizing an eating disorder-specific HRQOL survey is that such disease-specific surveys account and adjust for the ego syntonic nature of eating disorders, remarkably Anorexia Nervosa, to which generic HRQOL surveys are insensitive. Experts in the eating disorder field have designed four remarkable surveys, in collaboration with individuals in recovery and impacted family members (Engle, et al, 2006, Engle, et al, 2009, Adair, et al, 2007).

This study purposefully utilized the Eating Disorder Quality of Life Scale (EDQLS) (Adair, et al, 2007) at all three test times with intention to evaluate outcomes and educate providers and third-party paying sources of the impact residential treatment has on an individuals health-related quality of life and thus the importance of this level of care for those battling these diseases. In addition to studying HRQOL progress at the above mentioned test-times, this study also examined the relationships between the EDQLS scores and two unique surveys focusing on symptom reduction: (a) Beck Depression Inventory- second edition (BDI-II) (Beck, et al, 1996) and (b) Eating Disorder Risk Composite (EDRC) on the Eating Disorder Inventory, third edition (EDI-3) (Garner, 2004). Finally, the researcher examined the relationship between HRQOL and duration of illness.

The treatment of eating disorders involves complexity in terms of the medical stabilization process, and balance that awareness with understanding the emotional, interpersonal, and existential issues that emerge as an individual returns to a stable baseline, physically. A multi-disciplinary team must be aware of these complexities in order to approach each patient with individuality and expertise. There are internal

transformations that need to occur for an individual to truly consider recovery as a way of life. Health-related quality of life can be a helpful marker for maintenance of such existential gains, through treatment.

In the past decade health insurance companies and other third-party paying sources, have begun to recognize the significance of health-related quality of life as a part of an individuals' treatment and recovery, however utilization of this data is not standard practice. These paying sources, along with researchers and clinicians have begun to ascribe to a theoretical framework that defines recovery as more than symptom reduction and medical stabilization. It is the purpose of this research to provide data to support and reinforce the importance of utilizing multiple variables when determining necessary level of care and preparedness for discharge from a treatment program. Remarkably residential treatment, for the purpose of this designed study.

Organization of the Data Analysis

Outcome data from the Eating Disorder Quality of Life Scale (EDQLS) are the primary focus of this analysis. In the results section of this chapter the researcher will provide the findings to each of the four identified research questions and hypotheses. Each research question and preliminary hypothesis will be drafted in the next section of this chapter. The analysis will follow and will look at each question independently.

Descriptive Data

All patients entering the residential Eating Disorder Center at Rogers Memorial Hospital, between August 2011 and August 2012, were invited to participate in this research project. The researcher only evaluated paired data; subjects who did not

complete a pre-test or post-test were not included in any data analysis ($n = 81$). Various reasons could account for incomplete pairs: (a) immature or unexpected discharge, (b) transfer to high level of care, (c) refusal to sign the consent form to be a part of the study. The data were collected and organized by unique descriptives. Tables 1 and 2 highlight frequencies of mentionable descriptives that the researcher will reference in her findings including gender frequencies and diagnostic frequencies.

This research project included both adolescents and adults. There were 21 adolescents that participated, comprising 25.9% of the population and 60 adults, yielding 74.1%. Of the total 81 participating subjects, 52 provided the researcher with an active email address at which he or she could be contacted for a three-month post-treatment follow-up test. Of these 52, 20 subjects opened the survey that was emailed to them. Two subjects refused to answer the questions and 18 completed the EDQLS in its entirety, yielding a 34.6% completion rate and a 38% response rate. Unfortunately, these numbers were low and thus the data collected for Research Question 2 are considered preliminary and further follow-up is anticipated. For the purpose of this research study this is recognized as a limitation of the generalizability of the data.

Table 1. Gender Frequencies

| | Frequency | Percent | Valid Percent | Cumulative Percent |
|---------------|-----------|---------|---------------|--------------------|
| Valid Males | 24 | 29.6 | 29.6 | 29.6 |
| Valid Females | 57 | 70.4 | 70.4 | 100.0 |
| Total | 81 | 100.0 | 100.0 | |

Table 2. Primary Diagnosis Frequencies

| | Frequency | Percent | Valid Percent | Cumulative Percent |
|----------------|-----------|---------|---------------|--------------------|
| OCD | 1 | 1.2 | 1.3 | .13 |
| AN-R | 29 | 35.8 | 36.3 | 37.5 |
| AN-BP | 13 | 16.0 | 16.3 | 53.8 |
| BN | 18 | 22.2 | 22.5 | 76.3 |
| EDNOS | 19 | 23.5 | 23.8 | 100.0 |
| Total | 80 | 98.8 | 100.0 | |
| Missing System | 1 | 1.2 | | |
| Total | 81 | 100.0 | | |

Research Questions and Associated Hypotheses

Prior to initiating the collection of data for this study the researcher identified three one-part questions and one two-part question with associated hypotheses.

Table 3. Research Questions and Associated Hypotheses and Null-Hypotheses

| | Question | Hypothesis | Null-Hypothesis |
|----|--|--|---|
| 1 | Do individuals that receive eating disorder-specific residential treatment gain a statistically significant improvement in their health-related quality of life from admission to discharge? | Treatment at a residential level of care will result in statistically significant improvements in individuals' HRQOL from admission to discharge. | Residential treatment has no impact on the subjects' health-related quality of life. |
| 2 | Do individuals who receive eating disorder-specific residential treatment maintain their gains and/or continue to improve upon their HRQOL at 3-month follow-up, post-discharge? | Treatment at a residential level of care will provide a foundation for continued improvement or, at minimum, sustainable gains at three-month follow-up. | There will be no continued progress at three-month follow-up, specific to health-related quality of life. |
| 3a | What is the relationship between the change in subjects' HRQOL and | The researcher hypothesized that there will be a negative | There will be no statistical relationship between change in quality of life |

| | | | |
|----|--|--|--|
| | their level of depressive symptoms from admission to discharge? | correlation between the change in depressive symptoms and the change in HRQOL from admission to discharge. | and change in depressive symptoms for individuals receiving residential treatment for eating disorders. |
| 3b | What is the relationship between the change in subjects' HRQOL and their eating disorder symptomatology from admission to discharge? | The researcher hypothesized that there would be a negative correlation between the change in eating disorder symptomatology and the change in HRQOL from admission to discharge. | There will be no relationship between change in quality of life and change in eating disorder symptomatology for individuals receiving residential treatment for eating disorders. |
| 4 | What impact does duration of illness have on the change in HRQOL from admission to discharge at an eating disorder-specific residential treatment? | The researcher hypothesized that the longer the duration of illness, the less progress individuals make in residential treatment toward improved quality of life. | The duration of illness has no impact on the subjects' response to treatment, specific to their health-related quality of life. |

Analysis of Data

Statistical Analyses

All statistical analyses were conducted in SPSS- version 19. Paired *t*-tests were used to examine the change in health-related quality of life from admission to discharge, discharge to the three-month follow-up, and admission to three-month follow-up. Pearson's *R* correlation analysis was used to examine the relationship between change in quality of life from admission to discharge and the change in depressive symptoms as well as the change in eating disorder symptoms from admission to discharge. Analyses of variance (ANOVA) were conducted to examine variances between (a) gender and (b) diagnostic categories specific to the change in EDQLS scores. A significance level of .05

was used throughout this project, as this is identified as a standard level of confidence in research.

Discussion of Research Questions and Associated Hypotheses

Research Question 1

Do individuals who receive eating disorder-specific residential treatment maintain their gains and/or continue to improve upon their HRQOL at 3-month follow-up, post-discharge?

A paired t-test was used to analyze data and answer this research question. The change in health-related quality of life as evidenced by the score results of the EDQLS from admission to discharge had a Mean score of -41.049 (SD = 29.109). Subjects' health-related quality of life improved, on average, by 41 points on the EDQLS survey. This result was statistically significance ($p < .05$), supporting the researcher's hypothesis.

The researcher conducted an ANOVA statistical test, to examine the difference in EDQLS scores between (a) gender and, (b) diagnostic categories. In comparing the variances between males and females, the statistical significance recorded was .270, which suggests that there is not statistical significance between these two group's variances ($p = NS$). This suggests that men and women receiving treatment at a residential level of care respond similarly and make comparable gains from admission to discharge, specific to their health related quality of life.

The researcher compared variances of four primary eating disorder diagnoses, which included all subjects with two exceptions, one whose primary diagnosis was OCD and the other missing diagnostic data ($n = 79$). The researcher's evaluation across

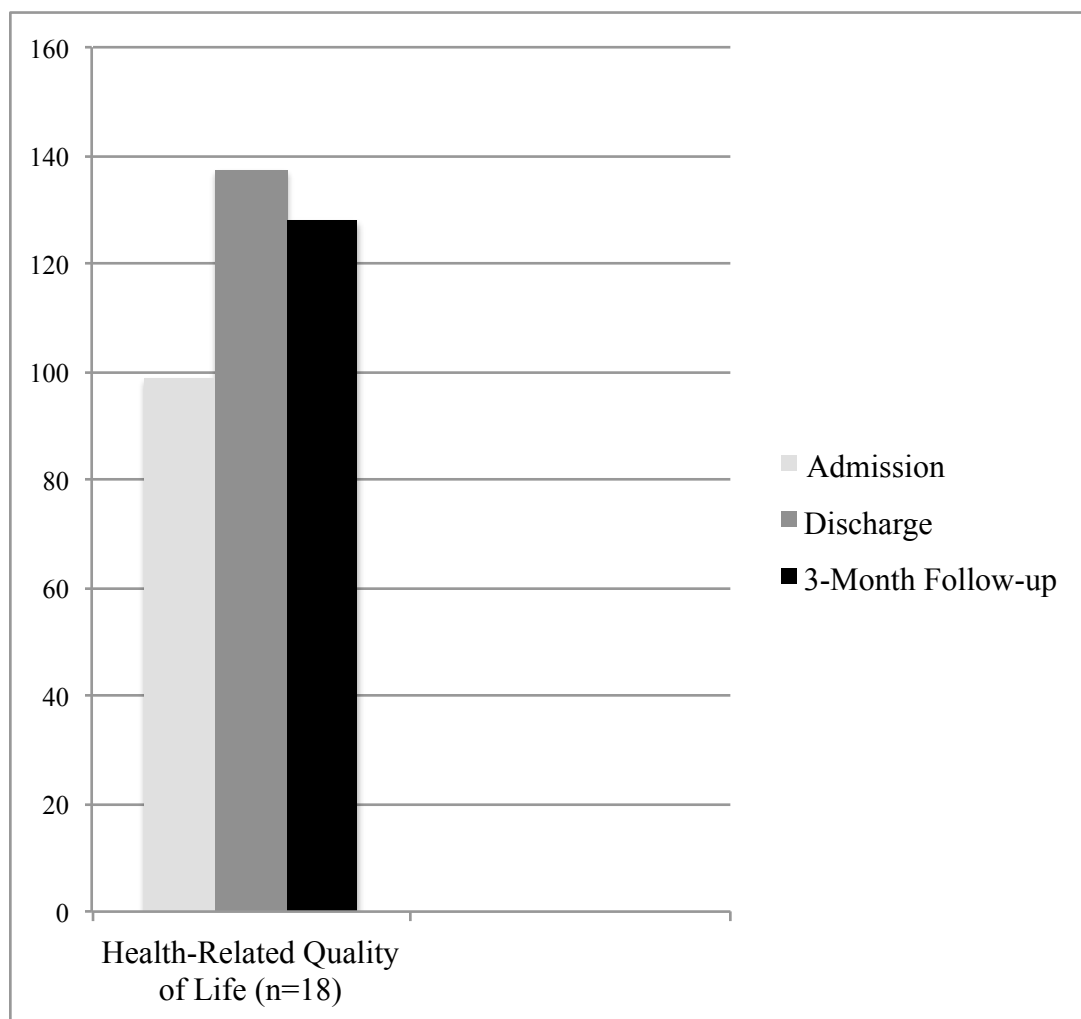
diagnoses including Anorexia Nervosa- Restricting subtype (AN-R), Anorexia Nervosa-Binge-Purge subtype (AN-BP), Bulimia Nervosa (BN) and Eating Disorder, Not Otherwise Specified (EDNOS) the significance recorded was .927, which suggests that there is not statistical significance in variance between groups ($p = \text{NS}$). Therefore, this research data suggests that all four diagnostic types of eating disorders respond equally well to residential treatment, specifically investigating change in quality of life from admission to discharge.

Research Question 2

Do individuals who receive eating disorder-specific residential treatment maintain their gains and/or continue to improve upon their HRQOL at 3-month follow-up, post-discharge?

The study yielded a 34.6% completion rate at three-month follow-up ($n = 18$), which is identified as a limitation to the generalizability of this question to the eating disorder population at large. Paired t-tests were completed to examine the significance of change in subjects' health-related quality of life from discharge (post-treatment) to three-month follow-up (post-post treatment follow-up). The Mean EDQLS score at admission (initial test-time) of the paired samples was 98.611 ($SD = 25.389$). The Mean EDQLS score at discharge (second test-time) of the paired sample was 137.222 ($SD = 33.451$). The Mean EDQLS score and three-month follow-up (third and final test-time) was 127.944 ($SD = 39.743$).

Graph 1. HRQOL at Admission, Discharge, and Post-Discharge Follow-up



It was already established in Question 1, that there was statistical significance from admission to discharge, suggesting that residential treatment provides a catalyst for individuals' to improve upon health-related quality of life during treatment. There was a decrease by 9.278 in the EDQLS Mean score from discharge to three-month follow-up. This regression in the mean of subjects' HRQOL was not significant (Sig. = .097, $p > .05$). Of note, there were statistically significant gains on the EDQLS from admission to

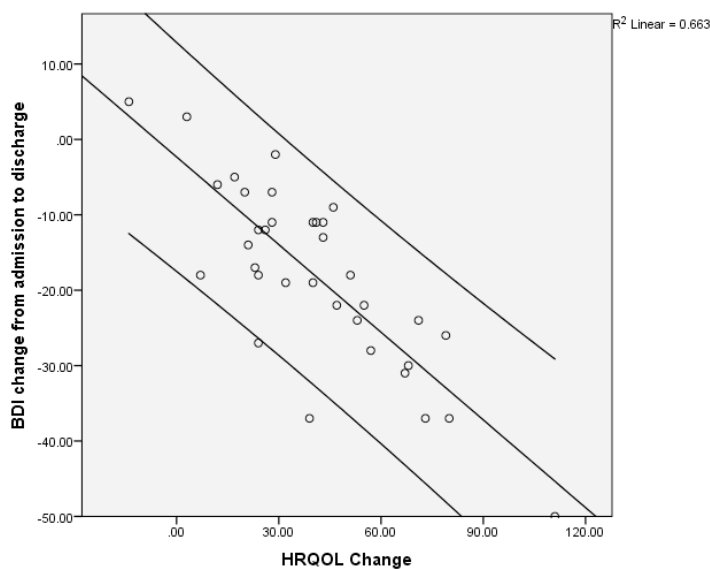
three-month follow-up ($p < .05$), suggesting that although minor setbacks in quality of life may occur immediately following discharge, the progress and gains made over the course of treatment, remain in tact three-months post treatment discharge. These outcomes are recognized as preliminary and further investigation at 3-month follow-up as well as more longitudinal follow-up is warranted.

Research Question 3a

What is the relationship between the change in subjects' health-related quality of life and the change in depressive symptoms from admission to discharge?

Rogers Memorial Hospital at large made a hospital-wide decision to remove the Beck Depression Inventory, second edition (BDI-II) from the standard battery of surveys and replaced it with a public domain survey called the Quick Inventory of Depressive Symptomatology (QIDS). This researcher chose to stop collecting data specific to depressive symptoms at that time, which limited the subject sample size for this research question ($n = 35$). Although the researcher reaped a small sample size, the results were remarkable. Analysis was computed using a Pearson's R correlation analysis, resulting with a strong correlation ($r = -.814$) and a statistically significant relationship ($p < .05$) between change in EDQLS scores and change in BDI scores. These results support the researcher's hypothesis. The limited subject sample size is recognized as a limitation to this study, specifically the results of this research question.

Graph 2. Pearson's R Correlation Analysis between the BDI-II and the EDQLS



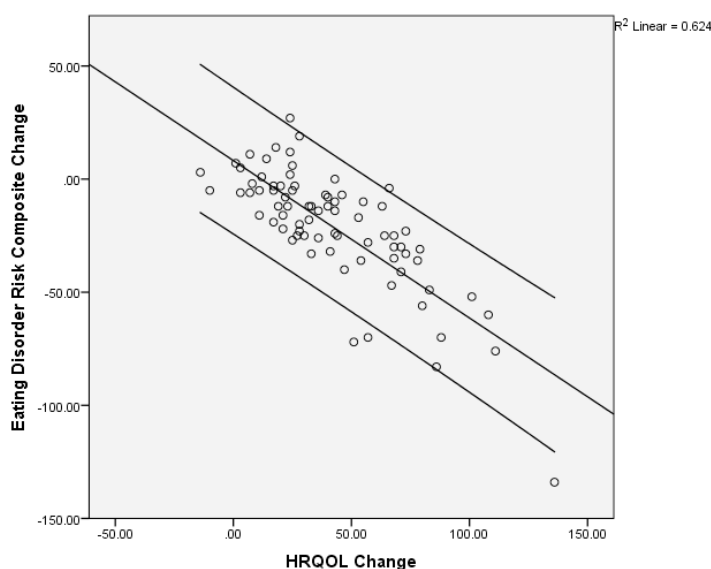
Question 3b

What is the relationship between the change in subjects' health-related quality of life and the change in eating disorder symptomatology from admission to discharge?

Composite scores of the Eating Disorder Quality of Life Scale (EDQLS) and the Eating Disorder Risk Composite (EDRC) within the Eating Disorder Inventory, Third Edition (EDI-3) were analyzed using a Pearson's R correlation analysis to examine this relationship. Within the EDI-3 there are 12 subscales and six composites. The Eating Disorder Risk Composite (EDRC) specifically was used for analysis of eating disorder symptomatology as this score represents the composite of the three eating disorder symptom sub-scales: Bulimia, Drive for Thinness and Body Image Dissatisfaction (Garner, 2004).

The correlation between self-reported quality of life and eating disorder symptomatology was strong ($r = -.790$), supporting a negative correlation between eating disorder symptom reduction and improved quality of life. As an individual's quality of life improves, over the course of residential treatment, the eating disorder symptomatology decreases. The correlation relationship is statistically significant ($p < .05$), thus the researcher's hypothesis was retained.

Graph 3. Pearson's R Correlation Analysis between changes in EDRC and EDQLS



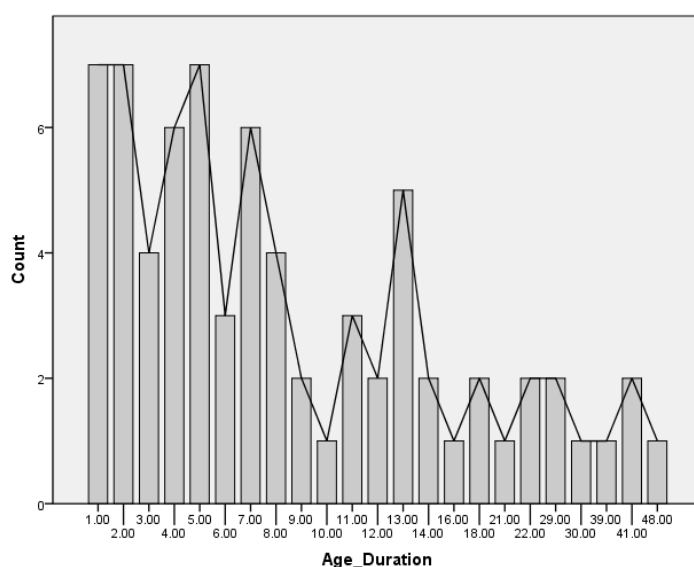
Question 4

What relationship does duration of illness have with the progress made in one's health related quality of life over the course of residential treatment?

The number of pair subject samples was slightly lower than the total sample, due to 10 participants not reporting the remarkable data to this question ($n = 71$). A Pearson's R correlation analysis was utilized to examine the relationship between duration of illness and change in quality of life over the course of treatment. The researcher hypothesized

that the longer the duration of illness, the less change in health-related quality of life from admission to discharge, resulting in less progress toward recovery. Contrary to hypothesized expectations, the magnitude of the Pearson's R was low ($r = .113$) with no statistical significance between the groups ($p > .05$) rejecting the researcher's hypothesis and supporting the null-hypothesis.

Graph 4. Breakdown of Duration of Illness by Years



Further analysis of the data would demonstrate an abnormal distribution of duration of illness between one year and 48 years (See Graph 4). This histogram illustrates a positive skew, suggesting that there is a higher prevalence of individuals reporting duration of illness to be between one year and seven years. Bamford and Sly (2010) found similar surprising results pertaining to the relationship between chronicity and quality of life.

CHAPTER FIVE

FINDINGS

Summary of the Study

The researcher collected data for a 12-month period of time, beginning in August 2011 and concluding in August 2012. Rogers Memorial Hospital offers unique levels of care including acute inpatient hospitalization, residential, and partial hospital programming/day treatment. Furthermore, the hospital specializes in the treatment of severe mental health diagnoses, including but not limited to eating disorders, obsessive-compulsive disorder, substance abuse disorders and other mood-spectrum and anxiety-spectrum disorders. The Eating Disorder Center (EDC) was the site of this research study.

The project included three test-times, (a) pre-test at admission, (b) post-test at discharge and (c) post-post test at three-month follow-up. The populations under investigation were adolescents and adults, males and females alike. The study yielded a total subject sample size of 81. Particular research questions yielded smaller *n*-values due to the nature of the question and changes within the Center for Research and Training (RCRT) and the hospital at-large, which were beyond the researcher's control. Furthermore, it is recognized that specific to the Eating Disorder Quality of Life Scale (EDQLS) and research questions 1 and 2 there is no non-clinical control group to which the researcher could compare results subsequently a limitation to generalizability is

recognized. The authors of the EDQLS (Adaire and Marcoux) were contacted and it was confirmed this data is not available. Additional limitations of particular questions are recognized throughout the discussion.

The researcher was interested in four specific research questions. The summary of the findings to each question will be expanded in the next section of this chapter. Particularly the data highlights and supports the researcher's argument that specialized-eating disorder residential treatment is a beneficial and, for some individuals battling eating disorders a necessary level of care. Furthermore, third-party paying sources and policy-makers need to take a serious look at ability and willingness to consistently recognize the value of this level of care as a viable and effective treatment option for severe eating disorder diagnosis. It is highlighted in the researcher's review of the literature that residential care, although requiring significant financial investment is cost-effective in comparison to recidivism, chronicity, and morbidity.

This chapter is dedicated to expanding the research findings specific to each of the four questions identified throughout this manuscript. Furthermore, this chapter will highlight further areas of research needed and identify next steps for this specific research project. The data are considered preliminary and further research in the identified areas are warranted and necessary.

Over the past 18 months, the Eating Disorder Center has evolved making theoretical changes to the structure of its program in order to remain competitive with other expert eating disorder treatment providers, at large. With these changes and

evolutionary processes the researcher has identified research opportunities specific to RMH-EDC that will help bridge the gap between treatment and policy. The researcher will speak of these opportunities in the Implications and Conclusions section of this paper. The findings of the research study support the defense that utilization of a disease-specific health-related quality of life survey in combination with symptom reduction, weight restoration, and medical stabilization provides a necessary comprehensive, 360-degree picture of patients' illness severity, existential compromise and progress in treatment. Furthermore, though preliminary, the outcomes of this project suggest that residential treatment provides a sustainable foundation for stabilizing health-related quality of life, at short-term follow-up. All paradigmatic constructs that are in-part making treatment decisions, i.e. family members, multi-disciplinary treatment team members, payers and policy-makers are encouraged to contextualize this data for their own decision-making needs.

Findings

It is the researcher's platform that residential treatment provides an opportunity for its' patients to grow, develop and secure a solid foundation upon which he or she can continue to build outside of the safety and security of the residential level of care. There are data and literature to support the effectiveness of residential treatment from a physical rehabilitation, stabilization and decreased symptomology perspective. And, as these factors are imperative to the recovery process they alone do not define recovery nor do they guarantee recovery will continue post-discharge. The researcher investigated the

health-related quality of life, as it is dedicated to the evaluation of an existential perception of one's being. The World Health Organization (WHOQOL, 1997) defines quality of life as "an individual's perception of their position in life in the context of the culture and values system in which they live and in relation to the goals, expectations, standards and concerns" (WHOQOL, 1997, p. 1). Linked with the philosophical framework of social constructionism, it is imperative that such factors also be analyzed and considered in combination with the aforementioned markers of recovery when recommending treatment options and evaluating an individual's treatment progress and discharge readiness. If an individual has not readily evolved and reconstructed his or her identity, free from an eating disorder, it can be assumed that their progress will be stunted and they will slide back toward their sick identity.

The Eating Disorder Quality of Life Scale (EDQLS) (Adair and Marcoux, 2008) highlights core features of an identity rooted in a society, not isolation. This disease-specific quality of life measure is designed to specifically highlight life domains that are gravely impacted by Anorexia Nervosa, Bulimia Nervosa and an Eating Disorder, Not Otherwise Specified. Research questions 1 and 2 focused on the change in health-related quality of life from admission to discharge and again from discharge to three-months post-discharge.

The results to research question 1 supported the researcher's hypothesis. There was statistically significant improvement from admission to discharge in the subjects' health-related quality of life. At admission the Mean EDQLS score was 99.358. Over

the course of residential treatment subjects improved, on average, by 41 points and at discharge the Mean score of all paired subjects was 140.407 ($n = 81$).

Unique descriptives were evaluated. Remarkably the researcher investigated gender as an independent variable and discovered that males and females responded to residential eating disorder treatment at Rogers Memorial Hospital similarly. In using an ANOVA to analyze the variance between genders there was no statistical significance. A like outcome was found in the researcher's analysis of variances between primary diagnoses. The researcher evaluated treatment response between Anorexia Nervosa-Restricting subtype, Anorexia Nervosa-Binge-Purge subtype, Bulimia Nervosa, and Eating Disorder, Not Otherwise Specified, as evidence by the EDQLS, and again found no statistical significance in the variances between each groups' response to treatment.

The researcher surmises that such insignificant results speak to residential treatment's capacity to individualize care regardless of gender or diagnosis. The EDC, similar to other residential treatment facilities that specialize in treating eating disorders, offers a variety of therapeutic interventions for patients. These include Cognitive Behavior Therapies (CBT) and Dialectical Behavior Therapies (DBT), experiential therapies, art therapy, music therapy, group and individual psychotherapy, meditation, fitness counseling, yoga therapy, and nutritional counseling. The multi-disciplinary clinical team can approach patients from different angles and different avenues in order to meet the patient "where he or she is at." There are a variety of approaches in order to meet each patient's learning style, readiness for change, and comfort level.

Furthermore, Rogers Memorial Hospital specializes in Exposure and Response Prevention (ERP) therapy, which is an evidence-based cognitive behavioral approach for individuals battling Obsessive Compulsive Disorder (OCD). There are similarities in presentations between individuals battling Anorexia Nervosa and those battling OCD, supporting ERP as a reliable treatment intervention for a percentage of individual treated at the EDC. Individuals that enter treatment with a co-morbid diagnosis of an eating disorder and OCD or a severe anxiety disorder are provided an additional clinical team member (Behavior Specialist) who is dedicated to hierarchy development and directing ERP. The behavior specialist provides extensive behavioral interventions rooted in CBT-ERP for severe anxiety-spectrum symptomatology.

This treatment model is a core feature of other residential programs at Rogers Memorial Hospital and has recently been embedded into the treatment modalities offered at the EDC. It is labor intensive and time-consuming to develop the hierarchy, with an expectation of a minimum 70% completion rate prior to discharge from residential treatment in order to produce the most favorable outcomes.

Although not a core research question to this project, the researcher performed an ANOVA between two groups: (1) Patients who received CBT-ERP ($n = 33$) and (2) Patients who received treatment as usual (TAU) ($n = 48$). Within the CBT-ERP track, the average change had a Mean score of 41.575 (SD = 26.608). Within the TAU group, the average change had a Mean score of 40.687 (SD = 30.982). There was no statistically significant difference between groups ($p > .05$).

These results were particularly of interest to the researcher, due to the exclusive quality of the ERP program at the Eating Disorder Center as compared to other eating disorder residential facilities nation-wide. In essence the lack of statistical significance between these two groups, suggests that the clinical team at the EDC are able to effectively treat individuals presenting with a secondary diagnosis of severe anxiety or OCD equally well to those who do not have this dual-diagnosis. Furthermore, the health-related quality of life of these individuals will respond to treatment equally to those who are offered eating disorder treatment as usual.

Individuals necessitating ERP support by a Behavior Specialist presented with a Mean admission score on the EDQLS of 93.242 (SD = 21.460) and discharged with a Mean score of 134.818 (SD = 31.124). Individuals who received treatment as usual and did not necessitate specialized OCD / anxiety treatment presented with a Mean admission score of 103.562 (SD = 26.794) and a discharge Mean score of 144.250 (SD = 30.151). It can be surmised that those necessitating the Exposure and Response Prevention (ERP) due to their co-occurring diagnoses enter treatment with more compromised quality of life than those receiving treatment as usual and the like at discharge suggesting that the co-morbidity of obsessive-compulsive disorder or severe anxiety symptomology has a dramatic impact on health-related quality of life. Due to the fact that these two groups respond equally well to the treatment approaches suggests that the multi-disciplinary team at the EDC has manufactured an effective approach to individualizing care and

matching the needs of its patients battling severe eating disorders, as well as those with co-occurring anxiety-spectrum illness.

Research question two evaluated subjects' health-related quality of life at three-month follow-up, post-discharge from the Eating Disorder Center. The researcher's initial hypothesis was rejected. Of the 81 subjects that participated in the pre- and post-test 52 provided an email address at which to be contacted. Of those 52 subjects 20 opened the email and 18 completed the survey. The study yielded a 34.6% completion rate. Due to the low response and completion rates, the data specific to this question are considered preliminary and has limitations to generalizability.

There was a slight regression back toward the Mean discharge EDQLS score for paired subjects who completed the post-post survey. The post-post Mean score for the 18 paired subjects was 127.944 compared to a discharge Mean score of 137.222 (SD=33.451). At a set 95% confidence level, the difference was not statistically significant.

Within these paired subjects, the difference between the admission (pre-test) EDQLS scores and three-month follow-up (post-post) EDQLS scores is remarkable. The difference between these two test times was statistically significant ($p < .05$) suggesting that individuals who receive residential treatment are able to maintain significant gains made in residential treatment three-months post discharge.

A slight setback can account for readjustment to an individual's natural environment outside of residential treatment. Although residential treatment facilities are

designed to provide a home-like environment and “real world,” in-vivo experiences it is not an exact replica of the society / community to which patients belong beyond the treatment doors. There are societal stressors and unique truths that only belong to the home environment therefore requiring a readjustment period. It is the researcher’s hypothesis that post-treatment health-related quality of life will stabilize. Additional research yielding a larger response rate and further longitudinal investigation can provide additional data to test this hypothesis, which is highly recommended.

Questions 3a and 3b investigated the relationship between paired subjects’ change in quality of life and their change in (a) depressive symptomatology and (b) eating disorder symptomatology as evidenced by the Beck Depression Inventory, second edition (BDI-II) and the Eating Disorder Risk Composite (EDRC) score in the Eating Disorder Inventory, third edition (EDI-3), respectively. The correlational outcomes were supportive of the researcher’s hypotheses. Over the course of residential treatment subjects’ health-related quality of life improved as the depressive symptoms decreased. Similarly, there was a negative relationship between health-related quality of life and eating disorder symptomatology. As the subjects’ HRQOL improved their identified eating disorder symptoms and depressive symptoms decreased. This is recognized as a correlational relationship and not a causal relationship therefore inherently the conclusions that can be drawn are limited. Furthermore, due to the small paired-subject sample size for question 3a ($n = 36$) a limited scope of generalizability is recognized.

The researcher highlights the importance of evaluating a patients' progress holistically through different, unique lenses. A 360-degree analysis provides family members, providers, third-party payers, policy-makers, and researchers a well-rounded perspective on the recovery progress, as well as the genuine nature of internalization of personal change. It can be assumed that an individual will forego use of unhealthy behaviors, such as restricting, bingeing and purging, while in an intensive treatment center. Medical stabilization and weight restoration is inevitable in a controlled environment such as residential treatment. Evaluating health-related quality of life adds to the understanding of these changes on an existential level. At times, symptom reduction and medical stabilization can provide a smoke screen and can distract from the necessary internal transformation that need occur for genuine recovery to take hold and for an individual to truly redesign and reconstruct him or herself and the psyche.

Over time eating disorders, by nature, become a part of a person's identity and inherently their reality. Disease-specific quality of life scales, such as the EDQLS, account for this ego syntonicity. Therefore, we can draw a connection between these results: if improvement in health-related quality of life continues to evolve as an individual becomes further separated from the eating disorder symptomatology and behaviors, it would appear as if the recovery process is being internalized and a new self-construction is occurring. Within the recovery process there need be a point where the existential conflict begins to change and quality of life genuinely transforms and improves. This point is when the individual begins to take back control of their mind:

power over the eating disorder becomes the reality versus the eating disorder having power and control over the person.

The distorted perceptions of body and self are core features of an eating disorder and when the person believes these perceptions to be true, such “truth” feeds the power of the eating disorder. Therefore, the point that an individual can begin to see the eating disorder thoughts and distortions as false-truths and can begin to fight those cognitive distortions is the point that their genuine truth is reborn and their quality of life can begin to transform. It is the researcher’s premise that weight restoration and behavioral maintenance can occur without a genuine rediscovery and recovery. When there is weight restoration, behavioral change, *and* significant improvement in quality of life, the chances of long-standing true recovery are more realistic and trustworthy.

The results from research question four were most surprising to the researcher. The researcher hypothesized that the longer duration of illness the less responsive a subject would be to treatment as evidenced by their change in health-related quality of life. Contrary to this hypothesis, there was no significant correlation between these two variables, suggesting that regardless of chronicity the change in HRQOL will be similar. There was a positive skew in the data, which suggest that the distribution was not normal. Fifty percent of subjects reported duration of illness being between one and seven years. The spread was one year to 48 years. Bamford and Sky (2010) studied the relationship between duration of illness and quality of life and were equally surprised to find a lack of relationship,

Contrary to clinical expectations, a longer duration of illness did not result in a lower quality of life. This finding can be seen to be in line with the opinion of previous authors who have suggested that the global functioning of these patients does not decrease even with the attenuation of eating symptomatology over time. (p. 151)

The outcome to this correlational analysis may suggest that as an eating disorder develops in chronicity the person afflicted readjusts his or her lifestyle, values, beliefs, and relational and existential expectations to be in-line with the eating disorder rather than an external society. The contextual perception of what is an acceptable lifestyle aligns with the goals and perceptions of the eating disorder, which has infiltrated and taken control of the mind. Therefore, the individual that reported struggling with an eating disorder for 48 years has reframed and restructured his or her lifestyle, values, and beliefs to adjust for the eating disorder resulting in the quality of life being comparable to someone who has struggled for fewer years. These results beg for further research; they are truly astounding to the researcher.

Further Research

Research specific to eating disorders and health-related quality of life, as well as research related to residential treatment, is limited. Further study is necessary in many areas. This researcher is committed to further research at Rogers Memorial Hospital-Eating Disorder Center. Using this particular project as a catalyst, the researcher would recommend continuation of three-month follow-up surveys in order to reap a larger subject sample size. Furthermore, a longitudinal study utilizing the EDQLS at 12-months and then again at five years would also be of interest and important to draw connections

between residential treatment, other phases of treatment, and the reconstruction of oneself in a natural environment. As a part of this longitudinal study, it would be necessary to analyze subjects' post-residential treatment recommendation follow-through and if there were additional hospitalizations or readmissions along the way. Residential treatment is a level of care that provides a foundation for an individual's recovery. It is an arena that allows for patients to create a new social construction that he or she believes in and with which he or she feels comfortable. It is a significant steppingstone in the journey of recovery. Therefore, longitudinal study must identify all variables as significant and be able to differentiate and account for all factors.

As mentioned throughout this manuscript, there appears to be a relationship between motivation and readiness for change and a person's quality of life and furthermore, their response to residential treatment. Bamford and Sly (2010) highlight the importance of evaluating an individual's readiness and motivation for change as an indicator for treatment response; McHugh (2007) also supports this initiative. McHugh (2007) studied readiness for change and found that individuals who have a high level of motivation and readiness for change resulted in more efficient use of treatment with shorter lengths of stay in contrast with individuals who were unmotivated for such change. Concretely understanding an individuals' level of motivation can help treatment providers design a treatment plan and communicate accurate lengths of stay to payers. Furthermore, a person's readiness for change in combination with the other concrete factors identified for recovery are all necessary components of assessment and need to be

seriously engaged. The researcher would concur that further research to look at stages of change theory and its relationship with these other factors would provide important information for treatment planning, assessment and discharge readiness. As a social constructionist, when a person is willing and ready for a new reality and have a desire to change, their internal and external world will respond more favorably to treatment.

Finally, as the field of psychology continues to evolve, so do treatment approaches. Rogers Memorial Hospital- Eating Disorder Center is committed to this evolutionary process. Recently the EDC has implemented a Dialectical Behavior Therapy-informed treatment approach for individuals battling eating disorders. Currently, there are two separate treatment tracks at the EDC, (1) CBT-ERP and (2) DBT-informed. The researcher has a personal interest in developing an integrated treatment model and hypothesizes that a strategic theoretical framework that combines ERP and DBT would yield favorable outcomes for a percentage of patients. Therefore, this researcher is committed to design a mixed-method, clinical case study involving subjects who receive a hybrid, treatment approach integrating both CBT-ERP and DBT-informed care during their treatment at the EDC. DBT is a cognitive behavioral treatment model that targets cognitive demise as well as the primary domains highlighted in eating disorder-specific health-related quality of life surveys. To integrate these two approaches at a residential level of care for individuals battling severe eating disorders has the potential of targeting all primary objectives and encompassing a 360-degree approach to assessment and treatment.

Conclusions and Implications

Continued research in this vein will begin to bridge the gap between medical and “mental health” necessity, as quality of life goes beyond the symptoms and physique and relates these changes to an existential transformation of oneself. This study utilized a well-renowned, residential eating disorder treatment facility. The treatment methods at RMH-EDC are in line with best practice and continue to evolve and develop in tandem with what experts believe to be the most evidenced-based treatment modalities. This study, and subjects therein, can be considered representative of the greater eating disordered population. With further research and the ability to consider these outcomes more generalizable, there is great potential to influence all paradigmatic constructs in search for an amalgamation of truth and values specific to treatment and recovery of eating disorders.

Social constructionism undergirds the researcher’s practicing beliefs on mental health treatment. According to Kenneth and Mary Gergen (2004), “Social constructionism is a metatheory about people’s interpretation of the world and their experiences. As such, it encompasses other theories about how and why people have particular cultural, social and personal meanings” (p. 388). It is through a social constructionist lens that the researcher conceptualizes how philosophically an individual’s life can be deconstructed by an eating disorder and furthermore how health-related quality of life is diminished by the wrath of this disease.

A society constructs truth and reality; or rather a community of people determine truth to be truth. Individual ideals and beliefs are influenced by societal beliefs. When a belief does not align with an individual's personal construction that person can conform their beliefs and evolve into the societal concept, find an alternative society, or isolate from society. Eating disorders have a particular societal construction, to which subscription is non-discriminatory. However the reality, values, and beliefs in which a severe eating disorder is rooted are dangerous, and at times deadly to the subscribing individual. Paradoxically, the Western culture and prescribed beauty myths fuel eating disorders, resulting in an epidemic and collision of unique constructed societies. Through a social constructionist lens, Gergen and Gergen (2004) state, "Everything we consider real is socially constructed or more dramatically, nothing is real unless people agree that it is" (p. 10).

Within the society of eleven million people that battle eating disorders in the United States, there are common societal constructs of body perfection, gender expectations, and self-conception. According to Piran and Cormier (2005), "It is expected that individuals identify with multiple widely disseminated social discourses, such as varied gender-related discourses, and internalize them" (p.549). Due to irrational beliefs and unobtainable constructs of body perfection, dissatisfaction prevails and results in avoidance and isolation from the society at large. Furthermore, an afflicted individual reverts internally trusting only his or her own distorted mind, which has been infiltrated by the eating disorder. Anorexia Nervosa, Bulimia Nervosa, and Eating Disorder, Not

Otherwise Specified naturally gain control of a mind and distort reality, ultimately resulting in regression and isolation.

Distrust of loved ones and a healthy community becomes a common characteristic of individuals battling an eating disorder as truth becomes distorted and loved ones become perceived liars. Similar to the nature of mental illness as a whole, eating disorders are progressive, becoming more severe and controlling of one's mind, which further fuels a retreat into the inner world. An individual battling the eating disorder holds on tightly to the relationship with the disease rather than social relationships in the "real world." According to Gergen and Gergen (2004):

When the 'inner world' is the most central feature of what it is to be a human being, we create a world of separation, isolation and conflict. We are unable to explain how communication is possible at all. Essentially, in our construction of the person we have contributed to an ideology of individualism, and implications for social life are not all-together satisfying... Can we begin to regard thoughts, feelings, desires, memories and the like as born in relationships, and as meaningless outside our relationships? If we were successful in our reconstruction, we would no longer see ourselves as isolated and independent, fundamentally self-seeking or endangered by competing others. We would see ourselves as a relational outcome. 'Self vs. other' would become 'self through other' (p. 37).

Residential treatment is a premier battleground for fighting eating disorders, as it is an environment dedicated to the re-construction of oneself through relationship with others. It promotes self-discovery and definition of self through a transactional experience within a milieu-enhanced treatment opportunity. Residential eating disorder treatment provides an alternative society in which individuals may begin to develop a "sense of self" separate from their plaguing mental illness. This new-self can be

practiced, molded, and accepted internally as well as communally within a milieu of collaborative individuals. Through isolation, the eating disorder has power to shut off the external world of friends, significant others, teachers, mentors, clergy, and family from the internal world of the self and the eating disorder. Treatment must allow for this isolation to be broken and socialization to become a part of an individual's life. The researcher believes that residential treatment is an unparalleled environment to create internal and external cohesion and safety for individuals afflicted with clinical eating disorders seeking recovery and inevitably self-reconstruction. It is an opportunity to rediscover one's strengths and personality through relationships, without being inundated with dangerous stimuli that fuels the disease.

The results of this study have important implications for treatment of eating disorders and provide valuable information to all paradigmatic constructs that are involved with the decision-making efforts specific to treatment options and recommendations. The identified decision-making societies include policy-writers, governmental organizations, third-party payers, treatment providers, and friends and family alike. Residential treatment is effective and needs to be recognized as a necessary level of care for the treatment of eating disorders by all paradigmatic constructs.

Of course there is no guarantee and, if treatment is cut short due to external or internal barriers it can be assumed that treatment will be less effective and recidivism rates, chronicity and morbidity will continue to rise. Residential treatment is designed to be a long-term intensive treatment option that allows for a reconstruction of one's identity

including physical, emotional and existential rehabilitation and rebirth. This transformation is not immediate. Individuals need to have the opportunity to holistically complete the development of a new reality- a true self in relationship between oneself and one's community. And, a globally accepted, comprehensive assessment of such identity reconstruction through analysis of symptom reduction, weight restoration, physical rehabilitation, and health-related quality of life is necessary.

The juxtaposition of mental health caregiving organizations and third-party payers' perceptions of eating disorder treatment and residential care is contradictory. In a field that requires corroboration, the outcome of having powerful paradigms in conflict with one another is grave for the afflicted individuals and family members seeking treatment. Unfortunately the patients and family members are caught in the crossfire of opposing truths and definition. It is imperative that third party payers, multi-disciplinary clinical teams, researchers, and family members collaborate and develop one agreed-upon definition and accepted truths that include standard assessment and strategy encompassing a 360-degree evaluation including physical, mental, emotional, relational and existential rehabilitation.

This study has laid groundwork in this area of much needed collaboration and research. As this study is expanded upon, it has the potential to educate policy-makers in the health-care field about these aforementioned gaps in interpretation and communication. Ultimately, this researcher has a vision, which is to influence change at a macro-paradigmatic level, which ultimately can trickle down and provide guidance and

structure, potentially uniting the unique societal constructs to support residential treatment as a well-respected and consistently authorized and covered level of care for the eating disordered population.

APPENDIX A
EATING DISORDER QUALITY OF LIFE SCALE

EDQLS

Quality of Life Scale

Version 1.0 released May 2008

Quality of life is the sense of satisfaction that a person has with her/his life and how much she or he enjoys various parts of it



Instructions:

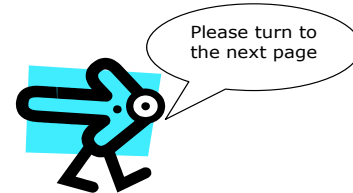
- Inside are 40 questions about how you feel about the quality of your life.
- Please rate the items according to your feelings, not how you think others might expect you to answer.
- Responses will be different for different people; there are no right or wrong answers.
- Answer based on your first impression. Even if you think an item doesn't apply to you, give it your best guess.

Here is an example item:

| | Strongly Disagree | Disagree | Neither Agree or Disagree | Agree | Strongly Agree |
|--------------------------------|----------------------|----------|---------------------------------|-------|-------------------|
| 1. I enjoy going to the movies | 1 | 2 | 3 | 4 | 5 |

Think about how you've felt in the LAST WEEK, and then circle the response that best fits for you.

| | Strongly Disagree | Disagree | Neither Agree or Disagree | Agree | Strongly Agree |
|--|----------------------|----------|---------------------------------|-------|-------------------|
| 1. I have fun with others | 1 | 2 | 3 | 4 | 5 |
| 2. I feel I don't have a life | 1 | 2 | 3 | 4 | 5 |
| 3. I have a very close relationship with at least one best friend or partner | 1 | 2 | 3 | 4 | 5 |
| 4. I have trouble concentrating | 1 | 2 | 3 | 4 | 5 |
| 5. My health is more important to me than my physical appearance | 1 | 2 | 3 | 4 | 5 |
| 6. My life is full of worry right now | 1 | 2 | 3 | 4 | 5 |
| 7. I show my true self to others | 1 | 2 | 3 | 4 | 5 |
| 8. I have lots of rules about food | 1 | 2 | 3 | 4 | 5 |
| 9. I have lots of energy | 1 | 2 | 3 | 4 | 5 |
| 10. I feel connected to others | 1 | 2 | 3 | 4 | 5 |
| 11. I get satisfaction from my main activity (e.g. school, work) | 1 | 2 | 3 | 4 | 5 |
| 12. I think about food constantly throughout the day | 1 | 2 | 3 | 4 | 5 |
| 13. I see positive things in my appearance | 1 | 2 | 3 | 4 | 5 |
| 14. I can allow myself to relax | 1 | 2 | 3 | 4 | 5 |
| 15. I skip meals on purpose | 1 | 2 | 3 | 4 | 5 |
| 16. I have fights with my family members about food or eating | 1 | 2 | 3 | 4 | 5 |
| 17. Every day is a struggle | 1 | 2 | 3 | 4 | 5 |
| 18. The number on the bathroom scale is very important to me | 1 | 2 | 3 | 4 | 5 |
| 19. I turn down opportunities to go out with friends | 1 | 2 | 3 | 4 | 5 |
| 20. I can focus on things other than food | 1 | 2 | 3 | 4 | 5 |



| | Strongly Disagree | Disagree | Neither Agree or Disagree | Agree | Strongly Agree |
|--|-------------------|----------|---------------------------|-------|----------------|
| 21. I feel hopeful about the future | 1 | 2 | 3 | 4 | 5 |
| 22. People don't understand me | 1 | 2 | 3 | 4 | 5 |
| 23. I don't go out with friends if I feel bad about my body | 1 | 2 | 3 | 4 | 5 |
| 24. I enjoy participating in different activities, not just exercise | 1 | 2 | 3 | 4 | 5 |
| 25. I'm constantly trying to fix my body | 1 | 2 | 3 | 4 | 5 |
| 26. I am able to see good qualities in myself | 1 | 2 | 3 | 4 | 5 |
| 27. I have plans for my future | 1 | 2 | 3 | 4 | 5 |
| 28. I feel understood by someone in my family | 1 | 2 | 3 | 4 | 5 |
| 29. Thoughts about food and eating dominate my life | 1 | 2 | 3 | 4 | 5 |
| 30. I put myself down a lot | 1 | 2 | 3 | 4 | 5 |
| 31. I feel self-conscious about my body around others | 1 | 2 | 3 | 4 | 5 |
| 32. My sleep is restful | 1 | 2 | 3 | 4 | 5 |
| 33. I feel comfortable eating in front of people | 1 | 2 | 3 | 4 | 5 |
| 34. The eating disorder affects what I can do every day | 1 | 2 | 3 | 4 | 5 |
| 35. I do things I normally wouldn't do because of my eating disorder | 1 | 2 | 3 | 4 | 5 |
| 36. I can consider my own happiness when making choices | 1 | 2 | 3 | 4 | 5 |
| 37. I feel like nothing I ever do is quite good enough | 1 | 2 | 3 | 4 | 5 |
| 38. I'm obsessed with my weight or my body shape | 1 | 2 | 3 | 4 | 5 |
| 39. The eating disorder has taken over my life | 1 | 2 | 3 | 4 | 5 |
| 40. I feel physically cold | 1 | 2 | 3 | 4 | 5 |

Keep up the good work, only one more page



In this last section please rate how IMPORTANT the following areas of life are to YOU.

| | Very Unimportant | Unimportant | Neither Important or Unimportant | Important | Very Important |
|--|------------------|-------------|----------------------------------|-----------|----------------|
| School/Work | 1 | 2 | 3 | 4 | 5 |
| Family and Close Relationships | 1 | 2 | 3 | 4 | 5 |
| Relationships with Others | 1 | 2 | 3 | 4 | 5 |
| Your Future | 1 | 2 | 3 | 4 | 5 |
| Your Feelings | 1 | 2 | 3 | 4 | 5 |
| Your Appearance (How you look) | 1 | 2 | 3 | 4 | 5 |
| Your Leisure (Free time activities) | 1 | 2 | 3 | 4 | 5 |
| Your Values and Beliefs | 1 | 2 | 3 | 4 | 5 |
| Thinking and Concentrating | 1 | 2 | 3 | 4 | 5 |
| Your General Physical Health | 1 | 2 | 3 | 4 | 5 |
| Your Psychological Health | 1 | 2 | 3 | 4 | 5 |
| Your Health Related to Food & Weight | 1 | 2 | 3 | 4 | 5 |
| <i>If there are any other areas of your life that are not listed in these 12 above please specify and rate</i> | | | | | |
| | 1 | 2 | 3 | 4 | 5 |
| | 1 | 2 | 3 | 4 | 5 |

Global Quality of Life Rating:

*Finally, please rate your overall quality of life in the last week on a scale of 1 to 10, where 1 is **Poor** and 10 is **Excellent***

1 2 3 4 5 6 7 8 9 10



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APPENDIX B
EATING DISORDER INVENTORY, 3RD EDITION



Appendix A2
COPY

Item Booklet

David M. Garner, PhD

DIRECTIONS

Enter your name, the date, your age, gender, marital status, and occupation. Complete the questions on the rest of this page. Then, turn to the inside of this booklet and carefully follow the instructions.

Name _____ Date ____/____/____
*Age _____ Gender _____ Marital Status _____ Occupation _____

- A. *Current weight: _____ pounds
- B. *Height: _____ feet _____ inches
- C. Highest past weight (excluding pregnancy): _____ pounds
How long ago did you first reach this weight? _____ months
How long did you weigh this weight? _____ months
- D. *Lowest weight as an adult (or lowest weight as an adolescent if not yet age 18): _____ pounds
How long ago did you first reach this weight? _____ months
How long did you weigh this weight? _____ months
- E. What weight have you been at for the longest period of time? _____ pounds
At what age did you first reach this weight? _____ years old
- F. If your weight has changed a lot over the years, is there a weight that you keep coming back to when you are not dieting? _____ Yes _____ No
If yes, what is this weight? _____ pounds
At what age did you first reach this weight? _____ years old
- G. What is the most weight you have ever lost? _____ pounds
Did you lose this weight on purpose? _____ Yes _____ No
What weight did you lose to? _____ pounds
At what age did you reach this weight? _____ years old
- H. What do you think your weight would be if you did not consciously try to control your weight?
_____ pounds
- I. How much would you like to weigh? _____ pounds
- J. Age at which weight problems began (if any): _____ years old
- K. Father's occupation: _____
- L. Mother's occupation: _____

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INSTRUCTIONS

First, write your name and the date on the EDI-3 Answer Sheet. Your ratings on the items below should be circled on the Answer Sheet. The items ask about your attitudes, feelings, and behaviors. Some of the items relate to food or eating; other items ask about your feelings about yourself.

For each item, decide if the item is true about you **ALWAYS (A)**, **USUALLY (U)**, **OFTEN (O)**, **SOMETIMES (S)**, **RARELY (R)**, or **NEVER (N)**. Circle the letter that corresponds to your rating on the Answer Sheet. For example, if your rating for an item is **OFTEN**, you would circle the "O" for that item on the Answer Sheet.

Respond to *all* of the items, making sure that you circle the letter for the rating that is true about you. **DO NOT ERASE!** If you need to change an answer, mark an "X" through the incorrect letter, and then circle the correct one.

1. I eat sweets and carbohydrates without feeling nervous.
2. I think that my stomach is too big.
3. I wish that I could return to the security of childhood.
4. I eat when I am upset.
5. I stuff myself with food.
6. I wish that I could be younger.
7. I think about dieting.
8. I get frightened when my feelings are too strong.
9. I think that my thighs are too large.
10. I feel ineffective as a person.
11. I feel extremely guilty after overeating.
12. I think that my stomach is just the right size.
13. Only outstanding performance is good enough in my family.
14. The happiest time in life is when you are a child.
15. I am open about my feelings.
16. I am terrified of gaining weight.
17. I trust others.
18. I feel alone in the world.
19. I feel satisfied with the shape of my body.
20. I feel generally in control of things in my life.
21. I get confused about what emotion I am feeling.
22. I would rather be an adult than a child.
23. I can communicate with others easily.
24. I wish I were someone else.
25. I exaggerate or magnify the importance of weight.
26. I can clearly identify what emotion I am feeling.

(continued)

27. I feel inadequate.
28. I have gone on eating binges where I felt that I could not stop.
29. As a child, I tried very hard to avoid disappointing my parents and teachers.
30. I have close relationships.
31. I like the shape of my buttocks.
32. I am preoccupied with the desire to be thinner.
33. I don't know what's going on inside me.
34. I have trouble expressing my emotions to others.
35. The demands of adulthood are too great.
36. I hate being less than best at things.
37. I feel secure about myself.
38. I think about bingeing (overeating).
39. I feel happy that I am not a child anymore.
40. I get confused as to whether or not I am hungry.
41. I have a low opinion of myself.
42. I feel that I can achieve my standards.
43. My parents have expected excellence of me.
44. I worry that my feelings will get out of control.
45. I think my hips are too big.
46. I eat moderately in front of others and stuff myself when they're gone.
47. I feel bloated after eating a normal meal.
48. I feel that people are happiest when they are children.
49. If I gain a pound, I worry that I will keep gaining.
50. I feel that I am a worthwhile person.
51. When I am upset, I don't know if I am sad, frightened, or angry.
52. I feel that I must do things perfectly or not do them at all.
53. I have the thought of trying to vomit in order to lose weight.
54. I need to keep people at a certain distance (feel uncomfortable if someone tries to get too close).
55. I think that my thighs are just the right size.
56. I feel empty inside (emotionally).
57. I can talk about personal thoughts or feelings.
58. The best years of your life are when you become an adult.
59. I think my buttocks are too large.
60. I have feelings I can't quite identify.

(continued)

61. I eat or drink in secrecy.
62. I think that my hips are just the right size.
63. I have extremely high goals.
64. When I am upset, I worry that I will start eating.
65. People I really like end up disappointing me.
66. I am ashamed of my human weaknesses.
67. Other people would say that I am emotionally unstable.
68. I would like to be in total control of my bodily urges.
69. I feel relaxed in most group situations.
70. I say things impulsively that I regret having said.
71. I go out of my way to experience pleasure.
72. I have to be careful of my tendency to abuse drugs.
73. I am outgoing with most people.
74. I feel trapped in relationships.
75. Self-denial makes me feel stronger spiritually.
76. People understand my real problems.
77. I can't get strange thoughts out of my head.
78. Eating for pleasure is a sign of moral weakness.
79. I am prone to outbursts of anger or rage.
80. I feel that people give me the credit I deserve.
81. I have to be careful of my tendency to abuse alcohol.
82. I believe that relaxing is simply a waste of time.
83. Others would say that I get irritated easily.
84. I feel like I am losing out everywhere.
85. I experience marked mood shifts.
86. I am embarrassed by my bodily urges.
87. I would rather spend time by myself than with others.
88. Suffering makes you a better person.
89. I know that people love me.
90. I feel like I must hurt myself or others.
91. I feel that I really know who I am.

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APPENDIX C
BECK DEPRESSION INVENTORY, 2ND EDITION

BDI-II

Date: _____

Appendix A3
COPY

Name: _____ Marital Status: _____ Age: _____ Sex: _____

Occupation: _____ Education: _____

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

1. Sadness

- 0 I do not feel sad.
- 1 I feel sad much of the time.
- 2 I am sad all the time.
- 3 I am so sad or unhappy that I can't stand it.

2. Pessimism

- 0 I am not discouraged about my future.
- 1 I feel more discouraged about my future than I used to be.
- 2 I do not expect things to work out for me.
- 3 I feel my future is hopeless and will only get worse.

3. Past Failure

- 0 I do not feel like a failure.
- 1 I have failed more than I should have.
- 2 As I look back, I see a lot of failures.
- 3 I feel I am a total failure as a person.

4. Loss of Pleasure

- 0 I get as much pleasure as I ever did from the things I enjoy.
- 1 I don't enjoy things as much as I used to.
- 2 I get very little pleasure from the things I used to enjoy.
- 3 I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings

- 0 I don't feel particularly guilty.
- 1 I feel guilty over many things I have done or should have done.
- 2 I feel quite guilty most of the time.
- 3 I feel guilty all of the time.

6. Punishment Feelings

- 0 I don't feel I am being punished.
- 1 I feel I may be punished.
- 2 I expect to be punished.
- 3 I feel I am being punished.

7. Self-Dislike

- 0 I feel the same about myself as ever.
- 1 I have lost confidence in myself.
- 2 I am disappointed in myself.
- 3 I dislike myself.

8. Self-Criticalness

- 0 I don't criticize or blame myself more than usual.
- 1 I am more critical of myself than I used to be.
- 2 I criticize myself for all of my faults.
- 3 I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes

- 0 I don't have any thoughts of killing myself.
- 1 I have thoughts of killing myself, but I would not carry them out.
- 2 I would like to kill myself.
- 3 I would kill myself if I had the chance.

10. Crying

- 0 I don't cry anymore than I used to.
- 1 I cry more than I used to.
- 2 I cry over every little thing.
- 3 I feel like crying, but I can't.

Subtotal Page 1

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11. Agitation

- 0 I am no more restless or wound up than usual.
- 1 I feel more restless or wound up than usual.
- 2 I am so restless or agitated that it's hard to stay still.
- 3 I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

- 0 I have not lost interest in other people or activities.
- 1 I am less interested in other people or things than before.
- 2 I have lost most of my interest in other people or things.
- 3 It's hard to get interested in anything.

13. Indecisiveness

- 0 I make decisions about as well as ever.
- 1 I find it more difficult to make decisions than usual.
- 2 I have much greater difficulty in making decisions than I used to.
- 3 I have trouble making any decisions.

14. Worthlessness

- 0 I do not feel I am worthless.
- 1 I don't consider myself as worthwhile and useful as I used to.
- 2 I feel more worthless as compared to other people.
- 3 I feel utterly worthless.

15. Loss of Energy

- 0 I have as much energy as ever.
- 1 I have less energy than I used to have.
- 2 I don't have enough energy to do very much.
- 3 I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

- 0 I have not experienced any change in my sleeping pattern.
- 1a I sleep somewhat more than usual.
- 1b I sleep somewhat less than usual.
- 2a I sleep a lot more than usual.
- 2b I sleep a lot less than usual.
- 3a I sleep most of the day.
- 3b I wake up 1-2 hours early and can't get back to sleep.

17. Irritability

- 0 I am no more irritable than usual.
- 1 I am more irritable than usual.
- 2 I am much more irritable than usual.
- 3 I am irritable all the time.

18. Changes in Appetite

- 0 I have not experienced any change in my appetite.
- 1a My appetite is somewhat less than usual.
- 1b My appetite is somewhat greater than usual.
- 2a My appetite is much less than before.
- 2b My appetite is much greater than usual.
- 3a I have no appetite at all.
- 3b I crave food all the time.

19. Concentration Difficulty

- 0 I can concentrate as well as ever.
- 1 I can't concentrate as well as usual.
- 2 It's hard to keep my mind on anything for very long.
- 3 I find I can't concentrate on anything.

20. Tiredness or Fatigue

- 0 I am no more tired or fatigued than usual.
- 1 I get more tired or fatigued more easily than usual.
- 2 I am too tired or fatigued to do a lot of the things I used to do.
- 3 I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

- 0 I have not noticed any recent change in my interest in sex.
- 1 I am less interested in sex than I used to be.
- 2 I am much less interested in sex now.
- 3 I have lost interest in sex completely.

24 25 26 27 28 29 30 A B C D E

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_____ Subtotal Page 2

_____ Subtotal Page 1

_____ Total Score

APPENDIX D
INFORMED CONSENT / ASSENT



OUTCOMES MEASURES ASSESSMENT PACKET

The materials in this assessment packet are used to monitor the impact of treatment and evaluate the outcomes of therapy in patients receiving care at Rogers Memorial Hospital. These measures help us assess and monitor the severity of your symptoms (such as anxiety and depression), your quality of life, and whether you are affected by substance use or dependence.

The data obtained from these packets will be available to your therapist and to individuals monitoring your treatment progress.

It is important for us to get a full assessment of your treatment needs.

You will be asked to fill out this packet within 48-72 hours of your admission and again 48-72 hours before discharge so we can monitor your progress. These measures can help us target areas in which you may need additional help. You may also be asked to fill out some of the measures in this packet throughout your treatment to monitor if your symptoms are changing.

It is important for us to know if we are helping you.

Sometimes your answers may be used for research aimed at improving our treatment programs. All personal and clinical information about our patients and research participants is treated in a confidential manner. When we share our research results, the collected data is reported only in an aggregate form.

Personal information such as your name or initials will never be used in any report. The aggregated data may also be presented at scientific meetings or posted on the Rogers Memorial Hospital website so individuals interested in being admitted to the program can learn how successful the program has been for individuals like themselves.

It is important for you to complete the entire packet and return it to your counselor.

We recommend that you find a quiet place where you can review this packet and complete all of the enclosed surveys. Once the surveys are completed, return the entire packet to your counselor.

If you have any questions, please contact your therapist or counselor and he/she will help you.

Patient Signature _____ Date _____

Patient name (print) _____



OUTCOMES MEASURES

FOLLOW-UP INFORMATION

You were asked to fill out surveys that helped us measure the severity of your symptoms within 48-72 hours of your admission and again 72 hours before your discharge. These surveys included that helped us target areas where you needed more or less help with treatment.

We would like to contact you 3 to 14 months after discharge to evaluate your progress after treatment. In order to do so, we need your permission. To participate in this ongoing measurement, please complete the information below.

We will contact you either by phone or secured (encrypted) e-mail and ask you similar questions related to your symptoms, quality of life and well-being. We share our observations of the changes you have experienced since discharge in an attempt to continue helping with your recovery.

Please note below the best way to reach you. Only include phone numbers where we may leave a message for you.

___ Primary phone number: _____

___ Secondary phone number: _____

___ E-mail: _____

___ Other (parent or friend phone number): _____

Patient Signature _____ Date _____

Patient name (print) _____

Parent/Guardian signature (if patient is a minor) _____

Parent/Guardian name (print) _____

Date: _____

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VITA

Education: Robyn M. Welk-Richards received her undergraduate degree in 1999 from the University of Iowa in Iowa City. Robyn received a BA in Communication Studies with an emphasis in Film and Television Production. In 2001 Robyn served in the United States Peace Corp, in Morocco, North Africa. Her post-graduate academic work at Loyola University Chicago began in January 2002 and concluded in May 2004. She completed a Masters in Social Work, with an emphasis in Health and Hospital Social Work. After obtaining her License in Clinical Social Work (LCSW), Robyn returned to academia and began working toward her Doctor of Philosophy in August 2006 and completed this degree in December 2012.

Professional Development: Robyn began her social work career path, following her Masters in Social Work degree conferment in Spring 2004. She was employed by Rush Behavioral Health Hospitals as a substance abuse counselor in Lake Forest, Illinois for 18 months, beginning in 2004 through November 2005. Following this position Robyn relocated to Southeastern Wisconsin and was employed by Rogers Memorial Hospital for four years and a Licensed Clinical Social Worker at the Eating Disorder Center, a residential treatment facility for adolescents and adults battling eating disorders. During this position, Robyn also carried a small private practice in Lake Forest, Illinois, where she served primarily adolescents battling eating disorders and co-morbid anxiety and mood disorders. After four years of employment at Rogers Memorial Hospital she

resigned her position to develop and open an Intensive Outpatient Treatment Program (IOP) for adolescents and young adults battling self-destructive behaviors including substance abuse, eating disorders and self-harm. This program was a DBT-informed treatment center. She continued her private practice during this three-year ownership, and in 2012 left the company to return to Rogers Memorial Hospital as the Clinical Services Manager of the Eating Disorder Center, at which she is currently employed. The Clinical Services Manager position is an eclectic position that includes management, clinical work, supervision and research.

License and Training: Robyn is a Licensed Clinical Social Worker (LCSW) in the states of Illinois and Wisconsin. She has been intensively trained in Dialectical Behavior Therapy (DBT), by trainers employed by Behavioral Tech, LLC (Dr. Marsha Linehan's company). Furthermore, she is a member of the Academy of Eating Disorders (AED), The Residential Eating Disorder Consortium (REDC), through her position at Rogers Memorial Hospital, and The Association for the Advancement of Social Work with Groups.